AN EVALUATION OF THE IMPACT OF SOCIAL AND STRUCTURAL DETERMINANTS OF HEALTH ON FORGONE CARE DURING THE COVID-19 PANDEMIC IN BALTIMORE, MARYLAND

by
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Abstract

The Coronavirus 2019 (COVID-19) pandemic led to widespread disruptions in healthcare utilization. This included forgone care, defined as someone who perceives a need for healthcare but does not receive it. These disruptions exacerbated the morbidity and mortality associated with the pandemic and disproportionately impacted those who experience inequities across the social and structural determinants of health (SSDoH). Existing literature on the impacts of the pandemic on healthcare utilization predominately describe outpatient and hospital trends. However, very few studies have captured patient-reported forgone care.

The purpose of this dissertation was to investigate the impacts of the COVID-19 pandemic on healthcare access and utilization by specifically looking at forgone chronic and preventive care, emergent care, and elective and dental procedures among adults living in Baltimore, MD. Cross-sectional survey data were abstracted from two parent studies that used different, yet complimentary sampling strategies that increased representation of minoritized and under-resourced populations. The resulting combined analytic sample provided a platform to explore forgone care within one urban city that has historically suffered from systemic and structural racism, leading to widespread disparities across the SSDoH.

Several cross-cutting themes emerged as important considerations in this exploration of forgone care during the COVID-19 pandemic. First, individuals experiencing housing instability had higher rates and odds of forgone care when comparing those who reported not experiencing housing instability. Second, under-resourced and marginalized individuals who require frequent engagement with the health system suffered higher rates and odds of forgone care. Third, the correlates of forgone care are likely indicative of existing health disparities. Finally, community-level determinants of health were found not to account for forgone care, above and beyond individual-level factors.

Understanding the overall rate of forgone care during the COVID-19 pandemic and its intersections with the SSDoH provides a more comprehensive view of the health impacts of the pandemic. It can also inform the development of models of care that can help dismantle systems that

perpetuate inequities across the SSDoH and that can be leveraged during future public health emergencies to maintain individual and community health.

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Dedication

This dissertation is dedicated to the memory of my grandmothers, Marian (Anita) Armstrong and Alyce Meyer. Two fierce yet loving women who forged the path before me so that I could explore, learn, flourish, and make what I hope will be a positive change in the world.

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Dissertation Organization

This dissertation is organized into six chapters. The first chapter provides an overview of the background and rationale for this study, the purpose and aims, and the conceptual framework that guided selection of key variables.

Chapter two (manuscript one) is a systematic review of the literature, which was published in the journal *AIDS and Behavior* in August 2022. The systematic review aimed to capture the impacts of the COVID-19 pandemic on healthcare utilization by specifically looking at healthcare service engagement, treatment adherence, and viral suppression among people living with human immunodeficiency virus (PWH) in the United States. We elected to conduct this case study because of the high risk for forgone care during the COVID-19 pandemic within this population. People living with HIV require consistent engagement with the healthcare system to help maintain viral suppression and to prevent further disease transmission. It is thus likely that they were particularly negatively impacted by pandemic-related interruptions in care, such as decreased access to in-person services (e.g., laboratory testing), pharmacies, and social service providers. Additionally, PWH often experience poverty, discrimination, and other health inequities that may influence how they use the healthcare system. Exacerbation of these inequities during the COVID-19 pandemic, such as income loss and lack of public transportation, likely further hindered their ability to access the care required to maintain viral suppression. Synthesizing the evidence available on the impacts of the pandemic on this specific population provided a case study into its downstream impacts on healthcare utilization, including forgone care. The findings also speak more broadly to other minoritized and economically disadvantaged communities that were disproportionately impacted by interruptions in healthcare access and utilization during the COVID-19 pandemic.

Chapter three (manuscript two) is the first data-based manuscript arising from study data. This chapter reports the findings of Aim 1, which evaluated the rate of forgone care during the COVID-19 pandemic in Baltimore, MD.

Chapter four (manuscript three) is the second data-based manuscript and describes associations between individual and community-level factors with the odds of forgone care amongst a sample of Baltimore, MD residents.

Chapter five (manuscript four) is the third data-based manuscript and describes and compares the correlates of forgone emergent care with the correlates of forgone surgical/dental procedures.

Chapter six provides a critical synthesis of the results with implications of these findings for future research and healthcare delivery models and policies, and strengths and limitations of the study methods and findings.

CHAPTER 1: INTRODUCTION

Background and Rationale

Evidence suggests that the Coronavirus 2019 (COVID-19) pandemic led to widespread disruptions in healthcare utilization in the United States (US). However, much of this research describes overall outpatient and hospital trends in healthcare utilization.[1–7] For example, reductions in preventive screenings such as colonoscopies, mammograms, and Papanicolaou tests, along with decreased volumes of primary care appointments and emergency room visits, have been noted in the literature.[1–3,7–10] Few studies describe patient-reported forgone care, defined as "one who does not use healthcare, despite perceiving a need for it."[11,12] Those that have been published utilize primarily convenience sampling methods, which likely lack representation of economically disadvantaged and minoritized populations. For example, several cross-sectional online surveys used nationally representative samples of the US population to study forgone care during the pandemic (Table 1)[13–19], but their findings may not be representative of cities such as Baltimore, which are more diverse[20] and often experience higher rates of poverty.[21]

Table 1. Sampling strategies used by existing studies on forgone care during the Covid-19 pandemic among US adults

Author(s) and Publication Year	Sampling Strategy	Study Sample Characteristics (% of study sample)
Anderson et al. (2021)	Recruited a sub-set of adult individuals enrolled in NORC's AmeriSpeak Panel (n=1,337). The NORC panel uses a multi-staged probability sample representative of the US population, includes approximately 35,000 individuals, and has a recruitment rate of 34%. Participants complete surveys via internet or telephone.	Race ▪ White: 63% ▪ Black/AA: 12% Hispanic/LatinX: 17% Income <$35,000: 32%
Bertolodo et al. (2022)	Randomly selected participants (n=8,318) from the Dynata Panel to participate in an online survey. Used matching to build a sample representative of the 2019 census (by age, race, gender, and income).	Race ▪ White: 63.5% ▪ Black/AA: 11.8% Hispanic/LatinX: 16.4% Income <$30,000: 15.4%
Czeisler et al. (2020)	Adult respondents of the COVID-19 Outbreak Public Evaluation Initiative survey (n=5,412; 54.7% response rate). Survey weighting was applied to improve representativeness to the 2010 US census (for gender, age, and race/ethnicity).	Race ▪ White: 63.7% ▪ Black/AA: 12.2% Hispanic/LatinX: 16.3% Income <$25,000: 13.4%
Giannouchos et al. (2021)	Used data from the second and third wave of the Urban Institute's Coronavirus Tracking Survey, a nationally representative online survey of nonelderly adults (n=155,825).	Race ▪ White: 62% ▪ Black/AA: 11% Hispanic/LatinX: 17.5% Income <$50,000: 36.9%

Gonzalez et al. (2021)	Used data from wave 2 of the Urban Institute's Coronavirus Tracking Survey, a nationally representative online survey of nonelderly adults (n=4,007). Participants for these surveys are drawn from the Ipsos's online Knowledge Panel, which uses address-based sampling frames to cover the U.S. population.	[Demographics not reported]
Park & Stimpson (2021)	Recruited respondents (n=23,058) to the Medicare Current Beneficiary Survey COVID-19 Supplement. Surveys were completed online.	Race ▪ White: 77.2% ▪ Black/AA: 8.8% Hispanic/LatinX: 9.3% Income <$25,000: 32.9%
Zhang et al. (2022)	Recruited a sub-set of participants (multi-staged, stratified sampling, with oversampling of minority populations) drawn from the NORC AmeriSpeak Panel and the Dynata Panel (n=2,552). Surveys were completed via internet or telephone.	Race ▪ White: 61.9% ▪ Black/AA: 11.8% Hispanic/LatinX: 16.5% Income: Not reported

NORC- National Opinion Research Center, AA-African American

Existing research on forgone care also does not reflect the disparate impacts of the pandemic by community. For example, many of the articles identified in Table 1 focused on individual social and structural determinants of health (SSDoH), such as socioeconomic status, education, and income and their associations with healthcare utilization and forgone care. However, previous research has highlighted how community factors such as Area Deprivation Index, crime rate, internet coverage, reliance on transportation, walkability, racial and ethnic segregation, and proximity to care are also critical SSDoH that stem from systems rooted in racism and oppression.[22–31] Lack of acknowledgement of these factors and their relationship with forgone care during the pandemic is a critical gap, as other COVID-19 related studies demonstrated stark disparities across communities, including in SARS-CoV-2 case counts and mortality rates[32,33] and inequitable access to SARS-CoV-2 testing and treatment.[34–36] Similar inequities may have occurred amongst individuals who experienced forgone care. This is supported by published COVID-19 studies where individuals cited several community-level factors as reasons for forgoing care, including closures of local health facilities, transportation challenges, and lack of internet coverage required for telemedicine.[13,37–39]

Inequities across individual-level SSDoH, such as socioeconomic status, were associated with higher odds of forgone care during the pandemic.[13–15,19] For example, Anderson et al. (2021) found that those who were low-income, unemployed, or on Medicaid reported more missed doses of prescription medication in their cross-sectional survey.[13] Disparities between racial and ethnic groups have also been

identified. Czeisler et al. (2020) found that Black/African American and Hispanic/LatinX adults had a higher prevalence of urgent or emergency care avoidance during the pandemic, compared to non-Hispanic/LatinX White adults.[15] Similarly, Gonzalez et al. (2021) found that 39.7% of Black/African American adults had forgone care during the pandemic, compared to 34.3% of White adults.[14] Those who reported experiencing racial discrimination have also experienced more episodes of forgone or delayed care.[19] These disparities indicate that minoritized and economically disadvantaged individuals suffered disproportionate impacts on their ability to seek healthcare during the pandemic. This raised the question of whether similar disparities occurred within defined geographic areas that experience higher levels of racial and ethnic segregation, poverty, and crime and lack resources such as reliable transportation, access to healthcare services, and internet coverage. Also concerning was that minority and economically disadvantaged communities suffered higher rates of SARS-CoV-2 infection early in the pandemic[33] and likely needed additional healthcare services as a result. An inability to receive this care would have further exacerbated inequities experienced during the pandemic.

Baltimore, Maryland is a diverse city comprised of 55 community statistical areas (CSAs) and is a prominent example of how "place" and several other upstream SSDoH determine health outcomes.[40] The population is 62.4% Black, 21.2% live below the federal poverty level, and only 61.8% of individuals age 16+ are employed.[41] Health outcomes vary widely depending upon one's CSA, with life expectancy ranging from 67-87 years.[42] COVID-19 also differentially impacted certain Baltimore communities, with higher COVID-19 prevalence in neighborhoods with higher deprivation indices.[43] Disparities in which communities had access to SARS-CoV-2 testing have also been noted[44], which likely led to forgone care as a negative test was required by some area clinics and hospitals to attend in-person appointments or procedures early in the pandemic. Disparities in health outcomes also exist across other SSDoH within Baltimore, including by education status, employment, income, and health insurance coverage.[42] Extreme differences across race and ethnicity are also present—with White individuals having a lifespan 4 years longer than Black/African American individuals.[45]

The aim of this study was to address gaps in knowledge on how individual and community-level SSDoH influence healthcare utilization during a large-scale public health emergency by specifically looking at forgone care during the COVID-19 pandemic. Research on forgone care prior to the pandemic has typically focused on barriers that may lead to forgone care and subsequent unmet healthcare needs, such as financial and geographic accessibility and overall availability of services.[46] Forgone healthcare has been studied in several different contexts, including healthcare equity[47–51], cancer[52,53], and chronic disease research.[54–57] Inequities across the SSDoH, including lack of health insurance, high costs of healthcare, poor access to affordable housing, lack of access to primary care providers, and poverty have all previously been shown to be associated with forgone care.[50,57–59] Measuring forgone care is one indicator of healthcare utilization and access.[11] However, broader healthcare utilization trends are typically measured using administrative data, epidemiologic trends, and service volume indicators, which is reflected in the large number of COVID-19-related studies that focus primarily on inpatient and outpatient metrics and not patient-reported forgone care.[60]

Forgone care can lead to short and long-term health consequences, and much of these will likely not become evidence for years to come. For example, health systems have seen drastic reductions in screenings for breast, lung, colon, cervical, and prostate cancer[61], which will lead to delays in cancer diagnoses, more extensive and costly treatment, and worse prognoses. Avoidance of emergent care for life-threatening conditions such as strokes and heart attacks could similarly lead to greater long-term morbidity and mortality.[1,62,63] Importantly, a recent study by Carabello et al. (2023) found that the Black/African American population living in the US experienced 80 million excess years of life lost, compared to the White populations, over a 22-year period from 1999-2020.[64] Many of these excess deaths were attributed to cardiovascular disease and cancer. These inequities are a stark reminder of the systemic barriers to healthcare that the Black/African American population faces every day—inequities that deepened during the COVID-19 pandemic and will likely lead to even greater disparities in excess years of life lost in the coming decade.

Purpose and Study Aims

Guided by Gelberg et al.'s adaptation of the Andersen Model of Healthcare Utilization for vulnerable populations (described in the section titled "Conceptual Framework")[65], a secondary data analysis was conducted using a combined analytic sample from the Community Collaboration to Combat COVID-19 (C-FORWARD) and COVID-19 Prevention Network 5002 (CoVPN 5002) studies. Both studies aimed to measure the prevalence of the SARS-CoV-2 virus and understand the clinical and social impacts of the pandemic in Baltimore, Maryland. C-FORWARD (n=1,978) used a population representative sampling strategy, organized by census block groups. CoVPN 5002 (n=1,022) used randomized, venue-time sampling with over-sampling of venues in lower socio-economic communities in Baltimore. The aims of this study were:

- **Aim 1:** To characterize the rate of forgone care in Baltimore during the COVID-19 pandemic by individual-level factors through a cross-sectional analysis of a combined analytic sample of CoVPN 5002 and C-FORWARD participants.
- **Aim 2**: To examine the relative importance of individual and community-level SSDoH with the odds of forgone care. *H1: People living in more disadvantaged communities in Baltimore, as measured by components of the Area Deprivation Index, will have higher odds of forgone care.*
- **Aim 3**: In an exploratory analysis, compare the correlates of forgone emergency care with correlates of forgone surgical/dental procedures.

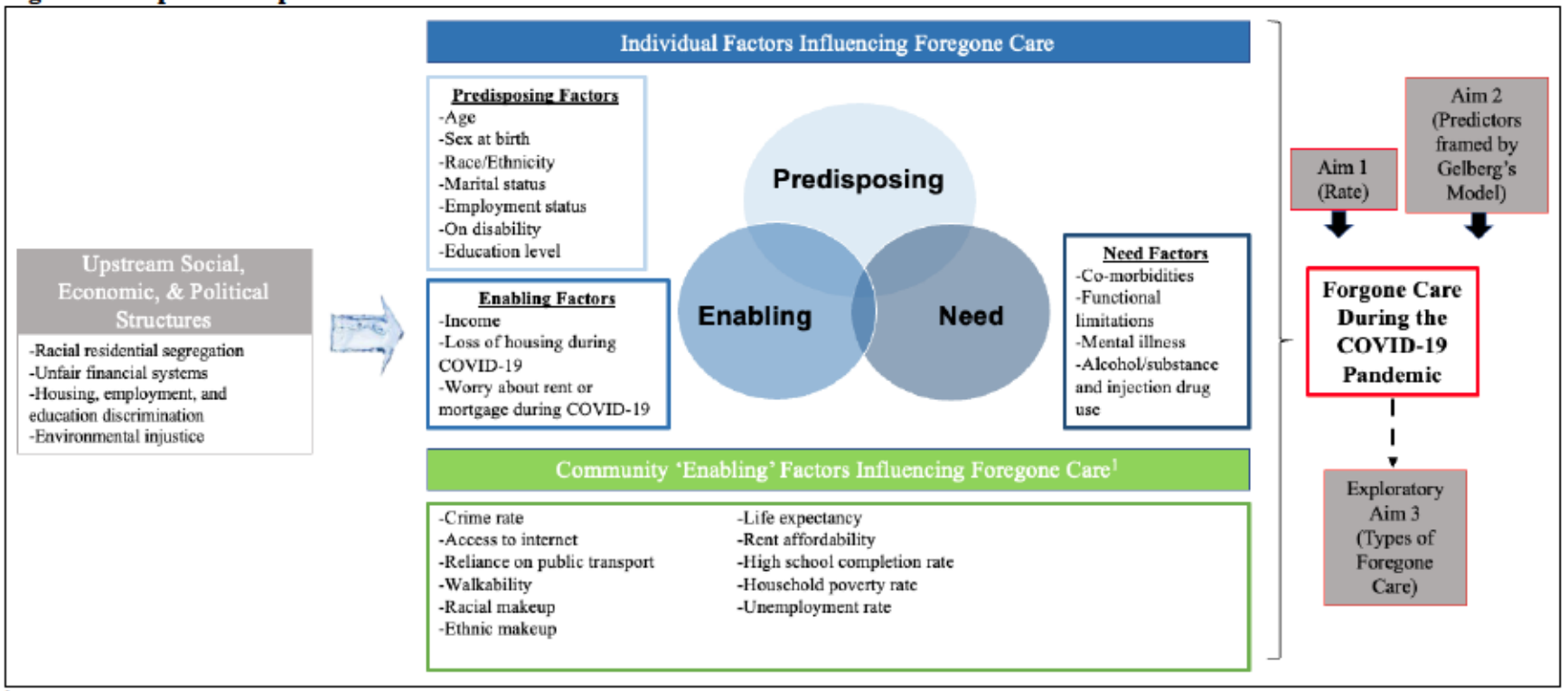
Conceptual Framework

This study was informed by the Gelberg et al. Behavioral Model for Vulnerable Populations.[65] This model is a revision of the Andersen and Newman Model of Healthcare Utilization[66], which has previously been used to examine forgone care, including during the COVID-19 pandemic.[18,19,67,68] The Gelberg et al. model was selected as it incorporated predictors of healthcare system access and utilization relevant to minoritized and underserved populations living in Baltimore, which faces higher rates of poverty, homelessness, crime, and substance use compared to cities of similar size, and experiences

widespread disparities across the SSDoH.[41,69–71] Gelberg's model has been previously used to describe primary care engagement in Baltimore amongst people who inject drugs.[72]

Gelberg et al.'s model highlights the complexities of healthcare utilization and how they are influenced by individual and community-level factors. These factors are organized into three categories: pre-disposing, enabling, and need-level.[65] Pre-disposing factors are described as those that may increase a person's propensity for seeking care and include demographic, social, and structural characteristics, such as age, race, ethnicity, and employment status. Enabling factors are resources that support use of the healthcare system, such as income, community of residence, and availability and accessibility of health service resources. Need-level factors are self-perceptions of the need for healthcare, including for diseases relevant to underserved populations such as sexually transmitted infections. This study used data available from the C-FORWARD and CoVPN 5002 studies to better understand the predisposing, enabling, and need-level factors that influenced forgone care during the COVID-19 pandemic, both at the individual and community-level. Figure 1 (page 7) depicts the adaptation of the Gelberg et al. model for this study on forgone care using variables available from the C-FORWARD and CoVPN 5002 datasets. This adaptation included the addition of the upstream social, economic, and political structures that disenfranchise people of color and other minoritized communities and lead to differential and inequitable access to the resources that influence utilization of the healthcare system.[73]

Figure 1. Adapted conceptual framework



[1]Measured at the Community Statistical Area level

Innovation

This study characterized forgone care during the COVID-19 pandemic in a large, urban population by SSDoH at the individual and community-levels. The operationalization of the SSDoH was informed by the Gelberg et al. Behavioral Model for Vulnerable Populations, which highlights the pre-disposing, enabling, and need-level factors relevant to healthcare utilization. It was also informed by previous research studies that have identified which community-level factors support or hinder use of the healthcare system.

Use of a combined analytic sample leveraged the strengths of two robust sampling strategies. The C-FORWARD study utilized a multi-staged, random household by census block group (CBG) sampling strategy that was stratified by race, ethnicity, and socioeconomic status, with oversampling of CBGs with a higher proportion of racial minorities and CBGs with lower socio-economic status. The CoVPN 5002 study utilized a venue-time sampling strategy with venues randomly selected across Baltimore, including federally qualified health centers, low-income housing, food pantries, and shelters. Combining these datasets increased the power needed to examine how individual and community-level SSDoH were associated with forgone care during the COVID-19 pandemic. It also improved representation of minoritized and underserved communities that are not likely represented in the current COVID-19 forgone care literature. This allowed for a more comprehensive picture of how the SSDoH influenced forgone care during the pandemic and will be generalizable to other urban areas with similar populations.

Knowledge gained from this study can help health systems better understand which individuals and communities may be at highest risk for short and long-term health consequences of forgone care. It also helps elucidate who may be at continued risk for forgone care as the health system adjusts to the long-term impacts of the pandemic, including shortages of supplies and healthcare workers. Finally, in a world where pandemics and other humanitarian emergencies are becoming more common due to population growth, climate change, and global travel, this research can help highlight the downstream impacts of large-scale health emergencies on healthcare access and utilization that go well beyond the

morbidity and mortality caused by the event itself. This can help support advocacy efforts around the importance of strengthening health systems as a key component to improving overall global health security against future threats. For example, it may help inform policies and identify key factors that are necessary to strengthen models of care so that health systems can continue to support individual and community health during future public health emergencies. Importantly, this will include advocating for the need to address the upstream social, economic, and political structures that allow for inequities to persist across the SSDoH and subsequently undermine the world's ability to support individual and community health during large-scale public health emergencies.

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CHAPTER 2: MANUSCRIPT ONE

Impact of the COVID-19 pandemic on HIV healthcare service engagement, treatment adherence, and viral suppression in the United States: A systematic literature review

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Abstract

The COVID-19 pandemic has necessitated adaptations in how healthcare services are rendered. However, it is unclear how these adaptations have impacted HIV healthcare services across the United States. We conducted a systematic review to assess the impacts of the pandemic on service engagement, treatment adherence, and viral suppression. We identified 26 total studies spanning the beginning of the pandemic (March 11, 2020) up until November 5, 2021. Studies were conducted at the national, state, and city levels and included representation from all four CDC HIV surveillance regions. Studies revealed varying impacts of the pandemic on HIV healthcare retention/engagement, medication adherence, and viral suppression rates, including decreases in HIV healthcare visits, provider cancellations, and inability to get prescription refills. Telehealth was critical to ensuring continued access to care and contributed to improved retention and engagement in some studies. Disparities existed in who had access to the resources needed for telehealth, as well as among populations living with HIV whose care was impacted by the pandemic.

Introduction

There are over 1.2 million people living with human immunodeficiency virus (PWH) in the United States (U.S.) [1]. Current treatment recommendations for PWH include initiation of care for those newly diagnosed, regular attendance of appointments with HIV providers, and antiretroviral therapy (ART) access and adherence [2]. These services are critical to reaching and maintaining viral suppression, which prevents HIV-associated morbidity and mortality and prevents further disease transmission [3]. Unfortunately, the Coronavirus 2019 (COVID-19) pandemic has led to widespread disruptions in the U.S. healthcare system and cancellation or postponement of preventive and routine healthcare appointments, including those that provide critical services to PWH [4]. These disruptions, coupled with pre-existing health inequities experienced by PWH including lack of transportation, limited access to technology, and poverty [5], could have a lasting impact on individual and community health. One modeling study predicted that disruptions in HIV-related services during the pandemic, including ART initiation and viral suppression, could lead to an additional 4.8 deaths in a population of 2000 HIV-infected men who have sex with men over a year in Baltimore, Maryland [6].

People with HIV are at high risk for pandemic-related disruptions because they require consistent and regular engagement with the healthcare system to maintain viral suppression [5]. There is also greater representation of people with socio-economically disadvantaged backgrounds, as well as over representation of minority communities, which may also influence health seeking behavior and engagement in care during the pandemic [7]. Barriers such as lack of access to the technology required for telemedicine and inability to travel to receive health services may disproportionately impact these individuals [5]. Additionally, PWH often suffer from other comorbidities that may increase their risk for COVID-19-related morbidity and mortality, and thus may be more fearful to attend in-person appointments, including laboratory appointments necessary to monitor their health [8].

The COVID-19 pandemic has necessitated several adaptations in how HIV services are rendered, such as massive upscaling of telemedicine, increased outreach by social workers, and increased use of mail-order pharmacies [9]. It remains to be seen how the transition of healthcare services during the

pandemic has impacted access to and use of HIV healthcare services across the U.S. The objective of this systematic review is to synthesize existing literature to better our understanding of how the COVID-19 pandemic has impacted engagement and retention in HIV healthcare services, treatment adherence including ART access and utilization, as well as viral suppression for PWH in the U.S. Additionally, it aims to identify some of the unique and innovative strategies implemented during the pandemic to adapt HIV care models and maintain these critical services.

Methods

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Supplementary Table 1) [10]. This review and protocol have been registered on PROSPERO (CRD42021249550).

Data sources

Electronic databases searched for this review were PubMed, Embase, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, and PsycINFO. PubMed and Embase were used as they provide extensive access to the biomedical literature. CINAHL, Web of Science, and PsycINFO provided additional access to the nursing and allied health literature, behavioral and social science literature, and literature from other disciplines such as arts and humanities.

The search used a combination of PubMed Medical Subject Heading terms, including variations of 'COVID-19' and 'HIV' that were developed in consultation with a medical librarian and later adapted for CINAHL, Embase, Web of Science, and PsycINFO (Supplementary Table 2). The COVID-19 search string was modified from The Johns Hopkins University Welch Medical Library [11]. Additional search terms (e.g., "United States") were added to narrow the focus of the review to the U.S. Searches of relevant organizational websites (e.g., the Centers for Disease Control and Prevention, National Institutes for Health) and of the grey literature (e.g., Google, Google Scholar) were also conducted to locate resources not identified in the database search. An initial search using the PubMed, CINAHL, and

Embase databases was conducted on September 9, 2021. The same search was re-run prior to data analysis on November 5, 2021 to identify any newly published articles. The PsycINFO and Web of Science databases were later added (using a date cutoff of November 5, 2021) to capture any additional literature not identified in the previous databases.

Inclusion and exclusion criteria

Included studies were published in English-language journals and discussed impacts of the COVID-19 pandemic on retention and engagement in HIV healthcare services (e.g., changes in the number of clinic visits, non-attendance rates, etc.), treatment access and utilization (e.g., ART prescription refills, ability to obtain ART, treatment adherence, etc.), and viral suppression rates specific to PWH.

Exclusion criteria included articles that focused solely on healthcare access during the pandemic for PWH to treat conditions other than HIV (e.g., for hypertension, substance use, mental health disorders, etc.) or that only discussed HIV prevention (e.g., PrEP, condom use) or testing during the COVID-19 pandemic. "Calls to action", notes from the field, or other types of commentaries or letters that provided anecdotal recommendations or data, such as discussion of changes made to HIV care models, but that did not either collect data from providers or patients or discuss the study methodology used were also excluded. Finally, the scope of this review was limited to only those studies published in the U.S. to allow for a more thorough and targeted understanding of the impacts of the pandemic on different regions of the US.

Study selection

Article titles and abstracts were divided up amongst research team members (DM, OO, BD, or SES) and screened independently for eligibility by two reviewers using the previously stated inclusion criteria. Articles included after title and abstract review were then reviewed at-length independently by two reviewers for study inclusion. Any discrepancies that arose between the two reviewers during title

and abstract screening or full article review were discussed until consensus was reached. References of the included articles were also screened for relevance. Article screening and review was completed using the web-based software Covidence [12].

Data extraction

Data was independently extracted by four reviewers, in pairs of two (DM, OO, BD, or SES) using a survey created in Google Forms previously piloted by the research team. Any discrepancies that arose between the reviewers during data extraction were discussed until consensus was reached. Extracted data included study design; study outcome(s); study location; sample description; observable measures; time period of study data collection; data on retention or engagement in HIV healthcare services, medication adherence, and viral suppression; and adaptations in HIV healthcare delivery models made to overcome challenges introduced by the COVID-19 pandemic. After abstraction, studies were organized by the Centers for Disease Control (CDC) and Prevention HIV surveillance regions and by study sample characteristics (e.g., economically disadvantaged, older adults, etc.) to facilitate comparisons of COVID-19 impacts.

Quality of evidence assessment

The quality of evidence included in this review was assessed independently by two study researchers (DM, OO, BD, or SES) using the Mixed Methods Appraisal Tool (MMAT) [13]. This tool is designed to be used for systematic literature reviews that include studies with qualitative, quantitative, and mixed methods approaches [13]. Studies are assessed across five different criteria depending on the study type. These criteria include [13]:

- Qualitative studies: adequacy of research approach used, adequacy of data collection, appropriate derivation of data, appropriate interpretation of data, coherence of data across sources

- Quantitative (randomized controlled trials) studies: appropriate randomization, comparability of groups at baseline, completeness of outcome data, blinding, adherence of participants to intervention
- Quantitative (non-randomized) studies: representativeness of the sample to target population, use of appropriate measurements, completeness of outcome data, accountment of confounders, intervention administered as intended
- Quantitative descriptive studies: relevance of sampling strategy, representativeness of the sample to target population, use of appropriate measurements, low risk for nonresponse bias, use of appropriate statistical analysis
- Mixed methods studies: adequate rationale for study design, appropriate integration of study components, appropriate interpretation of data, adequacy in addressing divergencies in study data, adherence to quality criteria for each method used

Any discrepancies that arose between the two reviewers during the quality assessment process were discussed until consensus was reached.

Statistical analysis

Due to the heterogeneity of study data reported in this systematic review, a meta-analysis was not conducted. The results are instead presented according to thematic areas present across studies.

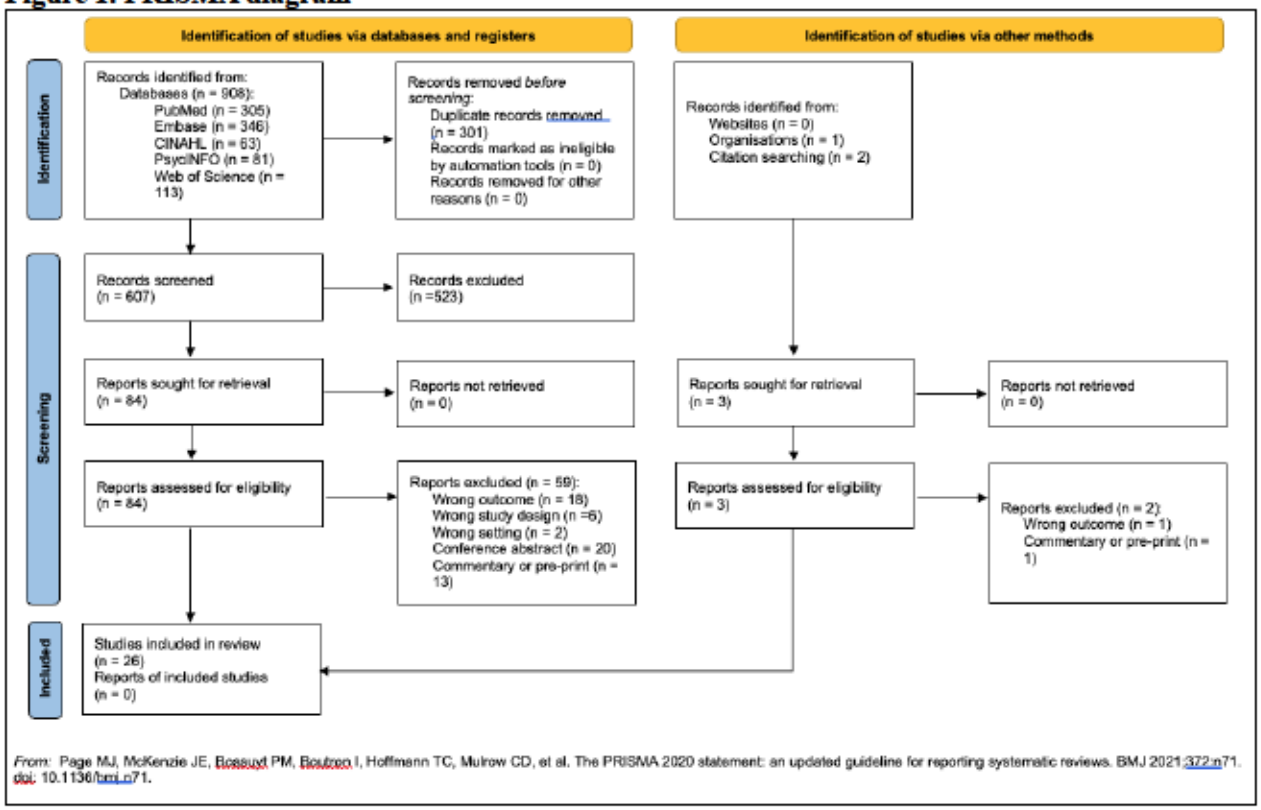
Results

Study selection

In total, the five database searches yielded 908 articles. After de-duplication, a total of 607 article titles and abstracts were screened. Five hundred and twenty-three studies were excluded during title and abstract screening, and 84 underwent full text review. Two additional articles and one report were later

screened that were identified through the search of organizational websites and grey literature and review of included article citations. In total, 26 articles were included in the review (Fig. 1).

Figure 1. PRISMA diagram



Methodological quality of the included studies

Quality of evidence was assessed using the MMAT. The one qualitative study identified in this review met all five methodological quality criteria (Table 1). Of the twenty quantitative descriptive studies (Table 2), most used a relevant sampling strategy for the research question (95%), appropriate measurements (90%), and appropriate statistical analyses based on the research question (90%). Nearly three-quarters (70%) used a sample representative of the target population and 40% had a low risk for nonresponse bias. Of the five mixed methods studies (Table 3), all (100%) had rationale for using a mixed methods design and integrated and interpreted the different study components adequately. Over half (60%) of the studies addressed inconsistencies in the data and adhered to the criteria necessary for the methods utilized.

Table 1. Description and quality of evidence assessment for qualitative studies (n=1)

		Quality of Evidence Assessment[a]				
Study Reference	**Sample, Sample Size, & Location**	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**
Rhodes et al. (2021)	-Participants of the *weCare* intervention (n=15) -North Carolina	Y	Y	Y	Y	Y

[a]Mixed Methods Assessment Tool questions:
Q1. Is the qualitative approach appropriate to answer the research question? Q2. Are the qualitative data collection methods adequate to address the research question? Q3. Are the findings adequately derived from the data? Q4. Is the interpretation of results sufficiently substantiated by data? Q5. Is there coherence between qualitative data sources, collection, analysis, and interpretation?

Legend: Y-yes, N-no, ?-unclear

Table 2. Description and quality of evidence assessment for quantitative descriptive studies (n=20)

		Quality of Evidence Assessment[a]				
Study Reference	**Sample, Sample Size, & Location**	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**
Algarin et al. (2020)	-Older adults enrolled in a clinical trial (n=16 PWH) -Miami, FL	N	?	Y	N	Y
Bogart et al. (2021)	- Black Americans participating in an RCT (n=101 PWH) -Los Angeles County, CA	Y	Y	Y	N	Y
Chen et al. (2021)	-Black MSM and transgender women enrolled in an existing study (n=90 HIV+, n=132 HIV-) -Chicago, IL	Y	Y	?	N	Y
Cooley et al. (2021)	- Patients who were previous study enrollees (n=133 HIV+, 54 HIV-) -St. Louis, MO	Y	Y	?	N	?
El-Nahal et al. (2021)	-Patients enrolled in an HIV clinical cohort with a scheduled visit (Pre-C19 n=2,010; during C19 n=1,929) -Baltimore, MD	Y	Y	Y	Y	Y
Ennis et al. (2021)	-Patients from community healthcare clinics living with or at risk for HIV (n=4,280 HIV+, 593 HIV-; 11,006 encounters) -Florida	Y	Y	Y	Y	Y
Fadul et al. (2021)	- Visits to an HIV clinic (n=1,559 scheduled clinic visits, including new patients; 1,167 established patient visits) -Nebraska	Y	Y	Y	Y	?
Genberg et al. (2021)	- Members of the AIDS Linked to the IntraVenous Experience cohort (n=144 HIV+, 295 HIV-) -Baltimore, MD	Y	Y	Y	Y	Y
Hickey et al. (2021)	- Patients enrolled in POP-UP, a care model for PWH experiencing homelessness (n=85) -San Francisco, CA	Y	?	Y	Y	Y
Hochstatter et al. (2020)	- PWH and substance use disorder at HIV clinics (pre-C19 n=194 weekly surveys, 60 individuals; during C19, n=148 weekly surveys, 43 individuals) -Wisconsin	Y	N	Y	?	Y
Kalichman et al. (2020)	- PWH (ages 20-37 years) who were also positive for active substance use (n=162) and currently participating in an ART adherence study -Atlanta, GA	Y	Y	Y	Y	Y
Kalichman et al. (2021)	- African American/Black MSM, recruited through social media and snowball sampling (n=148 HIV+ men, 338 HIV- men) -Atlanta, GA	Y	Y	Y	N	Y
McGinnis et al. (2021)	- Members of the Veterans Aging Cohort Study living with HIV with at least one outpatient visit (n=27,674 records) -National	Y	Y	Y	Y	Y

McKay et al. (2021)	- LGBTQ individuals (age 18+) recruited on social media (n=728 gay/bisexual men) -National	Y	Y	Y	N	Y
Nguyen et al. (2021)	- Individuals (>50 years of age) who identified as being HIV+ (n=100) -Palm Springs, CA	Y	N	Y	N	Y
Sanchez et al. (2020)	- Responses from the American Men's Internet Survey (n=1,051, 122 identified as HIV+) -National	Y	Y	Y	N	Y
Sorbera et al. (2021)	- PWH who needed ART renewals or follow-up during C19 (n=211 patients) -Brooklyn, NY	Y	Y	Y	Y	Y
Spinelli et al. (2020)	- PWH on publicly funded insurance who attend a safety-net clinic (pre-C19 n=4,153 visits; during C19 n=1,997 visits) -San Francisco, CA	Y	Y	Y	?	Y
Tamargo et al. (2021)	- Participants from the Miami Adult Studies on HIV cohort (n=183 HIV+, 116 HIV-) -Miami, FL	Y	Y	Y	?	Y
Wion & Miller (2021)	- PWH (ages 18+) recruited via social media platforms (n=85) -National	Y	Y	Y	N	Y

[a]Mixed Methods Assessment Tool questions:
Q1. Is the sampling strategy relevant to address the research questions? Q2. Is the sample representative of the target population? Q3. Are the measurements appropriate? Q4. Is the risk of nonresponse bias low? Q5. Is the statistical analysis appropriate to answer the research question?

Legend: Y-yes, N-no, ?-unclear, C19-COVID-19, ART-anti-retroviral therapy, HIV-human immunodeficiency virus, PWH-people living with HIV, RCT-randomized controlled trial, MSM-men who have sex with men

Table 3. Description and quality of evidence assessment for mixed methods studies (n=5)

		Quality of Evidence Assessment[a]				
Study Reference	**Sample, Sample Size, & Location**	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**
Auchus et al. (2021)	-Patients at a HIV primary care clinic (n=966 records, n=202 surveys) -San Francisco, CA	Y	Y	Y	?	?
Campbell et al. (2021)	-Message exchanges between PositiveLink members (n=497 patients) and their care team (n=6,668 exchanges) -Virginia	Y	Y	Y	Y	Y
Dawson & Kates (2020)	- Directly funded Ryan White medical provider grantees (n=161) -National	Y	Y	Y	?	N
Gwadz et al. (2021)	- African American/Black or Latino PWH from low-SES background participating in an existing study (n=96 surveys, n=26 interviews) -New York City, NY	Y	Y	Y	Y	Y
Qiao et al. (2021)	- Ryan White clinics (n=27) -South Carolina	Y	Y	Y	Y	Y

[a]Mixed Methods Assessment Tool questions:
Q1. Is there an adequate rationale for using a mixed methods design to address the research question? Q2. Are the different components of the study effectively integrated to answer the research question? Q3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? Q4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? Q5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Legend: Y-yes, N-no, ?-unclear, HIV-human immunodeficiency virus, PWH-people living with HIV, SES-social economic status

Studies characteristics

Descriptions of the study type, sample, sample size, and study location can be found in Tables 1-3 and Supplementary Table 3. Most articles (n=20) were quantitative, non-experimental, descriptive studies and included cross-sectional and longitudinal surveys, a time series analysis, and retrospective reviews of electronic health records or other data sources. The articles also included mixed methods studies (n=5) and one qualitative study. Studies were conducted at the city and state levels and included all four U.S. CDC National HIV Surveillance System regions. Thirty-eight percent of studies were conducted in the southern region of the U.S., which is also disproportionately impacted by HIV [14]. Five studies used data collected from a nationally representative sample.

Included studies primarily used convenience sampling and recruited participants from various sources. Several studies used survey responses or other data (e.g., from electronic health records, interviews) from participants who were previously or currently enrolled in clinical trials or other study cohorts or interventions (n=12) [15–26] or who were existing HIV clinic patients (n=7) [27–33]. Three studies recruited participants using social media [34–36], one study used participants who completed an separate online survey that linked to a COVID-19 survey [37], and one study recruited participants using mailing lists [38]. Two studies utilized data provided by Ryan White clinics [9,39].

Fifteen studies looked at the impacts of the pandemic within specific communities living with HIV, including those who identified as Black or LatinX [16,18], identified as a member of the LGBTQ community or MSM [23,34,37], identified as Black MSM [26,35], were of older age [19,38], were economically disadvantaged [22,24,28], or those who reported substance use [21,25,30]. Of the other nine studies that reported participant data (e.g., excluding the two studies that used data provided by Ryan White clinics), seven included varying levels of representation across genders, sexual orientations, races, ethnicities, and other demographic factors [15,17,20,29,31,32,36]. Two did not provide a demographic overview of the study sample [27,33].

Themes included impacts on retention and engagement in HIV healthcare services, challenges in filling or obtaining ART prescriptions, and changes in viral suppression rates. Table 4 provides a summary of the relevant findings of each article, organized by study sample characteristics. Supplementary Table 3

provides a more thorough database of specific findings and statistical tests, as they relate to the research questions of this systematic review.

Table 4. Summary of evidence by study sample characteristics

Reference	Region[1]	Summary of Findings Relevant to Research Question
HIV Service Providers		
Dawson & Kates (2020)	National	Almost all (99%) Ryan White providers surveyed (n=161) reported currently offering telehealth services, compared to only 22% prior to the pandemic. Other services provided included multi-month and mail-order prescription services. Providers reported increases in new and uninsured patients, reduced frequency of laboratory visits, and varied impacts on patient retention and ability to meet patients' healthcare needs.
Qiao et al. (2021)	South	Over half (56%) of Ryan White clinic program reports analyzed (n=27) reported partial interruptions in HIV services offered. Clinics reported reducing hours, limiting in-person appointments, stopping home visits and support groups, using telehealth, and assisting with medication pick-up. The severity of service interruption did not correspond to the density of C19 cases. Evidence suggested that areas with no HIV service interruptions had a higher percentage of insured individuals.
Minority Race and Ethnicities		
Bogart et al. (2021)	West	Among a sample (n=101) of Black PWH, participants reported cancelling appointments/avoiding care (18%), inability to get HIV medications (6%), and negative impacts on their HIV care or care for other health conditions (22%). Participants who reported more disruptions due to the pandemic (e.g., decreased work, decreased access to transportation) had lower odds of ART adherence.
Chen et al. (2021)	Midwest	Among a sample of Black MSM and transgender women enrolled in an existing study, those with HIV (n=90) interviewed earlier in the pandemic (April-June, 2020) reported no significant difference in access to ART compared to those interviewed later (June-July, 2020). However, those exposed to interpersonal violence, who lost insurance, and who experienced a higher financial burden to travel had greater perceived difficulty in getting ART during the pandemic.
El-Nahal et al. (2021)	South	Amongst Black PWH enrolled in an HIV clinical cohort, participants reported a significant increase in visit completion during C19, compared to pre-C19.
Ennis et al. (2021)	South	Black and Hispanic patients of a community health clinic with HIV or at risk for HIV had lower odds of completing telehealth visits via video than White and non-Hispanic individuals.
Gwadz et al. (2021)	Northeast	A sample of African American/Black and Latino PWH (n=96) reported cancellations of medical (69.8%) and social worker appointments (60.4%), avoidance of healthcare facilities (41.7%), and an inability to get to a pharmacy (13.5%) or their medications (9.4%). Over half reported an increased desire for ART adherence during C19, and 39.5% reported increasing how often they took their ART.
Kalichman et al. (2021)	South	Amongst a sample of African American/Black MSM, those with HIV were significantly more likely than those without HIV to report cancelling a doctor's appointment or having an appointment cancelled by a clinic or doctor.
McGinnis et al. (2021)	National	Percentage of PWH who had virtual visits (≥ 1 visit) in 2019 and 2020 was similar across race (Black, White) and ethnicity (Hispanic, not Hispanic). While fewer VL tests were completed in 2020, the percentage of PWH who had VL measured was similar across race/ethnicities. ART coverage was similar across race/ethnicities for both years.
Spinelli et al. (2020)	West	In a sample of PWH who attend a safety-net clinic, younger (≤35 years) and Black patients had increased odds of viral nonsuppression both before and during C19.
Reported Gender/Sex		
El-Nahal et al. (2021)	South	Amongst women living with HIV enrolled in an HIV clinical cohort, participants reported a significant increase in visit completion during C19, compared to pre-C19.
McGinnis et al. (2021)	National	Percentage of patients who had virtual visits (≥ 1 visit) in 2019 and 2020 was similar for men and women. Women were more likely to have virtual appointments (vs. in-person) and less likely than men to have VL measured for both years.
LGBTQ Community and MSM		
McKay et al. (2021)	National	LGTBQ identifying men living with HIV were 55% more likely to report challenges in accessing healthcare during the pandemic than men who reported being HIV-negative.
Rhodes et al. (2021)	South	Among a small cohort of racially and ethnically diverse gay and bisexual MSM and transgender women living with HIV (n=15), participants did not report interruptions in HIV

		care, but some did have challenges accessing other types of medical care. Participants were able to get their HIV medications but reported challenges in adherence.
Sanchez et al. (2020)	National	MSM living with HIV (n=122) reported decreased access to HIV care and laboratory testing. A smaller percentage reported challenges with ART access and/or adherence.
Economically Disadvantaged Populations		
Ennis et al. (2021)	South	Publicly insured patients of a community health clinic with HIV or at risk for HIV had lower odds of completing telehealth visits via video than those with private insurance.
Hickey et al. (2021)	West	Percentage of patients with a monthly visit and odds of viral suppression did not change significantly when comparing time periods during the pandemic to periods prior to the pandemic among 85 unstably housed individuals enrolled in a program to address HIV care barriers.
Spinelli et al. (2020)	West	In a sample of PWH who attend a safety-net clinic, those who attended via telephone had a reduced odds for no-show (compared to in-person) during C19. Patients had increased odds of viral nonsuppression during C19 compared to before C19. Those experiencing homelessness had higher odds of viral nonsuppression during C19.
Tamargo et al. (2021)	South	In a cohort of underserved PWH (n=183), only 6% reported missing a clinic visit with an HIV service provider. A small percentage of PWH also reported avoiding pick up their ART (13.2%) and missing at least one dose of ART in the past month (8.2%) due to the pandemic.
Older Adults		
Algarin et al. (2020)	South	Of a sample of older adults living with HIV (n=16), all were able to receive their ART. Most individuals reported little impact on their ability to keep HIV care appointments or maintain contact with their case manager.
Ennis et al. (2021)	South	Older patients of a community health clinic with HIV or at risk for HIV had lower odds of completing telehealth visits via video than younger individuals.
Nguyen et al. (2021)	West	Impacts reported among a sample of older (≥50 years of age) PWH (n=100) included inability to attend healthcare provider appointments (46%) and missed doses of HIV medications (24%). Those who reported an inability to attend provider appointments had greater odds of missing a dose of their HIV medications.
People Who Use Substances		
Genberg et al. (2021)	South	Among PWID enrolled in a community-based cohort, 130 of 144 PWH reported being on ART. Of those, 86% reported having a 4-week supply and 94% had received information about how to get their medications during COVID-19 related restrictions.
Hochstatter et al. (2020)	Midwest	Percentage of PWH and substance use disorder who missed an ART dose ≥2 days of the week increased to 12% during C19, compared to 5% pre-C19. Confidence in one's ability to keep next appointment with HIV provider decreased.
Kalichman et al. (2020)	South	Among a cohort of PWH enrolled in an ART study who tested positive for active substance use (n=162), 19% reported missing an appointment with their HIV provider in the last month and 45% of them stated it was due to C19. Forty-five percent reported cancellations by a medical provider. Practicing greater C19 protective measures was significantly related to inability to access medications or get to a pharmacy.
Samples not restricted to specific characteristics[3]		
Auchus et al. (2021)	West	The percentage of appointments conducted via telehealth at a primary care clinic increased when comparing 2020 attendance to 2019. Nearly half of all participants (n=202 PWH) preferred in-person appointments, and nearly a quarter reported being more likely to attend in-person (vs. virtual) visits.
Campbell et al. (2021)	South	There was a 25% increase during C19 in the number of messages exchanged using a mobile health intervention that provides health services to PWH. The mean member-sent and provider-sent message rate both increased significantly during C19 compared to pre-C19. The most common C19 related message topic was care coordination.
Cooley et al. (2021)	Midwest	PWH (n=133) reported greater impacts of the pandemic on medical access than those without HIV (n=54) amongst a sample of individuals who had previously been enrolled in research studies.
El-Nahal et al. (2021)	South	Amongst a sample of PWH enrolled in an HIV clinical cohort, participants reported a significant increase in visit completion during C19, compared to pre-C19.
Ennis et al. (2021)	South	Nearly all patients of a community health clinic with HIV or at risk for HIV completed scheduled telehealth visits via video. The odds of completing a video telehealth visit did not differ between PWH and those without HIV.
Fadul et al. (2021)	Midwest	Only 21% of scheduled visits were missed at an HIV clinic, and over a third of established patient visits (n=1,167) were telemedicine visits (vs. in-person). The percentage of telemedicine vs in-person visits did not differ within race, ethnicity, age, or gender categories.

		Higher VS rates were identified in those who attended visits via telehealth vs. in-person. There was a decrease in medical visit frequency and an increase in gaps in care.
McGinnis et al. (2021)	National	The number of virtual visits for all PWH enrolled in the Veterans Aging Cohort Study (n=27,674) with ≥1 visit in 2019 or 2020 increased from 27% in 2019 to 64% in 2020. Nearly all these visits were conducted by telephone (vs. video). The percentage of patients who had their VL measured decreased in 2020; the percentage taking ART was similar for both years.
Sorbera et at. (2021)	Northeast	In a sample of 211 PWH at a primary care clinic, no significant change was identified in the percentage virally suppressed or with an undetectable viral load, when comparing a period during C19 to pre-C19. The percentage with CD4 cell counts >200 cells/mm^3 decreased from 92.6% to 78.3%.
Wion & Miller (2021)	National	In general, participants (n=85 PWH) recruited via social media reported moderate to high confidence that they could contact their HIV provider or pharmacy, if required. Decreases were reported in access to social support groups and overall HIV self-management, when comparing during to pre-pandemic.

[1]Regions used in CDC's National HIV Surveillance System: Northeast (NE): CT, ME, MA, NH, NJ, NY, PA, RI, VT; Midwest (MW): IL, IN, IA, KS, MI, MN, MO, NE, ND, OH, SD, WI; South (S): AL, AR, DE, DC, FL, GA, KY, LA, MD, MS, NC, OK, SC, TN, TX, VA, WV; West (W): AK, AZ, CA, CO, HI, ID, MT, NV, NM, OR, UT, WA, WY

[2]Includes studies that used participant data from HIV clinics or from other cohorts or interventions not limited by other demographic variables (e.g., not limited to MSM, certain race/ethnicities, etc.). Several studies listed in this section are also listed elsewhere in the table as the authors report results in aggregate and by selected demographic categories.

HIV-Human Immunodeficiency Virus, PWH-people living with HIV, ART-antiretroviral therapy, MSM-men who have sex with men, C19-COVID-19, VL-viral load, VS-viral suppression

Retention and engagement in HIV healthcare services

Studies revealed decreased and missed HIV healthcare visits [18,22,25,29,35,37,38], cancellation of visits by healthcare providers [18,22,25,35], changes in and difficulty accessing medical care [17,21,34], decreased confidence or ability to manage HIV care [30,36], and an inability to access other support services such as social workers [18,36]. These findings primarily came from participant-reported cross-sectional data and included studies conducted at the national level and from all four geographic regions. The percentage of studies reporting decreased or missed HIV healthcare visits or changes in PWH's ability to attend visits ranged from 6% [22] to as high as 46% [38]. In the southern region, six of the seven studies that included quantitative data on HIV healthcare visits and challenges with care reported less than 20% of study participants had missed a scheduled HIV healthcare visit, did not complete a visit, or had challenges getting care [19–22,25,31]. Two studies conducted in the midwest region had similar findings, with 13.5% of participants in one study reporting changes or loss in medical care [17] and 21% of scheduled HIV clinic visits in another study missed by patients [29]. Three studies in total—one each from the western, northeastern, and southern regions—reported missed or cancelled

visits in approximately 45% of study participants [18,35,38]. Two of these studies were conducted in minority populations [18,35].

Participants in three studies—two from the southern region and one from the northeastern region—reported having visits cancelled by their healthcare provider, ranging from 45% [25] to nearly 70% of respondents [18]. Several studies also captured PWH who themselves had cancelled or avoided healthcare due to the COVID-19 pandemic, including due to fear of contracting SARS-CoV-2, the virus that causes COVID-19 disease [16,18,35]. The percentage of respondents who reported cancelling/avoiding medical care due to the pandemic ranged from 18% [16] to 45% [35].

Two studies from the western region found no changes in HIV healthcare visits when comparing time periods during the pandemic to time periods previous to the pandemic [24,28]. For example, Hickey et al. (2021) found no significant difference when comparing the mean number of visits per month. Additionally, one retrospective review of patient data from the southern region found a statistically significant increase in visit completion during the pandemic (either in-person or telehealth) [20]. This included an increase in the percentage of women and Black patients who completed visits, which was attributed in part to the increase in telehealth [20]. Ryan White providers reported anecdotal reductions in "no show" appointments and improved access to "hard to reach populations," which many attributed to the increased use and availability of telehealth [9].

Telehealth, along with the use of other technologies, helped to ensure continued access to HIV services during the pandemic. There were increases in the number of clinics that offered telemedicine services and the percentage of appointments conducted via telemedicine, when comparing time periods before the pandemic to those during the pandemic [9,15,20,27]. For example, one San Francisco HIV clinic conducted 86.9% of all appointments by telehealth from March to June 2020, compared to 5.3% from October 2019 to March 2020 [27]. Another technology that helped increase engagement during the pandemic included a mobile health intervention known as PositiveLinks that allowed sharing of messages between HIV providers and their patients [33].

Several studies that compared the impacts of COVID-19 within certain populations identified disparities in access to and engagement with healthcare services. Three studies found differences in the ability to engage with or access healthcare providers when comparing individuals with vs. without HIV [17,34,35], including in a population of Black/African American MSM [35] and amongst men who identified as LGBTQ [34]. For example, McKay et al., in a national study of members of the LGBTQ community, found that HIV positive men were 55% more likely to report challenges in accessing healthcare compared to HIV negative men [34]. Another study found disparities when comparing Black and LatinX patients to White patients, whom they found had a lower odds of completing video telehealth visits (vs. phone only) [31]. This study also found lower odds of completing video visits amongst older adults (compared to younger) and those on public insurance (compared to private)[31]. Another study found that ability to attend appointments via telephone, rather than in-person, improved the odds of visit completion amongst PWH who attended a safety-net clinic in California [28].

Disparities in which providers were impacted by COVID-19 related disruptions were also noted. Qiao et al. (2021) found evidence that less HIV service interruptions may have occurred in geographic areas with a higher percentage of insured individuals. Importantly, existing community-based interventions to improve HIV care engagement helped to ensure continuity of care during the pandemic, including for vulnerable communities such as those experiencing unstable housing [24,28,33].

Patient and provider perspectives on and challenges around the use of telehealth varied. Patient-reported advantages of telemedicine included that it was convenient [18,27] and was safer as it reduced opportunity for SARS-CoV-2 transmission [27]. Disadvantages included lack of access to technology and technical challenges [18,23,27], unfamiliarity with using video platforms [27], and lack of human connection with the HIV service provider [18,27]. Barriers around the use of telemedicine from the provider perspective included lack of patient access to technology [9,29], challenges with reimbursement [9], and lack of clarity around telemedicine documentation and on which patients met criteria for the use of telemedicine [29]. Workarounds to these barriers included the designation of "telehealth champions",

the use of templates to guide workflows, and the use of telephone visits instead of video [29], as well as providing patients' access to phone cards or data plans [9].

Challenges in filling or obtaining ART prescriptions

Studies also identified participants who reported having difficulties filling or obtaining their ART prescriptions and included a national study as well as studies from the southern, northeastern, midwestern, and western regions [16,18,22,25,26,37]. These percentages ranged from between approximately 6-22% of respondents living with HIV [16,18,22,25,26,37]. The largest percentage of individuals who reported difficulties in accessing ART was found in a sample of Black MSM and transgender women living in Chicago [26]. Studies also captured participant-reported missed ART doses [18,22,23,30,38]. For example, one study of PWH who reported alcohol/alcohol use found that 12% missed 2 or more ART doses during the week, compared to 5% before the pandemic [30]. The largest percentage of participants who reported missing ART doses was found in a cross-sectional survey of older adults (>50 years of age) living with HIV, where 24% reported missing a dose [38]. Some of the reported reasons for missing ART doses in the literature included forgetting to take doses [38], disruptions in regular routines [23], and inability to get a prescription or get to a pharmacy [18,25,37]. Studies that assessed ART adherence or coverage identified only small decreases when comparing time periods during the pandemic to before the pandemic [15,18,37]. One study reported increased adherence to ART due to heightened fears of participant's increased risk of COVID-19-related morbidity and mortality as a PWH [18].

Disparities were also noted in those who experienced interruptions in their ART regimen, and were particularly pronounced in individuals who experienced greater COVID-19 related impacts on their ability to work or travel [16,26], were unable to attend healthcare appointments [38], or practiced stricter COVID-19 protective measures [25]. For example, Bogart et al. (2021) found that HIV patients who had experienced COVID-19 related disruptions to their employment, ability to pay rent, and ability to use public transportation had a 41% reduction in their odds of ART adherence. Kalichman et al. (2020) found that those who followed stricter COVID-19 protective measures reported more difficulty in getting their

medications. One study also found that those who had been exposed to greater interpersonal violence also reported greater difficulties in obtaining their ART medications [26].

Providers took several measures to improve ART adherence during the pandemic. Some of these measures included extended or multi-month refills, mail-order pharmacy, and assistance with prescription pick-up [9,29,39], reaching out to patients on how to refill medications during COVID-19-related lockdowns [21], and regular adherence assessments by pharmacists [32].

Changes in viral suppression rates

Very few studies reported data on changes in viral suppression rates, when comparing time periods during the pandemic to periods before the pandemic. For the four studies that did, three found no significant difference in either the odds of viral suppression [24] or the proportion with viral suppression [15,32]. Importantly, one of these studies was conducted on unhoused individuals who had access to a "low-barrier, high intensity HIV primary care program", which likely mitigated the impact of the pandemic in this population [24]. However, while the percentage of those virally suppressed in this population did not change significantly during the pandemic (47%) vs. pre-pandemic (48%), rates were inadequate in both time periods [24]. Only one study found an increase in the odds of viral non-suppression when comparing the time periods [28]. This study also found higher odds of viral non-suppression in those experiencing homelessness during the pandemic compared to before the pandemic [28]. One study that compared viral suppression rates for those who attended visits via telephone vs. in-person during the pandemic found higher rates in those who could attend via telehealth [29].

Discussion

This systematic review highlights how the COVID-19 pandemic has impacted retention and engagement in HIV services, ART adherence, and viral suppression rates for PWH in the U.S. Articles were identified from all four CDC HIV Surveillance System regions and indicate varying impacts of the

pandemic within and across these regions. In the southern region, which has some of the highest rates of HIV diagnoses per 100,000 people [14], four of the studies identified in this review found minimal to no negative impacts on retention or engagement in healthcare services and medication adherence, and included studies conducted within older PWH [19], people who inject drugs [21], underserved populations [22], and an existing HIV cohort [20]. However, two studies found larger impacts on ability to attend HIV care appointments, including in Black MSM [35] and in people who were actively using substances [25]. Studies from the western, northeast, and midwest regions found some impacts within these areas, but again these differed by the city/state, how the participants were recruited, and how impacts within these areas were measured. Importantly, eleven studies identified disparities, such as by HIV status, race/ethnicity, age, income, housing status, and access to video telehealth, in those that were most impacted by COVID-19 related interruptions, and these disparities were found in studies from all but the northeastern region.

This review identified only four articles that compare pre-pandemic viral suppression rates to time periods during the pandemic. This may be due to the fact that impacts on viral suppression rates may take more time to appear clinically and be reported in the literature than the timeframe covered by this systematic review. While three of the studies that did look at changes in viral suppression rates found no significant changes [15,24,32], one did find a significant increase in the odds of viral nonsuppression after the initiation of shelter-in-place orders within PWH who utilize a safety-net clinic [28]. Data on changes in viral suppression rates, in addition to participant-reported incidences of missed or cancelled visits and challenges accessing ART, will be important to fully understanding the impacts of the pandemic on the long-term health of PWH. Additionally, data on HIV transmission rates will provide evidence as to whether pandemic-related changes in viral suppression rates led to increased disease transmission. This review also identified only two studies that addressed changes in visit frequency [24,29], likely because most studies were conducted in the first year of the pandemic. Additional research looking at changes in the chronicity and frequency of visits during the duration of the pandemic will also be critical to fully understanding its impacts.

As the U.S. continues to experience waves of COVID-19 outbreaks, it will be critical that HIV providers, health systems, and policy makers understand the additional burdens that the pandemic puts on PWH. For example, syndemic health problems in PWH, such as substance use, mental health disorders, and malnutrition, coupled with the additional challenges introduced by the pandemic, put them at increased risk for adverse outcomes related to the pandemic [40]. Additionally, several studies in this review found that specific communities, including those experiencing homelessness [28], with substance use disorders [25,30], who are of minority race/ethnicity [16,18], MSM [23,37], or who use public insurance or lost health insurance [26,31], have suffered interruptions in HIV services during the pandemic. This is particularly concerning as those who experience social inequality, stigma, racism, and discrimination have been disproportionately impacted by the pandemic, and interruptions in HIV treatment may make them more susceptible to COVID-19 related morbidity and mortality [41].

Several adaptations in care models for PWH, including telemedicine, messaging applications, and mail order pharmacy, were highlighted in this review and have been critical interventions to ensure continuity of care during the pandemic. This is supported by several studies in this review which highlighted minimal impacts on retention/engagement in care and medication adherence. However, there are severe disparities in which communities have access to the resources needed to utilize telemedicine. For example, one study found that 41% of Medicare beneficiaries lacked access to a computer, 40.9% lacked access to a smartphone with a wireless data plan, and access was lower in Black and Hispanic populations, the elderly, and those on Medicaid [42]. Additionally, lack of human connection, lack of knowledge on how to use telemedicine, and increased risk for disclosure of personal information similarly indicate that telemedicine is not a panacea to replace in-person visits. It is critical that HIV service providers implement diverse and flexible strategies that are cognizant of the resources available to and comfort of their patients and that help ensure access to services as the country continues to confront the COVID-19 crisis. This will be particularly important due to the protracted nature of this pandemic, with ebbs and flows in hospitalization rates (and subsequent triggering of changes in clinic operating status) and in the economic impacts on communities which may limit access to or use of care. Furthermore,

health systems must learn from their experiences providing care to these populations during this health emergency and incorporate them into preparedness plans to help ensure continued access to services during future public health emergencies.

This review is subject to several limitations. First, there remains the possibility that we omitted important and relevant articles. Second, the studies identified in this review relied primarily on patient reported interruptions in HIV services rather than clinical (e.g., viral suppression rates) or other data sources (e.g., clinic visit numbers). This increases the risk for bias (specifically, selection and recall bias) and decreases the generalizability of the data. Eleven studies also used data from patients previously or currently enrolled in studies or interventions, and these individuals may be systematically different than those who are not currently enrolled in a study. Additionally, the care received through these studies or interventions may not be representative of the standard or care experienced by other PWH across the U.S. Third, due to the protracted nature of the pandemic and the changing case numbers and subsequent impact on health systems, patient responses may have been only applicable to certain time periods within the pandemic. For example, this review was conducted prior to the emergence of the Omicron SARS-CoV-2 variant, which caused significant impacts on healthcare systems across the U.S. Differences in state responses (such as stay-at-home orders), as well as adaptations in service delivery by HIV clinics made early in the pandemic, may have also influenced which regions and populations were impacted. Finally, this review only included studies conducted in the U.S., and thus the results may not be generalizable to other countries.

However, there are several strengths of this study as well. First, the review adhered to rigorous PRISMA standards and was aided by an information specialist. Second, to our knowledge, this is the first systematic review that synthesizes data on pandemic-related impacts on HIV healthcare services in the U.S. We believe that this review provides an important snapshot of the impacts of the pandemic thus far on PWH, the challenges they have faced, and the changes providers have made to help ensure continued access to services.

Conclusion

This review suggests that COVID-19 has had varying impacts on HIV healthcare service delivery within and across CDC regions, and innovations in care delivery have been critical. Evidence also indicates that these innovations may improve access to and use of these services and should be maintained post-pandemic. Importantly, disparities were found to exist within certain communities in the magnitude of the impacts of the pandemic on HIV healthcare services that could lead to increased morbidity and mortality. It is critical that HIV service providers and health systems understand barriers faced by these communities and implement policy and practice changes that help ensure improved and continued access to care. Additional research will also be critical to better understand the impacts of interruptions in care on viral suppression rates. Disease surveillance will also help identify any impacts on HIV transmission rates. Finally, integrating these lessons learned into emergency preparedness plans will help reduce the impacts of future public health emergencies on the availability of services for PWH.

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CHAPTER 3: MANUSCRIPT TWO

The Rate of Forgone Care during the COVID-19 Pandemic in Baltimore, MD

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Abstract

Objective. To describe forgone care during the COVID-19 pandemic using a combined analytic sample from two population-representative surveys.

Methods. We conducted a cross-sectional evaluation of the rate of forgone care at study enrollment among a population of adults (n=2,003) living in Baltimore, MD. The data were extracted from two SARS-CoV-2 prevalence studies that included surveys on forgone care during the COVID-19 pandemic. We calculated the overall rate of forgone care and by sociodemographic and clinical characteristics using person-years in the pandemic.

Results. The overall rate of forgone care was 16.6 events per 100 person-years in the pandemic. Forgone care was highest amongst those age 35-49 years and among those who reported being on disability, experiencing financial strain, having functional limitations, having a mental illness, using substances, and having two or more comorbidities.

Public health implications. This study suggests that rates of forgone care during the COVID-19 pandemic are impacted by SSDoH, which may lead to greater long-term morbidity and mortality beyond that of the SARS-CoV-2 virus.

Introduction

Evidence suggests that reductions in healthcare utilization during the Coronavirus disease 2019 (COVID-19) pandemic may be contributing towards excess morbidity and mortality.[1–3] Much of this evidence consists of studies describing changes in the volume of services rendered, such as the number of primary care appointments and emergency department usage.[1] Fewer studies have evaluated COVID-19 related changes in healthcare utilization through the lens of patient-reported forgone care, which is defined as healthcare that is perceived as needed by the person but not received, and includes delayed, missed, or skipped visits with a healthcare provider.[4,5] The experience of forgone care suggests gaps in a person's ability to access and use the healthcare system.[6]

While limited, the available data on forgone care indicates that a large percentage of the population in the United States (US) has experienced delayed or missed clinic visits for chronic and preventive care, visits to the emergency room, and elective or dental procedures during the COVID-19 pandemic.[7–10] The incidence of forgone care may be disproportionally higher in some communities due to exacerbation of pre-existing inequities across the social and structural determinants of health (SSDoH), such as lack of access to affordable health care, transportation, and childcare.[7–10] Racial, ethnic, socio-economic, and other disparities in which populations were more likely to experience forgone care, including among Black/African American and Hispanic/LatinX adults, those who were unemployed, those who reported experiencing racial discrimination, those who reported having a functional disability, and members of the LGBTQ+ community, have also been highlighted in the existing literature.[7,8,11–13] However, the data are mixed as other studies have not found similar associations.[10] Forgone care during the pandemic has been attributed to several factors, including stay-at-home orders, cancellations of elective surgeries, closures of clinics, fears of contagion, lack of access to telehealth, and financial and structural barriers.[7,8,10,14]

Forgone care can have drastic consequences on individual and community health. Delayed and cancelled preventive care, including immunizations, dental cleanings, and cancer screenings, will have long-term health implications that go well beyond the end of the COVID-19 pandemic. For example, one

study identified decreases in screenings for breast, lung, colon, cervical, and prostate cancer ranging from 60% to 82% at one large health center in Massachusetts.[15] Delayed treatment for emergent conditions such as strokes, heart attacks, and orthopedic trauma likely have led to worse prognoses and more severe outcomes.[16–18] Furthermore, those with chronic conditions have previously been shown to be more likely to forgo care.[19] Given that the pandemic introduced or exacerbated existing barriers to healthcare access, these individuals could be at higher risk for severe downstream consequences of interruptions in care. This is reflected in mortality data published by the US Centers for Disease Control and Prevention, which suggests a large increase in excess deaths from chronic conditions such as heart disease and diabetes, highlighting the importance of continued access to care and the potential consequences of forgone care.[20]

While the existing literature provides critical insight into forgone care through analysis of national-level survey data, robust sampling strategies that ensure representation from economically disadvantaged and historically excluded populations are lacking. Therefore, these findings may not be representative of large, urban populations, which are more racially and ethnically diverse[21] and often have higher rates of poverty.[22] The aim of this study is to address this gap by describing forgone care during the COVID-19 pandemic in an urban population using a combined analytic sample from two population-representative surveys that included representation from historically under-resourced communities. A more thorough understanding of forgone care within these diverse communities will help better highlight who may be experiencing barriers to healthcare access, how existing barriers to care may have been exacerbated during the pandemic and help inform ongoing efforts to strengthen health systems for future large-scale health emergencies.

Methods

This study was a cross-sectional evaluation of forgone care at study enrollment among a population of adults living in Baltimore, MD. We determined the rate of forgone care per 100 person-years in the pandemic. The data were extracted from two COVID-19 studies, which are described below.

Parent studies

The first study, the Community Collaboration to Combat COVID-19 ("C-FORWARD"), was a comparative effectiveness trial of testing modalities for the SARS-CoV-2 virus, the virus that causes COVID-19 disease, and enrolled participants from February 2021 to December 2022. The second study, the COVID-19 Prevention Network 5002 ("CoVPN 5002"), was a multi-site SARS-CoV-2 prevalence study that enrolled participants from March to July 2021.[23] Further details of each study, including sampling strategy and study procedures, are summarized in Table 1.

Table 1. Characteristics of the C-FORWARD and CoVPN 5002 studies

	C-FORWARD	CoVPN 5002
Study design	Comparative effectiveness trial of SARS-CoV-2 testing modalities	Cross-sectional evaluation with weekly random selection of time/venue
Enrollment period	February 2021-December 2022	March-July 2021
Objective	Determine barriers to SARS-CoV-2 testing; measure the prevalence of SARS-CoV-2 in Baltimore; define optimal SARS-CoV-2 testing modalities; understand the clinical, social, & economic impacts of the pandemic	Measure the prevalence of SARS-CoV-2 in Baltimore; understand the clinical, social, & economic impacts of the pandemic
Location	Baltimore, MD	15 total research sites across the United States *The data reported in this manuscript only reflect data collected from the Baltimore, MD research site.*
Sample size	n=1,978	n=1,022 (Baltimore, MD research site)
Sampling strategy	Population representative, multi-stage random household sampling strategy, organized by census block groups, with oversampling of historically excluded and under-resourced communities	Venue-time sampling strategy with over-sampling of venues in lower socio-economic communities (venues included low-income housing, transitional housing, shelters, food pantries, places of worship, rehabilitation centers, & local FQHCs)
Survey procedures	One member from each HH (the "HH index member") completed a baseline survey on enrollment in the study. Topics addressed in the baseline survey included: demographics; COVID-19 symptoms, testing, and treatment; adoption of COVID-19 preventive behaviors; co-morbidities and healthcare access (including forgone care); coronavirus impact and pandemic stress; mental health; substance use; knowledge and attitudes towards COVID-19; and vaccines. Surveys were completed either online independently or over the telephone with a trained research assistant. Responses were captured in REDCap. This study also included a longitudinal component, where interested HH index members and members of their HH were followed for 6 months to assess their SARS-CoV-2 testing needs and the impacts of the pandemic via weekly and monthly surveys. *The data reported in this*	Participant completed a survey on enrollment in the study. Topics addressed in the survey included[a]: demographics; medical history (including forgone care); COVID-19 infection history, risk, and exposure; knowledge, attitudes, and behavior about COVID-19; COVID-19 impact; and willingness to participate in COVID-19 vaccine trials. Paper-based surveys were administered by a trained interviewer and later entered into Medidata.

	manuscript only reflect data collected from HH index members on enrollment into the study.	
Recruitment	Multi-modal: doorhangers, mailings, telephone, and/or online	All individuals entering/exiting the selected venue site during the time/location slot
Inclusion criteria	1) Primary residence within the sampled household, 2) HH index member must be ≥18 years of age 3) able to provide informed consent & 4) psychologically fit to complete the survey	1) Adults and children > 2 months of age (guardian present for those <16 years old), 2) willing and able to provide consent (assent for those <18 years with guardian consent), 3) recruitment at the selected venue
Study ID's	NIH study ID P30AI094189-09S1	DAIDS-ES ID 38749

*For the CoVPN 5002 study, a supplemental survey on needing/forgoing emergent care and surgical/dental procedures was added to the original survey in April 2021. Prior to that date, participants only responded to survey questions on needing/forgoing chronic/preventive care.
Note. HH=household; FQHC=federally qualified health center

Secondary data analysis

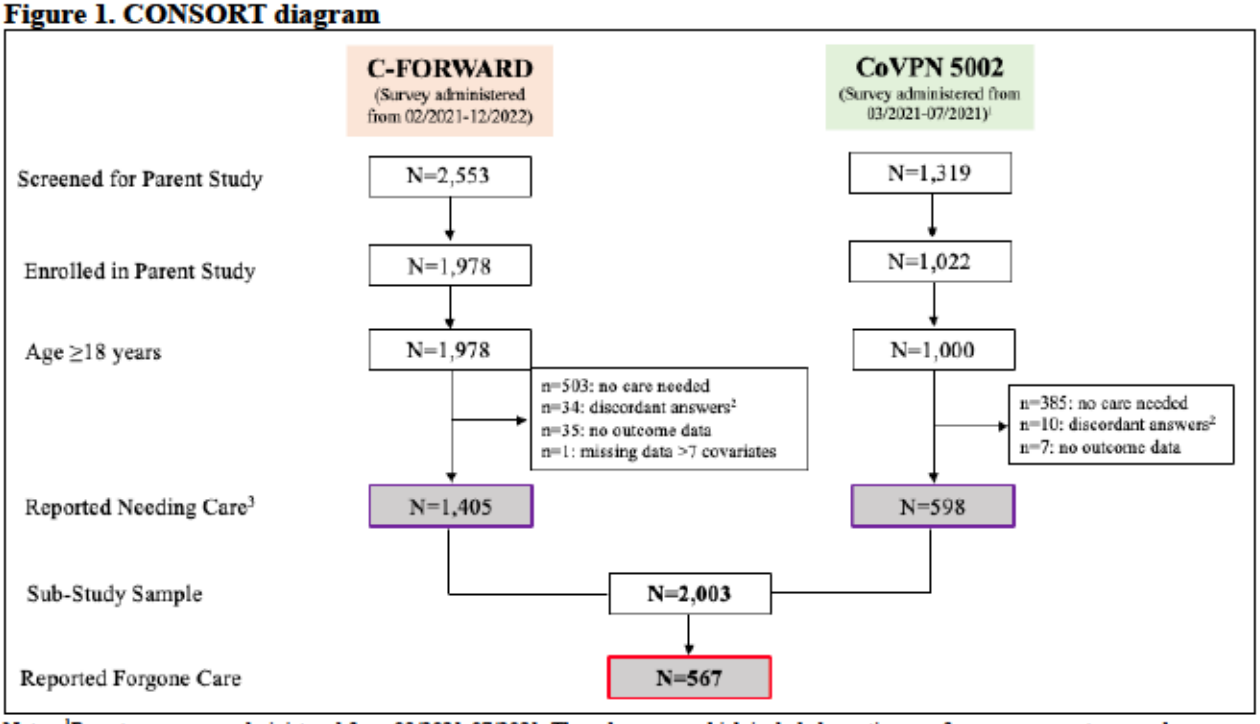
Inclusion and exclusion criteria

Each parent study enrollment survey included questions on demographics, comorbidities, and healthcare access during the COVID-19 pandemic, including questions on forgone healthcare, defined for the purposes of this study as healthcare that was skipped, missed, or delayed during the pandemic. The surveys included questions on forgone chronic or preventive care, emergent care, and major medical or dental procedures.[1] Participants from the CoVPN 5002 Baltimore, MD research site and Phase I of the C-FORWARD study (e.g., only household index members, see Table 1) were included in this analysis if they reported needing any type of care during the pandemic on their initial enrollment survey, including chronic, preventive, or emergent care or a major medical or dental procedure. Additionally, only adult participants were included, as the C-FORWARD study required the household index member who completed the initial enrollment survey be 18 years of age or older. Any participant missing data related to the inclusion criteria (e.g., it could not be ascertained whether they needed any type of care during COVID-19) or on the outcome (e.g., it could not be ascertained whether they experienced any type of forgone care) were excluded. Participants missing data for seven or more of the demographic variables were also excluded.

[1] For the CoVPN 5002 study, a supplemental survey on needing/forgoing emergent care and surgical/dental procedures was added in April 2021 to the Baltimore, MD research site only. Prior to that date, participants only responded to survey questions on needing/forgoing chronic/preventive care. All C-FORWARD participants responded to questions on needing/forgoing chronic, preventive, and emergent care and surgical/dental procedures.

After application of these criteria, seventy-one percent of C-FORWARD participants (1,405 of 1,978) met inclusion criteria for this secondary analysis. A smaller percentage of those enrolled in the CoVPN 5002 study (598 of 1,022; 59%) met inclusion criteria. This yielded a total sample size of n=2,003 (Figure 1).

Figure 1. CONSORT diagram



Notes. [1]Parent survey was administered from 03/2021-07/2021. The sub-survey, which included questions on forgone emergent care and surgical/dental procedures, was administered from 04/2021-07/2021. [2]Discordant answers included participants who said they either did not need care or left the need care question blank, but then responded to the question about forgone care (these individuals were dropped from the dataset). [3]Survey questions on whether a participant needed care and experienced forgone care are included in the parent study survey from C-Forward and in both the parent study survey and a sub-study survey from the CoVPN 5002 study. While some of these questions are worded slightly differently, the intent of the question remains the same.

Outcome measurement

Participants were defined as having the outcome of forgone care if they reported any type of forgone care during the COVID-19 pandemic in the initial enrollment survey. This included skipped, missed, or delayed clinic visits; not going to the emergency room when needed; or postponing a medical or dental procedure. See Appendix A for parent survey questions on demographics, healthcare needs, and forgone care used in this secondary data analysis.

Calculation of the Rate of Forgone Healthcare

The rate of any type of forgone care was calculated using the total number of person-years the participant experienced in the pandemic, measured from March 1, 2020 until completion of the enrollment survey. Using person-years accounted for the different enrollment periods used by the two parent studies and the differing lengths of time each participant had the opportunity to experience forgone care. Overall rate of forgone care was calculated as: total number of individuals who experienced the outcome / total person-years contributed by participants. Ninety-five percent confidence intervals were constructed for each rate using the method suggested by Daly and MedCalc statistical software.[24,25] The interpretation of this rate was: "In a group of 100 people, each spending one year in the pandemic, 'X' number would have experienced at least one episode of forgone care."

The rate of forgone care was calculated by sociodemographic and clinical characteristics by calculating the total number of outcomes and person-years in the pandemic for each strata. Classification of individuals by strata (e.g., race, marital/partner status, etc.) were based on response options defined by the parent studies and to ensure a sample size large enough to adequately detect the rate of forgone care with high precision. For those participants missing demographic data, a review of the institutional medical record ("EPIC") was conducted to identify any additional data that could be used to supplement the parent dataset. However, only C-FORWARD participants who had elected to enroll in Phase II of the parent study had EPIC profiles available for review. Rate of forgone care within a given category was calculated only amongst those participants with data for that specific variable. Those with and without missing data did not differ on the rate of forgone care. Differences in the rate of forgone care experienced by different sociodemographic and clinical subgroups since the beginning of the pandemic were tested for statistical significance using chi-square tests and MedCalc statistical software.[25] Differences were considered to be statistically significant if the 2-sided P value was less than .05. Data were analyzed from January to March, 2023.

Ethical considerations

This study was approved by the Johns Hopkins University School of Medicine Office of Human Subjects Research on December 19, 2022 (IRB#00348695). The C-FORWARD study was approved by

the Johns Hopkins University School of Medicine Office of Human Subjects Research on June 2, 2020 (IRB#00250298). The CoVPN 5002 study was approved by the Johns Hopkins University School of Medicine Office of Human Subjects Research on January 28, 2021 (IRB#00262004).

Results

Participant characteristics

Of those parent study participants who met study inclusion criteria, nearly 65% of the sample reported their sex at birth as female. Nearly all (96%) reported not being of Hispanic or Latino origin and 55% reported their race as Black or African American. Nearly 40% of the sample reported being married or partnered, slightly less than half (46%) were employed part or full-time, and 16% reported being on disability status. Over 20% of participants reported being worried about their ability to pay or being unable to pay their rent or mortgage during the pandemic, nearly 8% reported losing their housing during the pandemic, and 37% reported making less than $25,000 per year. Nearly 65% reported having at least one co-morbidity (Table 2).

Table 2. Characteristics of study sample

Characteristic	Number (%) n=2,003
Age (in years)	
18-34	357 (17.8)
35-49	420 (21.0)
50-64	735 (36.7)
≥65	491 (24.5)
Sex at birth	
Male	697 (34.8)
Female	1,291 (64.5)
Unknown/PNA	15 (0.7)
Race	
White	751 (37.5)
Black/African American	1,055 (52.7)
Other[1]	100 (5.0)
Unknown/PNA	97 (4.8)
Ethnicity	
Latino/Hispanic origin	75 (3.7)
Not of Latino/Hispanic origin	1,754 (87.6)
Unknown/PNA	174 (8.7)
Married/Partnered	
Yes	783 (39.1)
No	1,184 (59.1)
Unknown/PNA	36 (1.8)

Employed (full or part-time)	
Yes	904 (45.1)
No	1,047 (52.3)
Unknown/PNA	52 (2.6)
Reported being on disability	
Yes	310 (15.5)
No	1,641 (81.9)
Unknown/PNA	52 (2.6)
Highest education level	
High school or less	705 (35.2)
Some college or more	1,266 (63.2)
Unknown/PNA	32 (1.6)
Income	
<$25,000	602 (30.0)
$25,000-$49,999	306 (15.3)
≥$50,000	741 (37.0)
Unknown/PNA	354 (17.7)
Lost housing during the pandemic	
Yes	153 (7.6)
No	1,827 (91.2)
Unknown/PNA	23 (1.2)
Worried about or unable to pay rent or mortgage during the pandemic	
Yes	400 (20.0)
No	1,573 (78.5)
Unknown/PNA	30 (1.5)
Reported functional limitations[2]	
Yes	616 (30.7)
No	1,361 (68.0)
Unknown/PNA	26 (1.3)
Mental illness	
Yes	578 (28.9)
No	1,403 (70.0)
Unknown/PNA	22 (1.1)
Substance abuse	
Yes	235 (11.7)
No	1,756 (87.7)
Unknown/PNA	12 (0.6)
Number of comorbidities[3]	
Zero	714 (35.6)
One	653 (32.6)
Two or more	636 (31.8)

[1]Due to low sample size, individuals reporting their race as American Indian, Native Alaskan, Native Hawaiian, Pacific Islander, or multi-racial were grouped into one category; [2]Included physical, mental, or emotional functional limitations; [3]Comorbidities included: cancer, diabetes, renal disease, sickle cell anemia, respiratory disease, cardiac disease, & immune disease

Rate of forgone care

In total, 567 participants reported experiencing any type of forgone care, for an overall rate of 16.6 events per 100 person-years in the pandemic. This included 495 participants who reported forgoing chronic or preventive care, 33 participants who reported forgoing emergent care, and 94 participants who

reported delaying surgical/dental procedures. There were 3,412 person-years experienced in the COVID-19 pandemic. On average, participants had spent 1.7 years in the pandemic when they enrolled in the parent study and completed the cross-sectional survey, with a minimum of 0.88 years and a maximum of 2.8 years in the pandemic.

There were no statistically significant variations in the rate of forgone care by sex, race, marital status, employment status, education level, or income level (Table 3). However, individuals who reported their age as being between 35 and 49 years reported the highest rate of forgone care (21.0 per 100 person-years in the pandemic), compared to those age 18-34 years (p=0.01). Those who reported being on disability also had a higher rate of forgone care (22.3 per 100 person-years in the pandemic) compared to those who were not on disability (15.8 per 100 person-years in the pandemic; p<0.001). Respondents who reported financial strain during the pandemic also had a higher rate of forgone care, including amongst those who reported losing their home during the pandemic, compared to those who had not (25.7 per 100 person-years vs. 15.9 per 100 person-years; p<0.001), and amongst those who were worried about or who had been unable to pay their rent or mortgage during the pandemic, compared to those who had not (23.7 per 100 person-years vs. 14.8 per 100 person-years; p<0.001).

Table 3. Participants who reported forgoing care, by sociodemographic and clinical characteristics

Characteristic	Total Person-Years	Total Events	Rate per 100 person-years (95% CI)	P Value
Age (in years)				
18-34	623.7	98	15.7 (12.8-19.1)	Reference
35-49	704.0	148	21.0 (17.8-24.7)	0.01
50-64	1197.9	209	17.4 (15.2-20.0)	0.35
≥65	886.2	112	12.6 (10.4-15.2)	0.09
Sex at birth				
Male	1136.8	180	15.8 (13.6-18.3)	Reference
Female	2243.1	385	17.2 (15.5-19.0)	0.33
Race				
White	1370.0	220	16.1 (14.0-18.3)	Reference
Black/African American	1680.7	285	17.0 (15.0-19.0)	0.51
Other[1]	185.8	32	17.2 (11.8-24.3)	0.69
Married/Partnered				
Yes	1420.2	219	15.4 (13.5-17.6)	Reference
No	1916.3	343	17.9 (16.1-19.9)	0.06
Employed (full or part-time)				
Yes	1621.3	256	15.8 (13.9-17.9)	Reference
No	1691.5	297	17.6 (15.6-19.7)	0.17
Reporting being on disability				
Yes	475.0	106	22.3 (18.3-27.0)	<0.001
No	2837.9	447	15.8 (14.3-17.3)	Reference

Highest education level				
High school or less	1054.8	189	17.9 (15.5-20.7)	0.18
Some college or more	2294.3	368	16.0 (14.4-17.8)	Reference
Income				
<$25,000	983.2	188	19.1 (16.5-22.1)	0.07
$25,000-$49,999	537.1	71	13.2 (10.3-16.7)	0.11
≥$50,000	1358.6	220	16.2 (14.1-18.5)	Reference
Lost housing during pandemic				
Yes	257.0	66	25.7 (19.9-32.7)	<0.001
No	3114.8	495	15.9 (14.5-17.4)	Reference
Worried about or unable to pay rent/mortgage during pandemic				
Yes	642.0	152	23.7 (20.1-27.8)	<0.001
No	2714.2	403	14.8 (13.4-16.4)	Reference
Reported functional limitations[2]				
Yes	1012.8	218	21.5 (18.8-24.6)	<0.001
No	2347.1	337	14.4 (12.9-16.0)	Reference
Mental illness				
Yes	987.1	224	22.7 (19.8-25.9)	<0.001
No	2373.7	335	14.1 (12.6-15.6)	Reference
Substance abuse				
Yes	332.3	81	24.4 (19.4-30.3)	<0.001
No	3055.1	483	15.8 (14.4-17.3)	Reference
Number of comorbidities[3]				
Zero	1267.7	187	14.8 (12.7-17.0)	Reference
One	1091.8	185	16.9 (15.6-19.6)	0.15
Two or more	1052.2	195	18.5 (16.0-21.3)	0.02

[1]Due to low sample size, individuals reporting their race as American Indian, Native Alaskan, Native Hawaiian, Pacific Islander, or multi-racial were grouped into one category. [2]Included physical, mental, or emotional functional limitation; [3]Comorbidities included: cancer, diabetes, renal disease, sickle cell anemia, respiratory disease, cardiac disease, immune disease

The rate of forgone care varied by self-reported comorbidity status (Table 3). Those who reported having two or more comorbidities reported a higher rate of forgone care compared to those with no reported comorbidities (18.5 per 100 person-years vs. 14.8 per 100 person-years, p=0.02). The difference between those who reported one vs. no comorbidities was not statistically significant. Compared to those without a physical, mental, or emotional limitation, those who reported having a limitation had a much higher rate of forgone care (21.5 per 100 person-years vs. 14.4 per 100 person-years, p<0.001). Those who reported having a mental illness or suffering from substance abuse also reported higher rates of forgone care, compared to those who did not report having these conditions (22.7 vs 14.1 per 100 person-years, p<0.001; 24.4 vs 15.8 per 100 person-years; p<0.001).

Discussion

This study analyzed the rate of forgone care among a large, U.S. urban population. The use of a combined analytic sample leveraged the strengths of two robust sampling strategies. The C-FORWARD study utilized a multi-staged, random household by census block sampling strategy that was stratified by race, ethnicity, and socioeconomic status, with oversampling of minority communities. The CoVPN 5002 study utilized a venue-time sampling strategy with venues randomly selected across Baltimore, including federally qualified health centers, low-income housing, food pantries, and shelters. Combining these datasets increased the precision needed to examine the rate of forgone care and helped to ensure adequate representation of historically excluded and under resourced communities that are not likely represented in the current COVID-19 forgone care literature. This allowed for a more comprehensive picture of what communities have experienced the highest rate of forgone care during the COVID-19 pandemic.

Our study indicates that persons with two or more comorbidities, who reported being on disability, and who have functional limitations are experiencing a higher rate of forgone care than those without. This finding is consistent with existing research on forgone care during the COVID-19 pandemic.[7,8] These individuals may have more regular contact with the health system, and thus may have more opportunity to miss care. However, they may also have been more heavily impacted by pandemic-related disruptions in resources that they rely upon, such as public transportation, or may have had reduced access to technologies such as telemedicine that were widely implemented in the Spring of 2020.[26] These individuals also may have been more likely to avoid in-person medical visits, owing to an increased risk for worse outcomes associated with SARS-CoV-2 infection. Interestingly, this study also found a higher rate of forgone care amongst those age 35-49 years. This could be due to increased caregiver responsibilities during the pandemic, such as the need to care for children out of school, which introduced additional challenges to seeking healthcare when needed.

Those who have been diagnosed with a mental health disorder also reported a higher rate of forgone care than those without, which was a finding in our study that differed from the existing COVID-19 forgone care literature. This is a critical finding, given that COVID-19 has led to an increase in mental

health disorders and the exacerbation of mental health disorders among those with existing conditions. For example, one survey by the Kaiser Foundation found that, during the pandemic, 4 in 10 adults reported symptoms of anxiety and depressive disorder, compared to 1 in 10 prior to the pandemic.[27] Suicide rates have also increased, including amongst American Indian, Black, and LatinX individuals.[28] Lack of access to mental health providers during the pandemic, either via in-person appointments or telehealth, likely has, at least in part, driven much of these negative outcomes. Additionally, our study also found a higher rate of forgone care amongst those who suffer from substance abuse disorders, which has also not been previously captured in the literature. These individuals are already at a higher risk for the development and exacerbation of chronic diseases such as diabetes, and these interruptions in care may increase morbidity and mortality amongst this already vulnerable population.[29] Deaths from drug overdoses have also increased during the pandemic, further indicating gaps in accessing high-quality substance treatment disorder providers.[27]

Knowledge gained from this study is important to better understand which individuals and communities may be at highest risk for short and long-term health consequences of forgone care. It also helps to elucidate who may be at continued risk for forgone care as the pandemic endures across the country. For example, many hospitals and clinics have removed much of their COVID-19 precautions such as SARS-CoV-2 testing and masking. This may make those who are at increased risk for SARS-CoV-2-related morbidity and mortality (e.g., the immunocompromised, etc.) even more reticent to access in-person healthcare, further delaying potentially life-saving interventions for these communities. Healthcare providers should be cognizant of their concerns and implement strategies to ensure their safety, such as continued mask use amongst staff, encouraging other patients to wear masks, ensuring adequate ventilation, and offering resources to support the use of telehealth. Backlogged health systems and limited numbers of primary care, mental health, and substance treatment disorder providers may also further delay care for those who have already experienced higher rates of forgone care. The use of other strategies, such as harm-reduction services (e.g., access to naloxone), crisis intervention programs (e.g., the new "988" lifeline), and leveraging existing community-based interventions (e.g., co-location of

sexually transmitted infections/Human Immunodeficiency Virus/Hepatitis C testing and immunizations with syringe service programs) that care for the under-resourced could help bridge these gaps.

Limitations

This study has several limitations. First, we were unable to calculate the rate of forgone care by ethnicity due to low sample size. Similarly, low sample size prohibited us from reporting the rate of forgone care by care type (e.g., emergent care vs. surgical/dental care vs. chronic/preventive care). Second, we are unable to ascertain the frequency of forgone care prior to the pandemic among this population due to lack of survey items on this topic. This prior rate of forgone care would be useful for comparison to more accurately assess the impacts of the pandemic on forgone care. Third, the parent surveys did not collect data on individuals' health insurance status, which may have impacted their ability to seek care during the pandemic. Finally, this study is reliant upon participant-reported survey data, which is subject to recall bias.

Conclusions

This study suggests that certain populations are experiencing a higher rate of forgone care during the COVID-19 pandemic, which may lead to greater long-term morbidity and mortality outside of what has been directly related to infection with the SARS-CoV-2 virus. It is critical that the health system identify ways to enhance accessibility of care for these populations, and to quickly address any gaps in care that might have been experienced. Additionally, moving forward, pandemic and disaster planning must be cognizant of the downstream impacts of large-scale public health emergencies on health system access and use. Understanding which populations are most at risk for these impacts, as well as how these events may exacerbate or introduce new barriers to care, can help ensure that the needs of these communities are considered.

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CHAPTER 4: MANUSCRIPT THREE

An Evaluation of the Impact of Social and Structural Determinants of Health on Forgone Care during the COVID-19 Pandemic in Baltimore, Maryland

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Abstract

Objectives: This study assessed the effects of community-level correlates of forgone care beyond the contributions of individual-level characteristics.

Methods: This was a cross-sectional, secondary data analysis of participants who reported needing healthcare in two parent study surveys conducted in Baltimore, MD in 2021 and from 2021-2022. Abstracted data included the experience of forgone care, socio-demographic data, comorbidities, financial strain, and community of residence. Participant's community of residence were linked with data relevant to healthcare access and utilization acquired from the Baltimore Neighborhood Indicators Alliance, including crime rate, reliance of public transportation, and internet access, among others. The data were analyzed using weighted random effects logistic regression.

Results: Individual-level factors found to be associated with increased odds for forgone care included individuals ages 35-49 (compared to 18-34), female sex, experiencing housing insecurity during the pandemic, the presence of functional limitations and mental illness, and individuals with two or more comorbidities (compared to none). Black/African American individuals were found to have reduced odds of forgone care. No community-level factors were significant in the multilevel analyses.

Conclusions: It is critical that the health system identify ways to address any barriers to care that these populations might be experiencing, such as the increased use of mobile health services or telemedicine platforms. Additionally, moving forward, public health emergency preparedness planning efforts must account for the unique needs of these communities during crises, to ensure that their health needs can continue to be met. Finally, additional research is needed to better understand how healthcare access and utilization practices have changed during versus before the pandemic.

Introduction

The Coronavirus 2019 (COVID-19) pandemic, caused by the SARS-CoV-2 virus, led to widespread disruptions in healthcare utilization. This includes patient reports of forgone care, defined as someone who perceives a need for healthcare but does not receive it due to gaps in healthcare system access [1]. These disruptions likely led to increased morbidity and mortality associated with the pandemic and disproportionately impacted historically excluded and economically disadvantaged communities.[2,3]

Existing studies have identified several individual-level social and structural determinants of health (SSDoH) as important correlates of forgone care during the pandemic, although the findings have been at time contradictory, perhaps due to sampling differences.[4–12] Czeisler et al., using a nationally representative sample of adults, found a higher prevalence of forgone care among Black and LatinX adults in June 2020.[6] However, another nationally representative survey of forgone care from March to July 2020 among adults did not identify any statistically significant difference in the frequency of forgone care by race/ethnicity.[5] A separate study that looked at forgone care among Medicare beneficiaries found a higher prevalence among non-Hispanic White beneficiaries, compared to non-Hispanic Black beneficiaries in the summer of 2020, although these differences dissipated when looking at forgone care in the fall of 2020 and winter of 2021.[12] Other factors that have been identified in the literature as being significantly correlated with forgone care, although at times with mixed results, include experiencing food or income insecurity; education level; having comorbid conditions, including mental health problems and functional disabilities; older and younger age; having health insurance; and experiencing racial discrimination.[4–9,11–13] These studies indicate that certain individuals experienced disproportionate impacts on healthcare access and utilization during the pandemic, leading to forgone care.

Community-specific factors, such as Area Deprivation Index, crime rate, internet coverage, reliance on transportation, walkability, racial and ethnic segregation, poverty rate, and proximity to care are related to health outcomes.[14–23] Studies have identified geographic inequities related to the COVID-19 pandemic, including COVID-19 case counts and mortality rates [24,25] and inequitable access to testing and

treatment [26–28], but few have acknowledged these factors and their associations with forgone care. Similar inequities may have occurred within defined geographic areas in who experienced forgone care, such as in communities with high rates of poverty and crime, those with racial and ethnic segregation, and those without resources such as reliable transportation, access to healthcare services, and internet coverage. For example, several community-level factors have been cited in the literature as reasons for forgoing care during the pandemic, including closures of local health facilities, transportation challenges, and lack of resources required for telemedicine.[5,29–31] Also concerning is that many of the communities that suffered higher rates of SARS-CoV-2 infection also likely needed additional healthcare services as a result.

The aim of this study was to evaluate the impact of individual and community-level SSDoH on healthcare utilization during the COVID-19 pandemic by specifically looking at forgone care among a sample of adults living in Baltimore, Maryland. The objective was to determine whether community-level correlates accounted for forgone care above and beyond any individual participant-level correlates. Understanding the intersections of forgone care during the COVID-19 pandemic with SSDoH is critical to providing a comprehensive view of the health impacts of the pandemic and to understanding which individuals and communities experienced the greatest interruptions in care.

Methods

Study design and data sources

This was a secondary data analysis using baseline data abstracted from two parent studies funded by the National Institute of Allergy and Infectious Diseases. The combined analytic sample leveraged the strengths of two robust sampling strategies used in the parent studies, increasing the overall sample size, and helping to ensure adequate representation of economically disadvantaged and historically excluded communities that are not likely included in the current COVID-19 forgone care literature.

This nested study used a cross-sectional design to examine individual and community-level factors associated with forgone care during the COVID-19 pandemic in Baltimore, MD. Data abstracted from the parent studies included responses to survey questions regarding demographics, comorbidities, healthcare needs, and forgone care during the COVID-19 pandemic. For the purposes of this study, forgone care was defined as healthcare that was skipped, missed, or delayed during the COVID-19 pandemic. The two parent studies are described in more detail below.

The Community Collaborative to Combat COVID-19 study

The Community Collaborative to Combat COVID-19 (C-Forward) parent study was a two-phased comparative effectiveness trial. Enrollment of participants occurred from February 2021 to December 2022. The study aimed to evaluate three different SARS-CoV-2 testing modalities (fixed site, mobile, and home-based) using a representative sample of Baltimore households. The study enrolled households (HH) using a multi-staged sampling approach, organized by census block groups that were stratified by socioeconomic status and race/ethnicity, with oversampling of historically excluded and under-resourced populations (e.g., Hispanic/LatinX populations, low-income whites).

Household recruitment was multi-modal and included doorhangers, mailings, telephone calls, and online methods. The study included enrollment of one eligible member per HH, 18 years of age or older, who was able to provide informed consent (designated as the "HH index member"). The HH index member completed a baseline survey that covered demographics; history of COVID-19 symptoms, testing and treatment; adoption of preventive behaviors; comorbidities and health care access and utilization (including forgone care); COVID-19 impact and pandemic stress; mental health and substance abuse; and knowledge and attitude towards COVID-19. This survey was completed electronically or via telephone with a trained research assistant and entered into REDCap. HH index members also received SARS-CoV-2 antigen and antibody testing and other serum testing (e.g., chemistry profiles). A total of n=1,978 HH index members were enrolled. Additional information about this study, including other study phases that

were not included in this secondary data analysis, can be found on clinicaltrials.gov (clinical trial identifier # NCT04673292).

The COVID-19 Prevention Network 5002 study

The COVID-19 Prevention Network 5002 (CoVPN 5002) parent study was a multi-site, cross-sectional SARS-CoV-2 prevalence study conducted from March to July, 2021. The study used a venue-time sampling strategy, with random selection of venues and enrollment times. Venues included low-income housing, transitional housing, shelters, food pantries, places of worship, local federally qualified health centers, and rehabilitation centers, among others.[32]

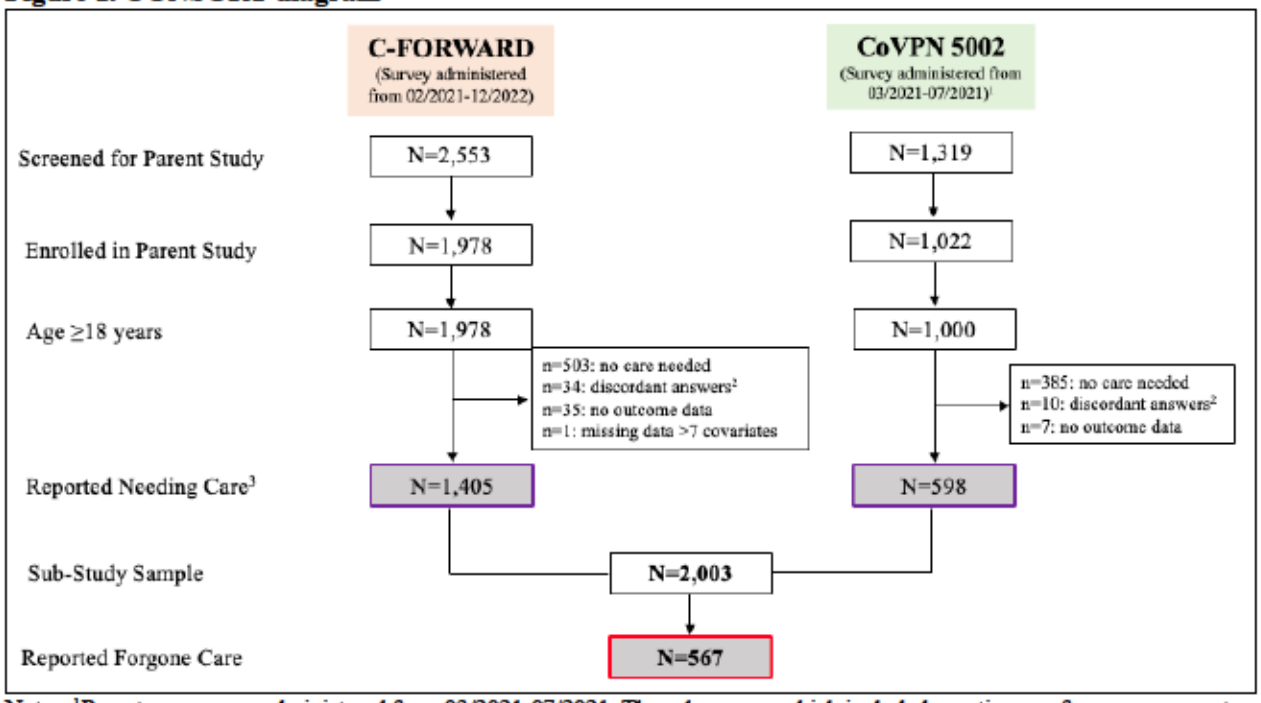
All individuals accessing the selected venue during the randomly selected time/location slot were approached to assess interest and eligibility to enroll in the study. Adults and children greater than 2 months of age who were willing and able to provide consent (assent for those <18 years of age, with the consent of a guardian) were eligible. Those who enrolled completed a paper-based survey with a trained research assistant that included questions on demographics; medical history (including forgone care); COVID-19 history included exposure; knowledge, attitudes, and behavior about COVID-19; economic impacts of COVID-19; and willingness to take the COVID-19 vaccine. All survey responses were later entered into Medidata. Individuals also received SARS-CoV-2 antigen and antibody testing. A total of n=1,022 individuals enrolled in the study at the Baltimore, Maryland site. Additional information about this study can be found on clinicaltrials.gov (clinical trial identifier # NCT04658121). The secondary data analysis presented in this manuscript describes only data collected from the Baltimore research site.

Secondary data analysis—Inclusion criteria

Inclusion in this secondary data analysis included all parent study participants who reported needing any care type during the COVID-19 pandemic in the parent study survey, including chronic/preventive care, emergent care, or a major medical/dental procedure (Figure 1). Parent survey questions can be located in Appendix A. Participants under the age of 18 were dropped (n=22), as C-

Forward only included enrollment of HH index members who were ≥ 18 years of age. Individuals were excluded if it could not be ascertained as to whether they needed any type of care during the pandemic (e.g., they left these survey questions blank or responses were discordant; n=44) or it was unclear whether they had experienced the outcome of forgone care (n=42). Surveys that had seven or more incomplete demographic questions were also dropped (n=1).

Figure 1. CONSORT diagram



Notes. [1]Parent survey was administered from 03/2021-07/2021. The sub-survey, which included questions on forgone emergent care and surgical/dental procedures, was administered from 04/2021-07/2021. [2]Discordant answers included participants who said they either did not need care or left the need care question blank, but then responded to the question about forgone care (these individuals were dropped from the dataset). [3]Survey questions on whether a participant needed care and experienced forgone care are included in the parent study survey from C-Forward and in both the parent study survey and a sub-study survey from the CoVPN 5002 study. While some of these questions are worded slightly differently, the intent of the question remains the same.

Measures

Outcome variable

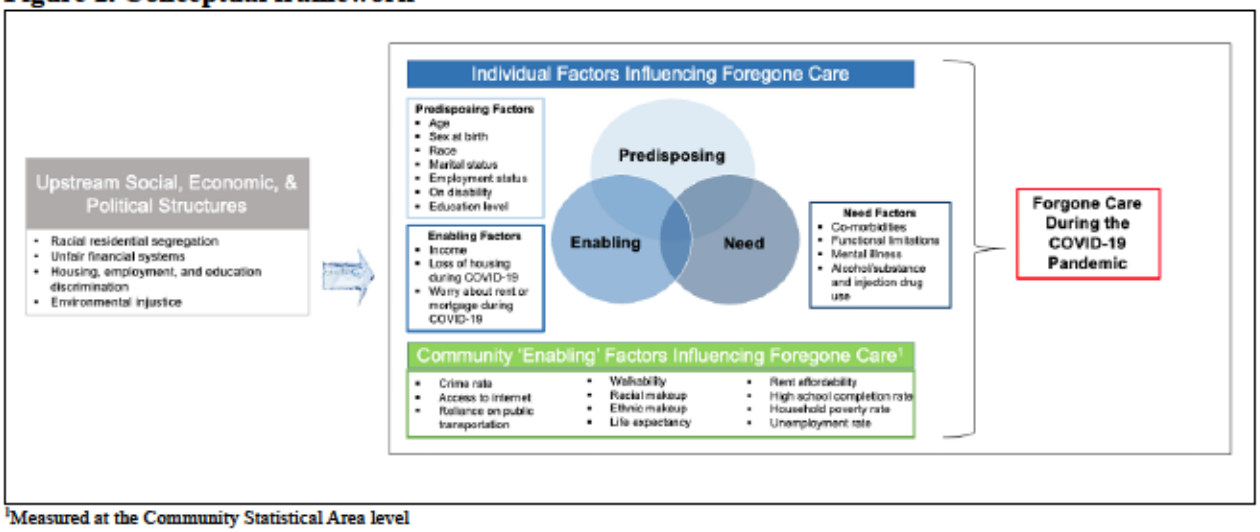
The outcome variable for this study was participant-reported forgone care on enrollment in either of the parent studies. This included any forgone care experienced since the beginning of the COVID-19

pandemic, measured from March 1, 2020 until completion of the survey. Questions on forgone care assessed the need for and receipt of chronic or preventive care, emergent care, and major medical or dental procedures. All participants enrolled in the C-Forward study responded to questions about forgone chronic/preventive, emergent, and surgical/dental care. Participants who enrolled in the CoVPN 5002 study prior to April 2021 only responded to questions about forgone chronic/preventive care. Those who enrolled in April 2021 or later also completed a supplemental survey that addressed needing/forgoing emergent care and surgical/dental procedures.

Independent variables—Individual level

The selection of individual-level variables was informed by the Gelberg Behavioral Model for Vulnerable Populations.[33] This framework, a revision of the Andersen and Newman Model of Healthcare Utilization [34], was chosen as it includes determinants of healthcare system access and utilization relevant to underserved populations living in Baltimore, which has higher rates of poverty, homelessness, crime, and drug use in comparison to other cities of its size and widespread disparities across the SSDoH.[35–38] Our adapted model (Figure 2) includes individual and community-level factors related to healthcare utilization and organizes them into three categories: predisposing—factors that may increase the propensity to seek care; enabling/impeding—factors that may enable or impede use of the health system; and need—factors that reflect perceived need for care.[33,34] For this study, predisposing factors included age, sex at birth, race, marital status, employment status, disability status, and education level. Enabling/impeding factors included income, loss of housing during the pandemic, and worrying about paying rent/mortgage during the pandemic. Need factors included number of comorbidities, presence of functional limitations, mental illness, and alcohol/substance and injection drug use. Our conceptual framework also sought to highlight the upstream social, economic, and political structures, such as racial residential segregation and housing discrimination, that lead to inequities across the SSDoH, including at the individual and community levels.

Figure 2. Conceptual framework



[1]Measured at the Community Statistical Area level

Independent variables—Community level

Participants were assigned community-level factors based on their community statistical area (CSA) of residence. CSA's are clusters of neighborhoods that were developed by Baltimore City's Planning Department and are based on city neighborhoods.[39] There are 55 CSA's in the city of Baltimore, with boundaries that align directly to census tracts.[39] The population of a given CSA ranges from 5,000 to 20,000 people and consist of anywhere from 1-8 Census Tracts.[40] C-Forward participants were matched to a CSA based on their census block group at enrollment. CoVPN 5002 participants were matched to a CSA based on the address of the venue in which they enrolled, as their actual physical address was not collected for the study. Forgone care was characterized across 11 binary community-level factors previously associated with healthcare access and utilization (Table 1).

Table 1. Community-level independent variables

Variable Name	Description	Range of Data (Min, Max)	Measurement	Determination of Cutoff Values	Year of Data Collection*
Crime rate [16]	Crime rate per 1,000 residents	13.4, 134.6	Low crime (<50 crimes per 1,000); high crime (≥50 crimes per 1,000)	Median split based on data	2020
Access to internet [17,18]	Percent of households with no internet	3.4, 38.6	Good access (<20% of HH don't have internet); poor	Median split based on data	2020

			access (≥20% of HH don't have internet)		
Reliance on public transportation [19]	Percent of population that uses public transport to get to work	3.8, 38.5	Low reliance on public transport (<20% of population uses public transport for work); high reliance on public transport (≥20% of population uses public transport for work)	Median split based on data	2020
Walkability [23]	Walkability score	19.7, 95.7	Low to medium walkability (score of 0-69); better walkability (score 70+)	Based on walkability score cutoff	2017
Racial makeup [20]	Percent of population that is Black/African American	3.9, 94.2	Majority other race (<50% Black); majority Black/AA (≥50% Black)	Median split based on data	2020
Ethnic makeup [20]	Percentage of population that is Hispanic	1.5, 50.3	Low Hispanic (<10% Hispanic); higher Hispanic (≥10%Hispanic)	Median split based on data	2020
Life expectancy [21]	Population life expectancy	63.2, 84.7	Lower life expectancy (<76.8 years); higher life expectancy (≥76.8 years)	Higher or lower than the mean life expectancy in Maryland	2018
Components of the Area Deprivation Index [22], including:					
Rent affordability	The percentage of households that pay more than 30% of their total household income on rent and related expenses out of all households in an area.	25.8, 71.3	Better affordability (<50% of HH pay 30% of income on rent); lower affordability (≥50% of HH pay 30% of income on rent)	Median split based on data	2020
High school completion rate	The percentage of 12th graders in a school year that successfully completed high school out of all 12th graders within an area	67.8, 100	Low completion (<80% of 12th graders graduate); high completion (≥80% of 12th graders graduate)	Median split based on data	2020
Household poverty rate	The percentage of households whose income fell below the poverty threshold out of all households in an area	0, 43.5	Low poverty (<20% HH live in poverty); high poverty (≥20% HH live in poverty)	Median split based on data	2020
Unemployment rate	The percent of persons who are not in the labor force out of all persons between	9.5, 52.9	Low unemployment (<30% of population not employed); high unemployment	Median split based on data	2020

	the ages of 16 and 64 in the area.		(≥30% of population not employed)		

*All data acquired from the Baltimore Neighborhood Indicators Alliance
HH: household

Covariates

Two "pandemic wave" binary variables were added to the models to help account for the different enrollment periods of the parent studies and what waves of the pandemic each participant experienced that may have impacted their ability or desire to seek healthcare. All participants who enrolled on or after August 1, 2021 were coded as having experienced the delta COVID-19 wave; those who enrolled on or after December 1, 2021 were coded as having experienced the omicron COVID-19 wave. A variable was also created to account for which parent study the data were acquired from.

Statistical analyses

Imputation of missing data

Patterns of missingness were explored to determine whether data were missing at random. Multiple imputation was then used to impute missing data using Stata version 16.0 (StatCorp, College Station, TX). Multiple imputation is a well-established method for handling missing data, and imputes missing values based on a set of researcher-selected predictors available in the dataset.[41] Multiple imputation helps to decrease biases that may result from omitting participants with incomplete observations.[41] The sequential imputation using chained equations method was employed for this study, using the individual-level independent variables, the outcome of forgone care, and the "study" variable as predictors of missing values. Five total imputed datasets were created. A sensitivity analysis was conducted at the completion of the model-building process to check for biases introduced during multiple imputation. For the sensitivity analysis, the final model was run using only participants with complete data. The magnitude of the resulting coefficients were then compared with those obtained from running the same model using the imputed dataset.

Model building—Level-one model

Weighted bivariate logistic regressions were conducted for each individual-level independent variable, with the binary outcome of any type of forgone care. Each observation was weighted in the regression model for the total amount of person-years the individual had experienced in the pandemic, measured from March 1, 2020 until the date of survey completion. Any individual-level variable significant at $p \leq 0.10$ was carried over to the level-one multivariable model. The multivariable weighted level-one model also included the "study" and "pandemic wave" variables. Collinearity of independent variables was also checked using variation inflation factor, with none noted.

Model building—Level-two multi-level model

The level-two model included weighted random effects logistic regressions with participants nested within Baltimore CSAs to test the significance of each individual community-level variable in the multivariable model. Any CSA-level variables significant at $p \leq 0.10$ were incorporated into the final multivariable model. The significance of variables in this final model were set a $p \leq 0.05$.

Power analysis

A power analysis based on preliminary data assumed an event rate of 0.41[5,6], an alpha of 0.05, 80% power, a sample size of n=1,662, and 30 Baltimore CSAs. Assuming these parameters and an intraclass correlation coefficient (ICC) of 0.010, the study was powered to detect odds ratios that ranged from 1.34 to 1.45, as the distribution of the predictor variable ranged from 20/80 split to a 50/50 split.

Ethical considerations

This study was approved by the Johns Hopkins University School of Medicine Office of Human Subjects Research on December 19, 2022 (IRB#00348695). The C-FORWARD study was approved by

the Johns Hopkins University School of Medicine Office of Human Subjects Research on June 2, 2020 (IRB#00250298). The CoVPN 5002 study was approved by the Johns Hopkins University School of Medicine Office of Human Subjects Research on January 28, 2021 (IRB#00262004).

Results

Participant characteristics

In total, 2,003 individuals from the parent studies (n=1,405 from C-Forward; n=598 from CoVPN 5002) met the inclusion criteria for this sub-study (see Figure 1). The majority of the sub-study sample was over the age of 50 years, with n=491 over the age of 65 years (24.5%; see Table 2). Nearly sixty-five percent of participants (n= 1,291) reported their sex at birth as female. Approximately 53% of the sample (n=1,055) reported being of Black/African American race and 3.7% reported Latin/Hispanic ethnicity. Thirty percent of participants (n=602) reported their income as less than $25,000 per year. Nearly 8% (n=153) reported losing their housing during the pandemic and 20% (n=400) reported worrying about or an inability to pay rent or mortgage during the pandemic. Nearly 65% of the sample reported having one or more comorbidities, including a cancer diagnoses, diabetes, renal disease, sickle cell anemia, respiratory disease, cardiac disease, or immune disease.

Table 2. Participant characteristics

		Reported Any Forgone Care	Reported No Forgone Care
Characteristic	**Number (%) n=2,003**	**Number (%) n=567[1]**	**Number (%) n=1,436[1]**
Age (in years)			
18-34	357 (17.8)	98 (17.3)	259 (18.1)
35-49	420 (21.0)	148 (26.1)	272 (18.9)
50-64	735 (36.7)	209 (36.9)	526 (36.6)
≥65	491 (24.5)	112 (19.8)	379 (26.4)
Sex at birth			
Male	697 (34.8)	180 (31.7)	517 (36.0)
Female	1,291 (64.5)	385 (67.9)	906 (63.1)
Unknown/PNA	15 (0.7)	2 (0.4)	13 (0.9)
Race			

White	751 (37.5)	220 (38.8)	531 (37.0)
Black/African American	1,055 (52.7)	285 (50.3)	770 (53.6)
Other[2]	100 (5.0)	32 (5.6)	68 (4.7)
Unknown/PNA	97 (4.8)	30 (5.3)	67 (4.7)
Ethnicity			
Latino/Hispanic origin	75 (3.7)	20 (3.5)	55 (3.8)
Not of Latino/Hispanic origin	1,754 (87.6)	499 (88.0)	1,255 (87.4)
Unknown/PNA	174 (8.7)	48 (8.5)	126 (8.8)
Married/Partnered			
Yes	783 (32.1)	219 (38.6)	564 (39.3)
No	1,184 (59.1)	343 (60.5)	841 (58.5)
Unknown/PNA	36 (1.8)	5 (0.9)	31 (2.2)
Employed (full or part-time)			
Yes	904 (45.1)	256 (45.1)	648 (45.1)
No	1,047 (52.3)	297 (52.4)	750 (52.2)
Unknown/PNA	52 (2.6)	14 (2.5)	38 (2.7)
Reported being on disability			
Yes	310 (15.5)	106 (18.7)	204 (14.2)
No	1,641 (81.9)	447 (78.8)	1,194 (83.2)
Unknown/PNA	52 (2.6)	14 (2.5)	38 (2.6)
Highest education level			
High school or less	705 (35.2)	189 (33.3)	516 (36.0)
Some college or more	1,266 (63.2)	368 (64.9)	898 (62.5)
Unknown/PNA	32 (1.6)	10 (1.8)	22 (1.5)
Income			
<$25,000	602 (30.0)	188 (33.2)	414 (28.8)
$25,000-$49,999	306 (15.3)	71 (12.5)	235 (16.4)
≥$50,000	741 (37.0)	220 (38.8)	521 (36.3)
Unknown/PNA	354 (17.7)	88 (15.5)	266 (18.5)
Lost housing during the pandemic			
Yes	153 (7.6)	66 (11.6)	87 (6.0)
No	1,827 (91.2)	495 (87.3)	1,332 (92.8)
Unknown/PNA	23 (1.2)	6 (1.1)	17 (1.2)
Worried about or unable to pay rent or mortgage during the pandemic			
Yes	400 (20.0)	152 (26.8)	248 (17.3)
No	1,573 (78.5)	403 (71.1)	1,170 (81.5)
Unknown/PNA	30 (1.5)	12 (2.1)	18 (1.2)
Reported functional limitations[3]			
Yes	616 (30.7)	218 (38.4)	398 (27.7)
No	1,361 (68.0)	337 (59.4)	1,024 (71.3)
Unknown/PNA	26 (1.3)	12 (2.1)	14 (1.0)
Mental illness			
Yes	578 (28.9)	224 (39.5)	354 (24.6)
No	1,403 (70.0)	335 (59.1)	1,068 (74.4)
Unknown/PNA	22 (1.1)	8 (1.4)	14 (1.0)
Substance abuse			
Yes	235 (11.7)	81 (14.3)	154 (10.7)
No	1,756 (87.7)	483 (85.2)	1,273 (88.7)
Unknown/PNA	12 (0.6)	3 (0.5)	9 (0.6)
Number of comorbidities			
Zero	714 (35.6)	187 (33.0)	527 (36.7)
One	653 (32.6)	185 (32.6)	468 (32.6)
Two or more	636 (31.8)	195 (34.4)	441 (30.7)

[1]Numbers are prior to imputation of missing values; [2]Due to low sample size, individuals reporting their race as American Indian, Native Alaskan, Native Hawaiian, Pacific Islander, or multi-racial were grouped into one category; [3]Functional limitations included physical, mental, or emotional functional limitations
PNA: preferred not to answer

Time in the COVID-19 pandemic at enrollment

In total, participants contributed 3,412 person-years to the study, with a mean of 1.7 years (standard deviation = 0.49) in the COVID-19 pandemic at time of parent study enrollment.

CSA characteristics

The sample included participants from 48 of the 55 CSAs in Baltimore. The number of participants per CSA ranged from 2 to 174. The calculated ICC was 0.09.

Correlates of forgone care

Results—Individual-level correlates of forgone care

Table 3 presents the results from the level-one model, which included separate weighted bivariate analyses of the outcome of forgone care with each individual-level independent variable. Several predisposing factors were found to be associated with increased or decreased odds of forgone care. Those in the age group 35-49 years were found to have a 1.48 higher odds of forgone care, compared to the age group 18-34 ($p=0.001$); conversely, those in the ≥65 age group were found to have a 25% lower odds of forgone care, compared to individuals 18-34 years ($p=0.020$). The odds of forgone care were also higher in those reporting female sex at birth (OR 1.24, $p=0.010$) and those on disability status (OR 1.43, $p=0.001$). Individuals reporting Black or African American race had a 15% lower odds of forgone care ($p=0.047$).

Two enabling factors were found to be associated with higher odds of forgone care, including those who reported losing their housing during the COVID-19 pandemic (OR 1.90, $p=<0.001$) and those who reported being worried about paying their rent or mortgage (OR 1.69, $p=<0.001$). Finally, significant need level factors with higher odds of forgone care included those with functional limitations (OR 1.66,

p<0.001), those with mental illness (OR 1.87, p<0.001), those who reported using substances (OR 1.43, p=0.004), and those with two or more comorbidities, compared to no comorbidities (OR 1.24, p=0.023).

Table 3. Individual-Level Correlates of Forgone Care

Characteristic	Unadjusted Odds of Forgone Care	95% CI	P-Value
Predisposing factors			
Age (in years)			
18-34	Referent	--------	--------
35-49	1.48	(1.17-1.87)	0.001*
50-64	1.04	(0.84-1.29)	0.716
≥65	0.75	(0.59-0.96)	0.020*
Sex at birth			
Male	Referent	--------	--------
Female	1.24	(1.05-1.46)	0.010*
Race			
Any other race	Referent	--------	--------
Black or African American	0.85	(0.72-1.00)	0.047*
Marital status			
Not married or cohabitating	Referent	--------	--------
Married or cohabitating	0.99	(0.85-1.16)	0.927
Employment status			
Other	Referent	--------	--------
Working full or part time	1.02	0.87-1.18)	0.832
Disability status			
Not on disability status	Referent	--------	--------
On disability status	1.43	(1.16-1.77)	0.001*
Highest education level			
High school or less	Referent	--------	--------
Some college or more	1.12	(0.94-1.32)	0.205
Enabling factors			
Annual income			
< $25,000	Referent	--------	--------
≥$25,000	0.88	(0.75-1.03)	0.119
Lost housing during COVID-19			
No	Referent	--------	--------
Yes	1.90	(1.46-2.47)	<0.001*
Worried about paying rent/mortgage			
No	Referent	--------	--------
Yes	1.69	(1.41-2.03)	<0.001*
Need factors			
Functional limitations			
No	Referent	--------	--------
Yes	1.66	(1.40-1.96)	<0.001*
Mental illness			
No	Referent	--------	--------
Yes	1.87	(1.59-2.19)	<0.001*
Substance abuse			
No	Referent	--------	--------
Yes	1.43	(1.12-1.82)	0.004*
Number of comorbidities			

Zero	Referent	--------	--------
One	1.10	(0.92-1.32)	0.297
Two or more	1.24	(1.03-1.48)	0.023*

*Denotes those variables in the level one model with p-values ≤0.10 that were carried over to the level two model
CI: confidence interval

Results—Community-level correlates of forgone care

None of the binary CSA-level variables were found to be significant at the p≤0.10 level when looking at the pooled estimates across the five imputed datasets (Table 4). Thus, none of the CSA-level variables were incorporated into the final, multivariate model.

Table 4. Community-level correlates of forgone care

CSA Variable Comparison[1]	Pooled Odds of Forgone Care[2]	95% CI	Pooled P-Value[2]
High vs. low crime rate	0.81	(0.61-1.06)	0.130
Poor vs. good internet access	0.79	(0.59-1.06)	0.118
High reliance vs. low reliance on public transportation	0.89	(0.67-1.19)	0.431
Better vs. poor walkability	0.88	(0.67-1.15)	0.356
Majority Black vs. majority other	1.1	(0.79-1.40)	0.602
Majority Hispanic vs. majority other	0.90	(0.65-1.26)	0.548
Life expectancy≥76.8 years vs. <76.8 years	1.02	(0.72-1.45)	0.895
Lower vs. better affordability	1.05	(0.80-1.38)	0.718
High vs. lower high school completion	0.89	(0.69-1.16)	0.390
High vs. low poverty	0.78	(0.58-1.07)	0.121
High vs. low unemployment	1.03	(0.78-1.36)	0.858

[1]See Table 1 for cutoff values of CSA-level variables
[2]Pooled estimates are across 5 imputed datasets
CSA: community statistical area

Results—Final multivariable model

The results of the final weighted multivariable model can be found in Table 5, adjusted for the pandemic wave and study variables. Predisposing factors that were statistically significant in the final model included those who reported being ages 35-49 years, who were found to have a higher odds of

forgone care compared to those in the 18-34 years age group (OR 1.51, p=0.001). Individuals who reported their sex at birth as female were also found to have higher odds of forgone care, compared to those who reported their sex at birth as male (OR 1.21, p=0.028). Individuals who reported their race as Black/African American had a 32% reduction in their odds of forgone care, compared to individuals of any other race (OR 0.68, p=≤0.001). Significant enabling factors included those who reported losing their house during COVID-19, compared to those who did not (OR 1.47, p=0.014) and those who reported being worried about paying their rent or mortgage, compared to those who were not (OR 1.37, p=0.005). Need level factors that remained significant in the final model included those with functional limitations, compared to those without (OR 1.46, p=≤0.001) and those who reported having a mental illness, compared to those without (OR 1.44, p=≤0.001).

Table 5. Adjusted odds of foregone care (n=2,003)

Characteristic	Adjusted Odds Ratio (aOR)	95% CI	P-Value
Predisposing factors			
Age (in years)			
18-34	Referent	--------	--------
35-49	1.51	(1.19-1.93)	0.001
50-64	1.05	(0.82-1.34)	0.724
≥65	0.80	(0.61-1.04)	0.092
Sex at birth			
Male	Referent	--------	--------
Female	1.21	(1.02-1.44)	0.028
Race			
Any other race	Referent	--------	--------
Black or African American	0.68	(0.55-0.83)	≤0.001
Disability status			
Not on disability status	Referent	--------	--------
On disability status	1.13	(0.87-1.47)	0.351
Enabling factors			
Lost housing during COVID-19			
No	Referent	--------	--------
Yes	1.47	(1.08-1.99)	0.014
Worried about paying rent/mortgage			
No	Referent	--------	--------
Yes	1.37	(1.10-1.71)	0.005
Need factors			
Functional limitations			
No	Referent	--------	--------
Yes	1.46	(1.20-1.78)	≤0.001
Mental illness			

No	Referent	--------	--------
Yes	1.44	(1.20-1.73)	≤0.001
Substance abuse			
No	Referent	--------	--------
Yes	1.08	(0.82-1.43)	0.572
Number of comorbidities			
Zero	Referent	--------	--------
One	1.11	(0.92-1.36)	0.282
Two or more	1.24	(1.00-1.55)	0.051

CI: confidence interval

Discussion

Several studies published during the COVID-19 pandemic on forgone care indicate that economically disadvantaged and historically excluded populations experienced a greater prevalence of forgone care. However, few studies have investigated correlates of forgone care that go beyond social and economic factors, such as examining the influence of the local community in which people live. Given the widespread impacts of the COVID-19 pandemic on both individuals and communities, it is important to take a socio-ecologic perspective and explore the myriad, multilevel influencers of health.[42] However, our study found that none of the community-level determinants, such as reliance on public transportation or internet access, accounted for the odds of forgone care above and beyond any individual-level correlates. This finding differs from previously published literature that has identified geographic disparities in COVID-19-related outcomes, although the geographic unit of analyses used in these studies differ from what was used in our study.[24–28]

In this racially and economically diverse sample, we found that Black/African Americans living in Baltimore were less likely to experience forgone care, which is in opposition to some previously published work on forgone care during the COVID-19 pandemic.[6,9,10] However, this finding was consistent with Tsuzaki & Taira, who found that non-Hispanic/LatinX Black Medicare beneficiaries were least likely to forgo care in the summer of 2020 compared to White beneficiaries.[12] These findings warrant additional exploration, including comparisons of healthcare utilization practices prior to versus

during the pandemic. This is critical, as there are long-standing, systemic inequities in healthcare access and utilization within the Black/African American communities that were further exacerbated during the COVID-19 pandemic. For example, a 2016 report by the University of Maryland found that Black/African American Maryland residents were 1.9 times more likely to be unable to afford a visit with a healthcare provider than White residents and were much more likely to die from heart disease, diabetes, stroke, and asthma.[43] Black/African American individuals included in our study sample may have reported less episodes of forgone care because they have historically experienced systemic racism and marginalization within the healthcare system. Therefore, they may have been less likely to use the healthcare system even prior to the pandemic, and thus less likely to report forgone care. Alternatively, efforts by the local health department and the broader health system to safely re-open clinics, including in under-resourced areas, may have limited impacts on this community.

In our analysis of individual-level correlates of forgone care, we identified those who have experienced housing insecurity during the pandemic, as evidenced by loss of housing or worrying about paying for housing, as having a higher odds of forgone care. Income inequities and financial instability have previously been identified as critical determinants of an individual's healthcare utilization practices and the experience of forgone care. [44] Unfortunately, the pandemic impacted the economic stability of millions of American households, particularly lower-income families, and many lost jobs as a result.[45] This may have drove increased rates of forgone care within individuals experiencing financial hardship and housing instability. Anderson et al., for example, found that 52% of respondents who reported missing medical care did so due to "financial repercussions of the COVID-19 pandemic."[5] Notably, several safety net programs, such as the Coronavirus Aid, Relief, and Economic Security (CARES) Act, which provided unemployment benefits and additional financial support to American families, and the continuous Medicaid enrollment provision under the Families First Coronavirus Response Act, were available to qualifying individuals early in the pandemic.[46,47] However, a study published in 2020 on access and enrollment in safety net programs during the pandemic found gaps in awareness for several programs, including health insurance exchanges.[48] Our study also found that individuals reporting female

sex at birth had higher odds of forgone care compared to those reporting male sex at birth. During the pandemic, many women had to take on additional caretaking roles, including homeschooling children and caring for ill family members.[49] These additional responsibilities may have impacted their ability to seek healthcare when needed.

The odds of forgone care were also higher in individuals reporting functional limitations. These individuals likely have a higher reliance on support services such as accessible transportation, and interruptions in these services may have disproportionately impacted their ability to access the health system. Those reporting a mental illness also reported an increased odds of forgone care, a finding that aligns with other published COVID-19 forgone care literature.[8] Individuals suffering from mental illness have previously been shown to be at higher risk for forgone care [50], and exacerbations in mental health crises during the pandemic may have disproportionately led to the increased risk of forgone care within this population.

In a world where pandemics and other humanitarian emergencies are increasingly likely due to population growth, interactions at the human-animal interface, climate change, and global travel, it is critical that we strengthen models of care so that health systems can continue to support individual and community health during future public health emergencies. One potential strategy is to increase the use of mobile-based healthcare services. Mobile health clinics have previously been shown to be effective in providing urgent care, preventive health, and chronic disease management.[51] Some of the benefits of mobile health clinics include the elimination of barriers such as lack of transportation, inconvenient operating hours, and long wait times and the ability to form trusting relationships within communities, particularly those who experience stigma.[51] Importantly, leveraging mobile clinics in the midst of an emergency have been shown to reduce disruptions in care, as they are already well-integrated into the community and can be effectively and quickly deployed.[51] Leveraging of mobile clinics during COVID-19 have been captured in the literature to-date. For example, co-location of COVID-19 vaccines within existing harm reduction mobile services has been demonstrated to be an effective way to deliver vaccines

to underserved populations.[52] More widespread use of these types of clinics now and in the future could help reduce forgone care, particularly among those who already experience barriers to healthcare access.

Another strategy that could help address inequities in forgone care during COVID-19 and future health emergencies would be adoption of programs that could extend telehealth services to those who currently lack access. This should include not only the resources required for telehealth, such as internet coverage and smartphones, but also changes in insurance policies that increase coverage and better education for consumers on how to utilize this technology.[53] For example, participants in one study reported that a major disadvantage of telehealth was their "unfamiliarity" with the platform and distrust that their information was secure and private.[54] Healthcare providers also expressed gaps in knowledge on how to use telemedicine and what services were covered by insurance [54], indicating additional opportunities for education to ensure more consistent and widespread use. Additionally, while important policy changes have been implemented to expand telehealth during COVID-19, permanent adoption of some of these changes, such as compensation for primary healthcare services, could help ensure continued access and would already be in place in the event of a new health emergency.[55]

Limitations

This study has several limitations. First, missing data for participants across several independent variables necessitated imputation of missing values for the model-building process, which may have led to biased results. However, a sensitivity analysis using only participants with complete data revealed similar magnitudes of odds ratios for all variables found to have significance at $p \leq 0.05$ in the final, imputed dataset. Second, low sample size amongst participants reporting Hispanic/LatinX origin prohibited incorporation into the final model. Lack of data on participant's insurance status in the parent dataset also prohibited inclusion. Third, because the CoVPN 5002 study did not collect participant's address, we had to assume their residence was within the venue of enrollment. While several venues were held within low-income housing developments, their assigned CSA may not have been accurately

reflected in the data. Finally, because this study is based upon participant-reported survey data, it may be subject to recall bias.

Conclusions

Despite these limitations, this study has important implications for addressing unmet healthcare needs that have occurred during the pandemic. Our study found that Black/African American individuals had a lower odds of experiencing forgone care, which differs from other published studies on this topic. Additional research will be critical to further understanding how healthcare access and utilization practices differed during versus before the pandemic and to more clearly identify those who are at highest risk of the downstream consequences of forgone care. Our study also found that individuals experiencing financial stress, who have functional limitations, and who have a mental illness suffered higher odds of forgone care during COVID-19. It is critical that the health system identify ways to address any barriers to care that these populations might be experiencing, such as the increased use of mobile health services or telemedicine platforms. Additionally, moving forward, public health emergency preparedness planning efforts must account for the unique needs of these communities during crises, to ensure that their health needs can continue to be met. This will require additional studies that seek to better understand the perspectives and experiences of these populations during the pandemic, and how models of care can be adapted to serve them better in the future.

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CHAPTER 5: MANUSCRIPT FOUR

Correlates of Forgone Emergent Care and Surgical/Dental Procedures during the COVID-19 Pandemic in Baltimore, Maryland

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Abstract

Forgone care, including for emergent conditions and for surgical or dental procedures, can have significant impacts on patient health outcomes, including more severe prognoses for acute medical events such as strokes and delayed cancer diagnoses. The objective of this study was to identify correlates of forgone emergent care and surgical/dental procedures during the COVID-19 pandemic to better evaluate what drove forgone care within each of these specific care types. We used a combined analytic sample of data abstracted from two SARS-CoV-2 prevalence studies conducted in Baltimore, MD, limited only to those parent study participants who had reported needing emergent and/or surgical/dental procedures during the pandemic. Abstracted data included the experience of forgone care, socio-demographics, housing instability, and comorbidities. Selection of predictor variables was guided by the Gelberg et al. Behavioral Model for Vulnerable Populations. Weighted multivariable logistic regression was used to identify significant correlates for each care type. Significant correlates of forgone surgical/dental procedures included income and experiencing housing instability during the pandemic. Significant correlates of forgone emergent care included sex, race, loss of housing during the pandemic, and comorbidity number. It is critical that actions be taken to address and mitigate the impacts that missed healthcare visits may have on short and long-term health. Additionally, efforts to improve health system resilience for large-scale public health emergencies must incorporate ways to ensure continued access to care for those most at-risk for interruptions, even in the midst of a crisis.

Introduction

The Coronavirus Disease 2019 (COVID-19) pandemic greatly impacted the healthcare system in the United States (US). At several points during the pandemic, hospitals and clinics have delayed or cancelled surgical procedures and appointments in response to reduced workforce capacity, to accommodate surges in critically ill patients, and to reduce the potential for further disease transmission. Patients also reported reluctance to visit healthcare providers, including for emergent health conditions such as strokes, due to fear of exposure to the SARS-CoV-2 virus, which causes COVID-19 disease.[1] Other socio-economic barriers, including loss of transportation and COVID-19 related financial losses, also led to disruptions in the ability of patients to access and utilize the healthcare system.[2,3] These disruptions led to forgone care, which is defined as "someone who does not use healthcare despite perceiving a need for it."[4]

Forgone care can have significant impacts on patient health outcomes. For example, the National Cancer Institute estimates that over 9 million cancer screening tests were missed in 2020, which may lead to delayed diagnoses and poorer prognoses.[5] Avoidance or delays in seeking care for potentially life-threatening acute medical events such as strokes and heart attacks similarly may lead to greater short- and long-term morbidity and mortality.[6]

The existing literature has identified several correlates of forgone care during the COVID-19 pandemic in the US. Giannouchos et al. (2021) identified higher odds of forgone care amongst older age groups, non-Hispanic Asians, those who identify as female, individuals with higher income and education levels, those experiencing financial strain, those with private insurance (compared to uninsured), and those who have poorer health status or who have mental health disorders.[7] However, less data are available on how the correlates of forgone care may differ by care type, including for emergent health conditions and surgical/dental procedures. This is an important gap, given that the populations who require major surgical/dental procedures may differ from those needing emergent care. For example, Americans who are socio-economically disadvantaged have previously demonstrated higher rates of

emergency department usage for preventable reasons, and thus they may have experienced higher rates of forgone emergent care during the pandemic.[8] Additionally, existing inequities in access to what are termed "elective procedures" such as dental surgeries may mean that only those with the financial and other means for receiving this type of care were impacted by pandemic-related interruptions.[9] Finally, much of the existing literature on forgone care during the pandemic is informed by data collected through national-level convenience sampling methods, which may not accurately represent all communities, particularly those who experience stigma within the health system, the socio-economically disadvantaged, and historically excluded and minoritized populations.

This study aimed to address these gaps by measuring the correlates of forgone emergent care and surgical/dental procedures using a representative sample of adults living in Baltimore, Maryland. The objective was to identify differences in correlates to better evaluate drove forgone care within each of these specific care types. This knowledge can elucidate which populations were most impacted by gaps in care experienced during the pandemic, as well as inform public health emergency planning efforts to strengthen health systems for future crises.

Methods

Data sources

We conducted a cross-sectional analysis of data from two merged data sets—the Community Collaboration to Combat COVID-19 and COVID-19 Prevention Network 5002 studies—to examine factors associated with forgone surgical/dental procedures and emergent care experienced during the COVID-19 pandemic in Baltimore, MD. Each study collected baseline survey data on emergent care and surgical/dental procedure needs and forgone care during the COVID-19 pandemic, as well as participant socio-demographics and comorbidities. Each parent study utilized robust sampling strategies, yielding a combined analytic sample that included representation of populations likely not included in the current

COVID-19 forgone care literature, including the unhoused and other economically disadvantaged populations. Details of the two parent studies are summarized below.

The Community Collaboration to Combat COVID-19 study

The Community Collaboration to Combat COVID-19 (C-FORWARD; clinical trial identifier # NCT04673292) study was a National Institute of Allergy and Infectious Diseases (NIAID) funded study that enrolled participants from February 2021 to December 2022. The study was a comparative effectiveness trial of SARS-CoV-2 testing modalities and aimed to determine best testing strategies, measure the prevalence of SARS-CoV-2, and understand the broader impacts of the pandemic on households in Baltimore, MD. Households (HH) across Baltimore were enrolled using a multi-staged approach, stratified by race, ethnicity, and socio-economic status, to obtain a population representative sample. The study consisted of two separate phases. Phase I sought to enroll one eligible HH member (designated as the "HH index member"), who had to be 18 years of age or older. Once enrolled, the HH index member completed SARS-CoV-2 antigen and antibody testing, other serum testing, and a baseline enrollment survey that covered, among other items, socio-demographics, comorbidities, healthcare needs, and forgone care during the pandemic. In total, n=1,978 HH index members enrolled into Phase I. Phase I enrollees were eligible to enroll in Phase II of the study, which has been described elsewhere.[10] The data presented in this study only includes data collected from the Phase I surveys completed by HH index members.

The COVID-19 Prevention Network 5002 study

The COVID-19 Prevention Network 5002 (CoVPN 5002; clinical trial identifier # NCT04658121) study was also funded by the NIAID and enrolled participants across 15 different sites in the US, including Baltimore. The data presented in this study only includes data collected from the Baltimore site, which enrolled participants from March to July, 2021. The goals of this cross-sectional study included to estimate the prevalence of SARS-CoV-2 infection and seroprevalence and to assess the

broader impacts of the pandemic on the clinical, social, and economic well-being of participants. The study used randomized venue-time sampling, the details of which have been published elsewhere.[11] Venues utilized at the Baltimore site included places of worship, food pantries, low-income housing developments, federally qualified health centers, and substance treatment centers. Individuals entering or exiting the site were invited to enroll, if eligible. Eligibility included any person over age 2 months who were able to provide consent (assent for those less than 18 years of age, with consent of a legal guardian). Initial enrollees completed SARS-CoV-2 antigen and antibody testing, as well as a paper-based survey that included, among other items, questions on socio-demographics, comorbidities, and routine healthcare needs during the pandemic. In April, an additional sub-survey was added at the Baltimore location to collect data on the need for surgical/dental procedures and emergent care, as well as on the experience of forgone care. This study only includes analysis of those participants who completed this additional sub-survey (n=566).

Sample inclusion criteria

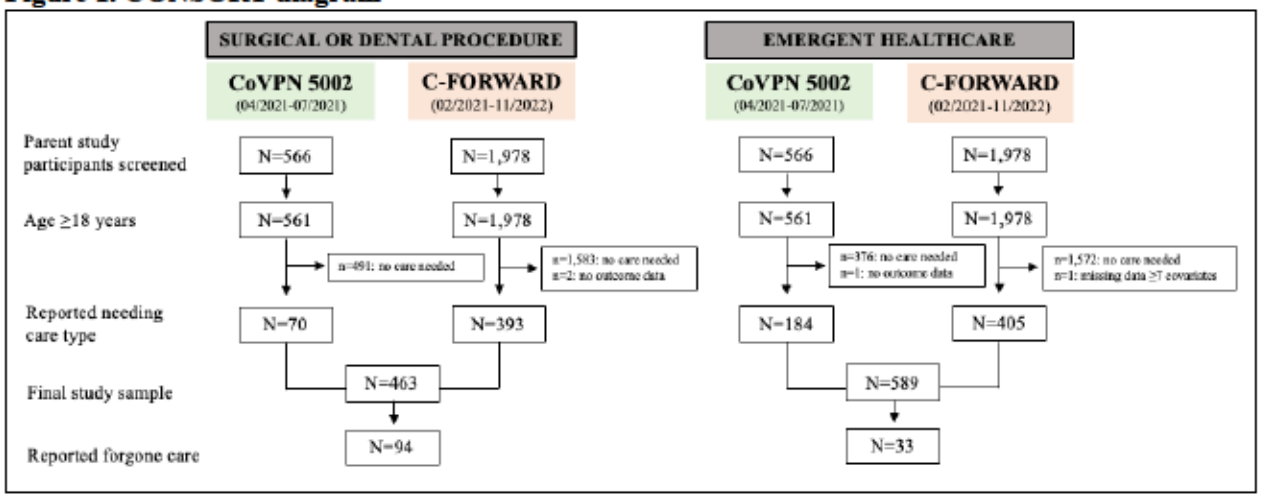
Only those parent study participants who reported needing a surgical/dental procedure or emergent healthcare since the beginning of the COVID-19 pandemic, March 1, 2020, until completion of the baseline enrollment survey, were included in this study. This was measured in both parent studies by the following two questions (see Appendix A for all parent survey questions used in this study):

1. Since the COVID-19 pandemic (March 1, 2020), did you need to go to the emergency room/hospital for a condition that was not related to COVID-19?
2. Since the COVID-19 pandemic (March 1, 2020), did you need to have a major medical or dental procedure such as surgery?

For those who met the inclusion criteria, extracted data included: socio-demographics, housing instability experienced during the pandemic, comorbidities, functional limitations, and forgone emergent care or surgical/dental procedures. The local institutional medical record (EPIC) was searched to attempt

to address any missing data for those participants with EPIC profiles. Those under the age of 18 years were later dropped, as the C-FORWARD study only included HH index members who were age 18 years or older (Figure 1). Additionally, individuals were dropped if it was unclear whether they experienced the outcome (e.g., questions were left blank) or if seven or more demographic questions were blank.

Figure 1. CONSORT diagram



Outcome measurement and variable definitions

The outcome measured for this study was the experience of forgone surgical/dental procedures or emergent care, defined as a procedure or healthcare that was skipped, missed, or delayed during the COVID-19 pandemic. This was measured in both parent studies at completion of the enrollment survey by the following two questions:

1a. Did you go to the emergency room/hospital when you needed to?

2a. Did you postpone your major medical or dental procedure because of COVID-19?

Selected correlates of forgone surgical/dental procedures and emergent care were informed by the Gelberg et al. Behavioral Model for Vulnerable Populations. This model is an adaptation of Andersen's theoretical model for healthcare utilization, which defines healthcare use as the function of predisposing, enabling, and need-based factors.[12] Gelberg's model incorporates correlates relevant to historically

excluded and economically disadvantaged populations.[13] For this study, the following correlates were used:

- Pre-disposing, defined as factors that contribute to an individual's attitudes and beliefs towards healthcare. These included the participant's age, sex at birth, race, marital status, employment status, disability status, and education level.
- Enabling/impeding, defined as factors that may support or prohibit use of the health system. These included the participant's income, loss of housing during the pandemic, and worrying about paying rent/mortgage during the pandemic.
- Need-based, defined as factors that may impact an individual's perceived need for care. These included the number of comorbidities, presence of functional limitations, mental illness, and alcohol/substance and injection drug use.

Classification of participants within predictor categories were based upon response options provided in the parent study surveys, as well as to ensure sufficient power. Other covariates included in this analysis were two binary "pandemic wave" variables, which aimed to account for the different enrollment periods used by the parent studies. This included a delta wave (for those who enrolled after August 1, 2021) and an omicron wave (for those who enrolled after December 1, 2021). A third binary variable was also added to account for the origin of the data (e.g., either C-FORWARD or CoVPN 5002).

Statistical analysis

Frequencies and patterns of missing data were explored across all predictor variables. Multiple imputation using chained equations was then used to address missing data. Multiple imputation is one mechanism for handling missing data and decreases the potential for biases that could result from dropping participants with incomplete observations.[14] Predictors of missing values included all predictor variables, the outcome of any experience of forgone care (regardless of type), and the binary variable used to account for the origin of the data. Five imputed datasets were generated. A complete case sensitivity

analysis was conducted at the completion of the model building process detailed below to assess for biases introduced in the imputation process. All analyses were conducted using Stata version 16.0 (StataCorp LLC, College Station, TX).

We calculated descriptive statistics of participant characteristics across the above stated predictor variables for those who reported needing surgical/dental procedures and emergent care. Amongst those who reported needing surgical/dental procedures, weighted bivariate logistic regressions were run for each of the previously identified predictor variables. Each observation was weighted based upon the total amount of person-years spent in the pandemic, which was measured from March 1, 2020 until completion of the parent study survey. All predictor variables with significance at $p \leq 0.10$ in the bivariate regressions were included into the final, multivariable model.

The final weighted multivariable model included all predictor variables with significance at $p \leq 0.10$ in the bivariate regressions and was adjusted for pandemic waves and the study (e.g., C-FORWARD or CoVPN 5002). This same model building approach was then used only amongst those participants who reported needing emergent care during the pandemic. Significance of variables in the final multivariate models was set at $p \leq 0.05$.

Ethical considerations

This study was approved by the Johns Hopkins University School of Medicine Office of Human Subjects Research on December 19, 2022 (IRB#00348695). The C-FORWARD study was approved by the Johns Hopkins University School of Medicine Office of Human Subjects Research on June 2, 2020 (IRB#00250298). The CoVPN 5002 study was approved by the Johns Hopkins University School of Medicine Office of Human Subjects Research on January 28, 2021 (IRB#00262004).

Results

Participant characteristics

In total, 463 participants from the CoVPN 5002 and C-FORWARD studies reported needing surgical/dental procedures during the COVID-19 pandemic (Table 1). The majority of participants needing surgical/dental procedures were over the age of 50 years (67.1%) and identified their sex at birth as female (67.4%). Nearly half (48.6%) of participants identified as Black or African American and 4.5% identified their ethnicity as Latino or Hispanic. Slightly over half (51.6%) reported not currently being employed (either part or full-time) and most (85.1%) denied being on disability. Several participants reported housing insecurity during the COVID-19 pandemic, including losing their housing (6.3%) and worrying about paying the rent or mortgage (19.9%). Functional limitations were fairly common amongst participants (32.8%), as was mental illness (28.7%). Over 861.8 person years were contributed by participants who reported needing surgical/dental procedures, with a mean amount of time spent in the pandemic of 1.86 years (standard deviation of 0.45).

Of the 463 participants who reported needing surgical/dental procedures, 94 (20.3%) reported forgoing the procedure due to the COVID-19 pandemic (Table 1). Of those 94 participants, 42 (44.7%) had still not had the procedure at time of parent study enrollment. Individuals ages 50-64 years had the highest frequency of reporting forgone surgical/dental procedures (37.2%) among the four age groups. Nearly half of those who reported forgoing a surgical/dental procedure reported their race as Black/African American (47.9%). A relatively large percentage of those who reported forgoing care reported worrying about paying their rent or mortgage during the COVID-19 pandemic (31.9%), had a functional limitation (38.3%), or had a mental illness (35.1%).

Table 1. Participant socio-demographics: Surgical or dental procedures[1]

Variable Name	Reported Needing Surgical/Dental Procedure (n=463)	Reported Forgone Care (n=94)	Reported No Forgone Care (n=369)
Age			
18-34	61 (13.2)	13 (13.8)	48 (13.0)
35-49	91 (19.7)	21 (22.4)	70 (19.0)
50-64	171 (36.9)	35 (37.2)	136 (36.9)

≥65	140 (30.2)	25 (26.6)	115 (31.1)
Sex at Birth			
Male	149 (32.2)	25 (26.6)	124 (33.6)
Female	312 (67.4)	69 (73.4)	243 (65.9)
Unknown/PNA	2 (0.4)	0 (0.0)	2 (0.5)
Race[2]			
White	188 (40.6)	31 (33.0)	157 (42.6)
Black/African American	225 (48.6)	45 (47.9)	180 (48.8)
Other	26 (5.6)	7 (7.4)	19 (5.1)
Unknown/PNA	24 (5.2)	11 (11.7)	13 (3.5)
Ethnicity			
Latino/Hispanic origin	21 (4.5)	8 (8.5)	13 (3.5)
Not of Latino/Hispanic origin	401 (86.6)	78 (83.0)	323 (87.5)
Unknown/PNA	41 (8.9)	8 (8.5)	33 (9.0)
Married/Partnered			
Yes	191 (41.3)	44 (46.8)	147 (39.8)
No	264 (57.0)	49 (52.1)	215 (58.3)
Unknown/PNA	8 (1.7)	1 (1.1)	7 (1.9)
Employed (Part of Full Time)			
Yes	215 (46.4)	44 (46.8)	171 (46.3)
No	239 (51.6)	49 (52.1)	190 (51.5)
Unknown/PNA	9 (1.9)	1 (1.1)	8 (2.2)
Reported on disability			
Yes	60 (13.0)	14 (14.9)	46 (12.5)
No	394 (85.1)	79 (84.0)	315 (85.4)
Unknown/PNA	9 (1.9)	1 (1.1)	8 (2.1)
Education Level			
HS or less	115 (24.8)	21 (22.3)	94 (25.5)
Some college or more	339 (73.3)	69 (73.4)	270 (73.2)
Unknown/PNA	9 (1.9)	4 (4.3)	5 (1.3)
Income			
<$25,000	130 (28.1)	36 (38.3)	94 (25.5)
$25,000-$49,999	76 (16.4)	12 (12.8)	64 (17.3)
≥$50,000	189 (40.8)	32 (34.0)	157 (42.6)
Unknown/PNA	68 (14.7)	14 (14.9)	54 (14.6)
Lost Housing During the Pandemic			
Yes	29 (6.3)	11 (11.7)	18 (4.9)
No	429 (92.6)	82 (87.2)	347 (94.0)
Unknown/PNA	5 (1.1)	1 (1.1)	4 (1.1)
Worry about Rent			
Yes	92 (19.9)	30 (31.9)	62 (16.8)
No	366 (79.0)	62 (66.0)	304 (82.4)
Unknown/PNA	5 (1.1)	2 (2.1)	3 (0.8)
Functional Limitations[3]			
Yes	152 (32.8)	36 (38.3)	116 (31.4)
No	304 (65.7)	55 (58.5)	249 (67.5)
Unknown/PNA	7 (1.5)	3 (3.2)	4 (1.1)
Mental Illness			
Yes	133 (28.7)	33 (35.1)	100 (27.1)
No	325 (70.2)	60 (63.8)	265 (71.8)
Unknown/PNA	5 (1.1)	1 (1.1)	4 (1.1)
Substance Abuse			
Yes	36 (7.8)	9 (9.6)	27 (7.3)
No	424 (91.5)	85 (90.4)	339 (91.9)
Unknown/PNA	3 (0.7)	0 (0.0)	3 (0.8)
Number of Comorbidities			
0	152 (32.8)	26 (27.7)	126 (34.1)
1	142 (30.7)	27 (28.7)	115 (31.2)
2+	169 (36.5)	41 (43.6)	128 (34.7)

[1]Numbers are prior to imputation of missing values; [2]Due to low sample size, individuals reporting their race as American Indian, Native Alaskan, Native Hawaiian, Pacific Islander, or multi-racial were grouped into one category; [3]Included physical, mental, or emotional functional limitations
PNA-preferred not to answer

Five hundred and eighty-nine combined participants reported needing emergent healthcare during the COVID-19 pandemic (Table 2). Most participants who reported needing emergent health services were over the age of 50 years (58.0%) and reported their sex at birth as female (63.2%). Nearly 60% reported their race as Black or African American, and only 3.7% reported their ethnicity as of Latino or Hispanic origin. Over one-quarter of participants (26.8%) reported worrying about paying their rent or mortgage during the COVID-19 pandemic, and 7.6% reported actually losing their housing during the pandemic. Over one-third (36.2%) reported having a functional limitation and 37.0% reported having two or more comorbidities. Mental illness and illicit substance abuse had relatively high frequencies within the sample, at 32.9% and 13.9%, respectively. In total, 1,036.8 person years were contributed by participants who reported needing emergent healthcare. The mean amount of time spent in the pandemic was 1.76 years (standard deviation of 0.51).

Only a small percentage of individuals who reported needing emergent care reported forgoing emergent care (n=33, 5.6%; Table 2). Most of those who reported forgoing emergent care reported their race as Black/African American (69.7%) and and were not of Hispanic or Latino origin (87.9%). Nearly one third of those who reported forgoing emergent care reported having a functional limitation (27.3%); 33.3% reported having a mental illness.

Table 2. Participant socio-demographics: Emergent care [1]

Variable Name	Needed Emergent Care (n=589)	Reported Forgone Care (n=33)	Reported No Forgone Care (n=556)
Age			
18-34	107 (18.2)	4 (12.1)	103 (18.5)
35-49	140 (23.8)	9 (27.3)	131 (23.6)
50-64	208 (35.3)	11 (33.3)	197 (35.4)
≥65	134 (22.7)	9 (27.3)	125 (22.5)
Sex at Birth			
Male	214 (36.3)	7 (21.2)	207 (37.2)
Female	372 (63.2)	26 (78.8)	346 (62.2)

Unknown/PNA	3 (0.5)	0 (0.0)	3 (0.6)
Race[2]			
White	180 (30.6)	5 (15.2)	175 (31.5)
Black/African American	353 (59.9)	23 (69.7)	330 (59.3)
Other	29 (4.9)	2 (6.0)	27 (4.9)
Unknown/PNA	27 (4.6)	3 (9.1)	4 (4.3)
Ethnicity			
Latino/Hispanic origin	22 (3.7)	0 (0.0)	22 (4.0)
Not of Latino/Hispanic origin	513 (87.1)	29 (87.9)	484 (87.0)
Unknown/PNA	54 (9.2)	4 (12.1)	50 (9.0)
Married/Partnered			
Yes	206 (35.0)	12 (36.4)	194 (34.9)
No	372 (63.1)	21 (63.6)	351 (63.1)
Unknown/PNA	11 (1.9)	0 (0.0)	11 (2.0)
Employed (Part of Full Time)			
Yes	231 (39.2)	14 (42.4)	217 (39.0)
No	339 (57.6)	19 (57.6)	320 (57.6)
Unknown/PNA	19 (3.2)	0 (0.0)	19 (3.4)
Reported on disability			
Yes	112 (19.0)	6 (18.2)	106 (19.1)
No	458 (77.8)	27 (81.8)	431 (77.5)
Unknown/PNA	19 (3.2)	0 (0.0)	19 (3.4)
Education Level			
HS or less	241 (40.9)	15 (45.5)	226 (40.6)
Some college or more	341 (57.9)	17 (51.5)	324 (58.3)
Unknown/PNA	7 (1.2)	1 (3.0)	6 (1.1)
Income			
<$25,000	213 (36.2)	10 (30.3)	203 (36.5)
$25,000-$49,999	83 (14.1)	4 (12.1)	79 (14.2)
≥$50,000	177 (30.0)	11 (33.3)	166 (29.9)
Unknown/PNA	116 (19.7)	8 (24.3)	108 (19.4)
Lost Housing During the Pandemic			
Yes	45 (7.6)	4 (12.1)	41 (7.4)
No	541 (91.9)	29 (87.9)	512 (92.1)
Unknown/PNA	3 (0.5)	0 (0.0)	3 (0.5)
Worry about Rent			
Yes	158 (26.8)	8 (24.2)	150 (27.0)
No	424 (72.0)	24 (72.7)	400 (71.9)
Unknown/PNA	7 (1.2)	1 (3.1)	6 (1.1)
Functional Limitations[3]			
Yes	213 (36.2)	9 (27.3)	204 (36.7)
No	368 (62.5)	24 (72.7)	344 (61.9)
Unknown/PNA	8 (1.3)	0 (0.0)	8 (1.4)
Mental Illness			
Yes	194 (32.9)	11 (33.3)	183 (32.9)
No	386 (65.5)	22 (66.7)	364 (65.5)
Unknown/PNA	9 (1.6)	0 (0.0)	9 (1.6)
Substance Abuse			
Yes	82 (13.9)	3 (9.1)	79 (14.2)
No	501 (85.1)	30 (90.9)	471 (84.7)
Unknown/PNA	6 (1.0)	0 (0.0)	6 (1.1)
Number of Comorbidities			
0	180 (30.6)	13 (39.4)	167 (30.0)
1	191 (32.4)	12 (36.4)	179 (32.2)
2+	218 (37.0)	8 (24.2)	210 (37.8)

[1]Numbers are prior to imputation of missing values; [2]Due to low sample size, individuals reporting their race as American Indian, Native Alaskan, Native Hawaiian, Pacific Islander, or multi-racial were grouped into one category; [3]Included physical, mental, or emotional functional limitations
PNA-preferred not to answer

Correlates of forgone surgical/dental procedures

Table 3 presents the results of the weighted unadjusted bivariate models. Only one predisposing factor—female sex at birth—was found to have significance at the p≤0.10 level, with females having a higher odds of forgone care, compared to males (OR 1.45, p=0.054). All three enabling factors had significance at the p≤0.10 level. Individuals with annual income greater than or equal to $25,000 were found to have a lower odds of forgone care (OR 0.58, p=0.003). Individuals who experienced housing instability during the pandemic, including loss of housing (OR 2.29, p=0.006) and worrying about paying the rent or mortgage (OR 2.46, p≤0.001), had increased odds of reporting forgone surgical/dental procedures. Finally, all but one of the need-level factors (presence of mental illness) had significance at the p≤0.10 level, with those who reported having a mental illness having increased odds of forgone surgical/dental procedures, compared to those without (OR 1.38, p=0.076). Each of these variables were subsequently incorporated into the adjusted multivariable model.

Table 3 also presents the results of this final model, with each observation weighted for person-years in the pandemic. All estimates are adjusted for the experience of the delta and omicron pandemic waves and for the origin of the data (e.g., C-FORWARD or CoVPN 5002). In the final weighted multivariable model, only two predictor variables, both enabling factors, remained significant at the p≤0.05 level. This included individuals who reported worrying about paying their rent or mortgage, who had 2.33 higher odds of experiencing forgone surgical/dental procedures, compared those who did not (p=0.001). Individuals who reported an income equal to or above $25,000 reported a 45% lower odds of forgone surgical/dental procedures, compared to those with income less than $25,000 (p=0.007).

Table 3. Correlates of forgone surgical/dental procedures

	Unadjusted Bivariate Model			Adjusted Multivariable Model[1]		
Variable	**Odds of forgone care**	**95% CI**	**P Value**	**Odds of forgone care**	**95% CI**	**P Value**
Predisposing Factors						
Age (in years)						

18-34	Ref	----	Ref			
35-49	0.98	(0.56, 1.71)	0.937			
50-64	0.83	(0.50, 1.38)	0.474			
≥65	0.72	(0.43, 1.23)	0.233			
Sex						
Male	Ref	----	Ref	Ref	----	Ref
Female	1.45	(0.99, 2.10)	0.054*	1.42	(0.96, 2.10)	0.082
Race						
Any other race	Ref	----	Ref			
African American/Black	1.03	(0.74, 1.45)	0.854			
Married/Partnered						
Not married/cohabitating	Ref	----	Ref			
Married/cohabitating	1.24	(0.89, 1.74)	0.206			
Employment Status						
Other	Ref	----	Ref			
Working full or part-time	0.91	(0.65, 1.27)	0.567			
Disability Status						
Not on disability status	Ref	----	Ref			
On disability status	1.40	(0.86, 2.29)	0.179			
Highest education level						
High school or less	Ref	----	Ref			
Some college or more	0.98	(0.65, 1.47)	0.919			
Enabling Factors						
Income						
<$25,000	Ref	----	Ref	Ref	----	Ref
≥$25,000	0.58	(0.40, 0.83)	0.003*	0.55	(0.36, 0.84)	0.007**
Lost housing						
No	Ref	----	Ref	Ref	----	Ref
Yes	2.29	(1.26, 4.14)	0.006*	1.33	(0.64, 2.74)	0.441
Worry about rent						
No	Ref	----	Ref	Ref	----	Ref
Yes	2.46	(1.67, 3.62)	≤0.001*	2.33	(1.43, 3.77)	0.001**
Need Factors						
Functional limitations						
No	Ref	----	Ref	Ref	----	Ref
Yes	1.61	(1.14, 2.28)	0.007*	1.23	(0.81, 1.85)	0.334
Mental illness						
No	Ref	----	Ref	Ref	----	Ref
Yes	1.38	(0.97, 1.96)	0.076*	1.14	(0.77, 1.67)	0.52
Substance use						
No	Ref	----	Ref			
Yes	1.58	(0.85, 2.93)	0.145			
Comorbidity Number						
0	Ref	----	Ref	Ref	----	Ref
1	1.10	(0.71, 1.70)	0.664	1.16	(0.64, 1.60)	0.949
2+	1.57	(1.06, 2.35)	0.025*	1.22	(0.79, 1.90)	0.366

[1]Model was adjusted for pandemic waves experienced and origin of the data (e.g., C-FORWARD or CoVPN 5002)
*Notates those variables in the bivariate models that had significance at p≤ 0.10 and were carried over to the final, multivariable model
**Notates those variables in the final, adjusted model that had significance at p≤0.05

Correlates of forgone emergent care

Table 4 presents the results of the weighted bivariate models of correlates of forgone emergent care. Two predisposing factors were found to have significance at the p≤0.10 level, including those who

reported their sex at birth as female, compared to male (OR 2.48, p=0.027) and those who reported their race as Black/African American, compared to any other race (OR 2.17, p=0.051). Those who reported losing their housing during the COVID-19 pandemic were also found to have higher odds of forgone emergent care (OR 1.46, p=0.008). Individuals with two or more comorbidities were found to have lower odds of forgone emergent care, compared to individuals with none (OR 0.54, p=0.062). Each of these variables were subsequently incorporated into the final, weighted multivariable model.

Table 4 also presents the results of this final model, with each observation weighted for person-years in the pandemic, again adjusted for the experience of the delta and omicron pandemic waves and for the origin of the data (e.g., C-FORWARD or CoVPN 5002). Two predisposing factors were identified as significant correlates of forgone emergent care. Participants who reported their sex at birth as female reported a 2.25 odds of experiencing forgone emergent healthcare, compared to males (p=0.015). Individuals who reported their race as Black or African American had a 2.63 times higher odds of forgone care, compared to any other race (p=0.030). Other significant correlates of forgone emergent healthcare included individuals who reported losing their housing during the COVID-19 pandemic (OR 2.79, p=0.010) and individuals with two or more comorbidities, compared to those with no comorbidities (OR=0.39, p=0.008).

Table 4. Correlates of forgone emergent care

	Unadjusted Bivariate Model			Adjusted Multivariable Model[1]		
Variable	**Odds of forgone care**	**95% CI**	**P Value**	**Odds of forgone care**	**95% CI**	**P Value**
Predisposing Factors						
Age (in years)						
18-34	Ref	----	Ref			
35-49	1.58	(0.68, 3.68)	0.286			
50-64	1.17	(0.52, 2.66)	0.703			
≥65	1.44	(0.62, 3.34)	0.398			
Sex						
Male	Ref	----	Ref	Ref	----	Ref
Female	2.48	(1.08, 3.81)	0.027*	2.25	(1.17, 4.32)	0.015**
Race						
Any other race	Ref	----	Ref	Ref	----	Ref
African American/Black	2.17	(1.00, 4.73)	0.051*	2.63	(1.10, 6.26)	0.030**
Married/Partnered						
Not married/cohabitating	Ref	----	Ref			

Married/cohabitating	1.09	(0.64, 1.86)	0.747			
Employment Status						
Other	Ref	----	Ref			
Working full or part-time	1.02	(0.60, 1.72)	0.953			
Disability Status						
Not on disability status	Ref	----	Ref			
On disability status	1.08	(0.56, 2.08)	0.813			
Highest education level						
High school or less	Ref	----	Ref			
Some college or more	0.74	(0.42, 1.29)	0.285			
Enabling Factors						
Income						
<$25,000	Ref	----	Ref			
≥$25,000	1.05	(0.61, 1.81)	0.859			
Lost housing						
No	Ref	----	Ref	Ref	----	Ref
Yes	1.46	(1.29, 5.66)	0.008*	2.79	(1.28, 6.06)	0.010**
Worry about rent						
No	Ref	----	Ref			
Yes	1.10	(0.58, 2.10)	0.772			
Need Factors						
Functional limitations						
No	Ref	----	Ref			
Yes	0.83	(0.48, 1.44)	0.500			
Mental illness						
No	Ref	----	Ref			
Yes	1.13	(0.66, 1.95)	0.648			
Substance use						
No	Ref	----	Ref			
Yes	0.80	(0.34, 1.88)	0.610			
Comorbidity Number						
0	Ref	----	Ref	Ref	----	Ref
1	0.86	(0.47, 1.58)	0.629	0.76	(0.40, 1.44)	0.392
2+	0.54	(0.28, 1.03)	0.062*	0.39	(0.19, 0.78)	0.008**

[1]Model was adjusted for pandemic waves experienced and origin of the data (e.g., C-FORWARD or CoVPN 5002)
*Notates those variables in the bivariate models that had significance at $p \leq 0.10$ and were carried over to the final, multivariable model
**Notates those variables in the final, adjusted model that had significance at $p \leq 0.05$

Discussion

Using a combined analytic sample derived from two studies that used distinct, yet complimentary sampling strategies, we explored the correlates of forgone care amongst individuals in Baltimore, MD needing surgical/dental procedures and emergent healthcare during the COVID-19 pandemic. Using the Gelberg et a. adapted model for healthcare utilization as our conceptual framework, we identified two significant enabling/impeding correlates of forgone surgical/dental procedures: an annual income of greater than or equal to $25,000, which appeared to be protective against forgone care, and worrying about paying the rent or mortgage during the COVID-19 pandemic, which increased one's odds of

experiencing forgone care. Significant correlates of forgone emergent healthcare covered all three of the categories for healthcare utilization defined by Gelberg et al. Individuals reporting their sex at birth as female and individuals identifying as Black or African American (predisposing factors), along with people who had lost their housing during the pandemic (enabling/impeding factors) were found to have increased odds of experiencing forgone care. However, having two or more comorbidities (need) was found to lower the odds of forgone care, compared to those with no comorbidities.

This study adds to the literature as it is the first, to our knowledge, to capture correlates of forgone surgical/dental procedures during the COVID-19 pandemic. We found that individuals with an annual income less than $25,000 and individuals who were worried about paying their rent or mortgage had higher odds of experiencing forgone surgical/dental procedures. This was not a complete surprise, given persistent disparities among the socio-economically disadvantaged in access to and completion of these types of procedures. For example, one cohort study conducted prior to the pandemic found that personal or financial reasons accounted for one-quarter of patient-related surgical cancellations.[15] Given that the economic impacts of the pandemic have most greatly impacted lower-income individuals, they are likely facing even greater financial barriers in accessing treatment.[16] One study that looked specifically at associations of the social determinants of health with access to elective procedures during the early phase of the pandemic found disparities based on socioeconomic status, among other factors including insurance status and distance to care.[9]

Delayed surgical and dental procedures can greatly impact patient's health and long-term well-being, with potentially deadly outcomes. For example, one study from the Icahn School of Medicine at Mount Sinai found that 10% of patients who had delays in transcatheter aortic valve replacement surgeries experienced a cardiac event in the first month after the delay.[17] Additionally, backlogs in procedures and shortages of materials such as imaging contrast have continued to delay access to certain procedures, even three years into the pandemic.[18,19] Importantly, forgone surgical procedures have also had significant economic impacts on US hospitals, with one study estimating a loss of approximately $16-17 billion dollars per month in revenue during COVID-19.[20] These impacts have led to bankruptcy filings

and closures of hospitals, particularly amongst those that serve rural communities, and will further exacerbate inequities in access to care.[21]

The findings of our analysis of correlates of forgone emergent care align somewhat with the existing literature on the topic. Czeisler et al., in their nationally representative survey, similarly found that Black adults (compared to White adults) had a higher prevalence ratio for forgone emergency care, as well as more broadly for all care types (e.g., routine and emergent care).[22] In contrast, Meyer et al. found that Black/African American individuals living in Baltimore had a lower overall odds of reporting forgone care, when all forms of care were considered.[23] This could be due to persistent health inequities that have disenfranchised people of color for decades in Baltimore[24], leading to reduced access to routine/chronic care amongst this population, and thus fewer opportunities for forgone care, when including all care types. However, when narrowing the analyses to only emergent care, our study found a 2.6 times higher odds of forgone care within this population. This may indicate higher usage of the emergent department for routine or chronic care (and thus more opportunities for forgone emergent care), and also a greater need for emergent care due to untreated chronic conditions, compared to individuals of other races.

We also found that individuals having two or more comorbidities have lower odds of experiencing forgone care, compared to those with none. This differs from Czeisler, who found that comorbidities increased the prevalence ratio of forgone care.[22] This may indicate that individuals with comorbidities represented in our sample have more established relationships with healthcare providers and were thus less likely to experience forgone care. Additionally, our study identified females as having higher odds of forgone care, which may indicate additional barriers to care within this population in Baltimore and may put them at increased risk for the downstream consequences of forgone care. For example, during the early phases of the pandemic, may women had to balance competing demands, such as caring for children unable to attend in-person schooling, which could have impacted their ability to seek urgent healthcare when needed.[25] Additionally, we identified higher odds of forgone emergent care among individuals who had lost their housing during the pandemic. This provides further evidence of the

compounding impacts of the pandemic on individuals' financial stability and ability to access critical healthcare resources.

Moving forward, concerted efforts will need to take place to help address the gaps in care that have occurred due to delayed and forgone surgical/dental procedures, especially in the face of continued backlogs. Identifying which populations were most impacted by pandemic-related interruptions is an important first step, but it will need to be followed by a systemic response to address existing barriers to care that continue to perpetuate disparities in access to surgical and dental procedures, including during crises such as pandemics. Additionally, as hospitals begin to incorporate lessons learned from COVID-19 into future public health emergency planning efforts, they must consider the downstream impacts of actions such as cancellations of surgical procedures and how to proactively address or prevent them. For example, ensuring an ample supply of personal protective equipment or creation of decision algorithms for risk-stratification of individuals scheduled for procedures could help build resilience within hospitals that provide surgical procedures.[26,27] Additionally, to help ensure patients continue to use the emergency department during future pandemics, hospitals must actively engage and communicate with the community to build trust and convey critical information such as availability of services and infection prevention and control measures.[1] Implementing home-based triage services similar to the US Centers for Disease Prevention and Control's "Flu on Call" helpline could also provide a mechanism for patients to inquire about health concerns prior to visiting an emergency department and help to reduce unnecessary visits in the midst of a crisis.[28]

Limitations

This study is subject to several limitations. First, lack of a sufficient sample size for individuals reporting forgone surgical/dental procedures likely reduced the power to detect significant differences in odds when comparing sub-groups. Similarly, the sample size of individuals reporting Hispanic/LatinX origin was too small to allow incorporation into the model. Second, imputation of missing data may have

introduced biases in the analysis. Third, this study relied on participant-reported data, which may have introduced biases in survey responses. Finally, because this study is a secondary data analysis of combined study data, it is limited to data collected by both studies. For example, it would have been beneficial to have additional data on why patients elected to forgo care (e.g., due to fears of contagion, etc.), their COVID-19 vaccination status, insurance status, and loss of employment experienced during the pandemic, as well as their healthcare utilization practices prior to the pandemic. However, these topics were either not addressed in one of the parent studies or the way in which the questions were asked were not comparable and thus prohibited aggregation across studies.

Conclusions

In summary, our study identified several correlates of forgone surgical/dental procedures and emergent healthcare that spanned all three categories of factors associated with healthcare utilization, as described by Gelberg et al. It is critical that actions be taken to address and mitigate the impacts that missed healthcare visits may have on short and long-term health. Additionally, efforts to improve health system resilience for large-scale public health emergencies must incorporate ways to ensure continued access to care for those most at-risk for interruptions, even in the midst of a crisis. This should also include advocacy efforts for the importance in addressing existing health inequities as a key component of emergency planning efforts, as no health system will be ready for a crisis until all members of the community have equitable access to care.

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CHAPTER 6: SYNTHESIS/DISCUSSION

Summary of Findings

This dissertation investigated the impacts of the COVID-19 pandemic on healthcare access and utilization by analyzing forgone chronic and preventive care, emergent care, and surgical and dental procedures among adults living in Baltimore, MD. Data were abstracted from two parent studies that used different, yet complimentary sampling strategies that increased representation of minoritized and under-resourced populations, including the unhoused, impoverished, and people who suffer from mental illness and substance use disorders. The resulting combined analytic sample provided a platform to explore forgone care within one urban city that has historically suffered from structural racism, leading to widespread disparities across the SSDoH. We believe the findings of this dissertation will supplement the existing literature on forgone care during the COVID-19 pandemic, which has primarily consisted of national-level surveys completed via convenience sampling methods.

Paper 1 (Chapter 2) of this dissertation systematically reviewed the existing literature on interruptions in service engagement, treatment adherence, and viral suppression among people living with HIV (PWH) in the United States during the COVID-19 pandemic. The purpose of this chapter was to serve as a case study of how the COVID-19 pandemic has impacted populations who require routine and consistent engagement with the healthcare system. Additionally, because PWH experience poverty, discrimination, and stigma that lead to health inequities, they likely provide a window into how the pandemic has impacted healthcare access and utilization among other marginalized and under-resourced populations.

Paper 2 (Chapter 3) was the first of three manuscripts based upon the combined analytic sample. This paper analyzed the overall rate of forgone care and by sociodemographic and clinical characteristics using person-time in the pandemic. Paper 3 (Chapter 4) evaluated the impact of individual and community-level SSDoH on forgone care during the COVID-19 pandemic. This chapter aimed to broaden our understanding of forgone care during the COVID-19 pandemic beyond individual-level correlates, recognizing the multilevel influencers of healthcare access and utilization, including an individual's

surrounding community. Paper 4 (Chapter 5) explored in greater depths the correlates of forgone emergent care and surgical/dental procedures, recognizing that the populations seeking out services within these venues may differ. Further clarification of the different drivers of forgone care within each of these care types can help inform models of care that prevent similar interruptions during future health emergencies.

Across these chapters, several cross-cutting themes emerged as important considerations in our exploration of forgone care during the COVID-19 pandemic amongst adults living in Baltimore, MD. These themes are summarized below.

Housing instability negatively impacts healthcare access and utilization.

Individuals experiencing housing instability had higher rates and odds of forgone care when comparing those who reported not experiencing housing instability. In paper 2, individuals who reported losing their homes and those who were worried about paying their rent or mortgage during the pandemic both had significantly higher rates of forgone care compared to those who did not. In paper 3, when looking across any type of forgone care, again individuals who reported losing their home or worrying about paying for their housing had higher odds of forgone care. Interestingly, when looking separately at different care types, only those who had lost their housing had a higher odds of forgone emergent care. Conversely, only those who reported worrying about paying their rent or mortgage remained significant when looking at correlates of forgone surgical/dental procedures. These findings together highlight that financial instability brought on or exacerbated by the pandemic may be forcing people to choose between housing, healthcare, and other basic needs. Additionally, those who reported losing their housing may be facing new geographic barriers to healthcare as they seek to locate new shelter.

Under-resourced, marginalized, and vulnerable individuals who require frequent engagement with the health system suffered more interruptions in care.

Individuals who reported being on disability status; reported functional limitations, such as a physical, mental, or emotional disability; and people who reported having a mental illness or substance use disorder all experienced higher rates of forgone care, as captured in paper 2. Paper 3 highlighted similar disparities, where the presence of a functional limitation and reporting of mental illness were both found to lead to a higher odds of forgone care. These individuals likely require more frequent and consistent engagement with the healthcare system, and thus likely had more opportunities for missed visits. Additionally, fears of contagion may have been an impetus for more forgone care in these populations, particularly for those with disabilities that make them more vulnerable to SARS-CoV-2 infection and associated morbidity and mortality. Interestingly, this relationship was not significant when looking individually at correlates of emergent care and surgical/dental procedures. This may be due to several reasons, including existing barriers in access to surgical/dental procedures amongst these populations (e.g., they would not have any procedures to miss) or existing relationships between patients and providers that prevented forgoing of emergent healthcare, even if they forwent chronic or preventive care.

Association between correlates and forgone care may be indicative of existing disparities.

Much of the analyses presented in papers 2, 3, and 4 align with existing research on forgone care during the COVID-19 pandemic, which found higher rates and odds of forgone care within under-resourced, vulnerable, and marginalized populations, including those experiencing housing instability, those with functional limitations, those who have a mental illness, and individuals of the female sex. However, one finding in our analysis that differed from existing research was the finding that individuals who reported Black or African American race had a lower odds of forgone care (any care type), when compared to people reporting other races. Given the persistent health inequities that have disenfranchised people of color for decades in Baltimore, this was a surprising finding. We hypothesize that this is likely due to reduced access to care amongst this population, that led to fewer opportunities for forgone care. This is supported by a finding in paper 4, which found that individuals reporting Black or African

American race had over two and a half times the odds of forgone emergent care. This may indicate higher usage of the emergency department for routine or chronic care (and thus more opportunities for forgone emergent care), and also a greater need for emergent care due to untreated chronic conditions, compared to individuals of other races. Additional research that seeks to understand how these individual's healthcare utilization practices changed during vs. prior to the pandemic would be an important next step in further investigating these findings and understanding how existing inequities have impacted healthcare access and use during the pandemic among people of color living in Baltimore.

Community level determinants were not associated with forgone care.

In paper 3, we investigated both individual and community-level determinants of forgone care. The impetus behind this analyses was other published literature on geographic inequities in COVID-19-related outcomes, such as SARS-CoV-2 case counts and mortality rates. It was also conducted in light of other, pre-pandemic research, which has shown inequities in health outcomes based upon geographic metrics such as neighborhood crime rate, walkability, public transportation accessibility, and proximity to healthcare resources such as clinics, hospitals, and pharmacies. However, our study did not identify any community-level factors that accounted for forgone care above and beyond individual-level factors such as income and employment. This may indicate that the pandemic impacted healthcare access and utilization ubiquitously across Baltimore, regardless of geographic location. This may differ from experiences pre-pandemic, which may have been more driven by community-level determinants. Additional research that seeks to compare pre-pandemic forgone care with forgone care experienced during different waves of the pandemic could help better tease out how community-level factors drive healthcare access and utilization during and outside of a large-scale health emergency.

Implications for Future Nursing Research, Policy, and Practice

The findings of this investigation into forgone care during the COVID-19 pandemic have implications for nursing research, policy, and practice, particularly within the context of large-scale public health emergency (PHE) preparedness and response and broader global health security (GHS) strengthening efforts. Most urgently, health system providers should use the findings of our study and others like them to identify which populations have experienced forgone care during the pandemic, so that resources can be prioritized to those most in need. This should include targeted resources and tailored plans of care that can mitigate or address any negative consequences of forgone care, such as loss of viral suppression for PWH who did not have access to antiretrovirals or increased hemoglobin A1C in individuals with diabetes who were unable to receive insulin. Registered and advance practice nurses deliver a large proportion of community-based care and have established deep ties within communities across the US, including the most marginalized.[1] Leveraging their knowledge and community relationships can help ensure that gaps in care experienced during the pandemic are addressed quickly and according to the needs and desires of the individual. Additionally, implementing community-based interventions such as mobile clinics (see Chapter 5), which are often staffed by nurses, can bring healthcare resources to the individual and could be an important means of addressing gaps in care experienced during the pandemic.

Additionally, health systems must identify ways to address forgone surgical/dental procedures, which put patients at increased risk for more severe diseases that would have otherwise been treated more expeditiously. Informed by the findings of our study, they can better prioritize those who are both at greatest risk for long-term morbidity and mortality and had higher risk of experiencing forgone care. This will be critical in light of health systems that are becoming increasingly constrained by dwindling nursing staff and supply shortages.[2,3] Implementing surveillance programs that can monitor the short and long-term impacts of forgone care, such as monitoring for increases in cancer death rates, will also be important to fully quantifying the impacts of the COVID-19 pandemic on population health.[4]

Moving forward, policy makers working in PHE preparedness and response and the broader GHS arena must take into consideration the importance of strengthening health systems so that they are more resilient in the face of large-scale threats such as pandemics. A resilient health system is one that can both "prepare for and effectively respond to crises" but also continue to maintain core functions, including the provision of routine healthcare that populations rely on a day-to-day basis.[5] An inability to continue to provide these services—whether it be due to factors at the individual, community, or health system level—exacerbates the toll of PHEs beyond the threat itself and can lead to health impacts that last for decades.[6] For example, in the first year of the pandemic, there were as many as 160,000 excess deaths—excluding those directly associated with COVID-19—and factors such as disruptions in healthcare access and utilization have likely contributed.[7,8] Additional research that seeks to better understand, both from the patient and health system perspective, the reasons for these excess deaths, including how forgone care may have contributed, can help inform resilience building efforts.

Recently, there has been increasing momentum behind incorporating components of health systems resilience into GHS strengthening efforts.[9] This includes stronger investments in universal health coverage and ensuring all individuals have access to "comprehensive, appropriate, timely, and quality health services, without financial burden."[10] Building and maintaining these core capacities in advance of a PHE such as a pandemic can help ensure healthier communities that are more trusting of the health system, which simultaneously helps strengthen syndromic surveillance for future infectious disease outbreaks.[10] In the face of the next PHE, these systems can more quickly adapt and re-organize to ensure continuity of care while managing the crisis at hand. A shift towards universal health coverage will be critical to strengthening health systems across the US, including in Baltimore, and reducing forgone care during future crises. Advocacy from healthcare providers, including nurses, will be critical to the success of these efforts.

Finally, pervasive social and structural inequities have led certain communities to bear a disproportionate burden of COVID-19 related outcomes, including cases and deaths. For example, in Baltimore City, Black/African American individuals were 1.3 times more likely to die from COVID-19

compared to White residents; Black/African American residents were also less likely to be vaccinated.[11] Addressing the upstream social, economic, and political structures that allow for inequities to persist across the determinants of health must become a major focus of GHS strengthening efforts.[12] In the most recent Future of Nursing report, nurses are highlighted as having a central role in addressing health inequities.[1] Building and supporting a diverse nursing workforce that has the knowledge, skills, abilities, and capacity to fulfill this role will thus be critical and must be integrated into GHS-related policy and planning.

Strengths and Limitations

The proposed study is subject to several limitations. First, because this dissertation included analysis of participant-reported survey data, there is the opportunity for recall bias, particularly for those participants who enrolled long after the beginning of the COVID-19 pandemic. Measurement bias may have also occurred, as participants may not have fully understood the survey questions. However, both studies used trained research staff who helped to answer questions about the study survey and facilitate memory of events relevant to the study outcomes, such as forgone care. Selection bias may have also occurred, where those who were more likely to enroll in the parent studies were more or less likely to report forgone care during the pandemic than the general population. However, the use of a multi-staged sampling approach with over-sampling of hard-to-reach populations in the C-FORWARD study and use of diverse venues and at different times/days of the week in the CoVPN 5002 study likely reduced the impacts of this bias. Second, multiple imputation was used to address missing data across several variables, which may have introduced biases in the analysis. However, a complete-case only sensitivity analysis was run to check for biases, with results similar to those computed using the imputed dataset. Third, lack of sufficient sample size prohibited calculation of rates and odds of forgone care among individuals reporting Hispanic/LatinX ethnicity. This was despite efforts by both parent studies to enroll individuals from this demographic, including use of bilingual staff members and translated study materials. Fourth, because we were missing participant's address for individuals recruited from the CoVPN 5002 study, their CSA was assumed to be the venue of enrollment. While many of these venues were housing developments, their assigned CSA may have not been accurate. Additionally, the use CSAs may not have been granular enough to represent challenges individuals face related to community level determinants of health. While data at the census block group would have been preferable, only data at the CSA level was available for Baltimore.

Conclusions

This dissertation revealed under-resourced, marginalized, and vulnerable populations had higher rates and odds of forgone care during the COVID-19 pandemic in Baltimore, MD. While both individual and community-level correlates of forgone care were investigated, only those at the individual-level were found to be significant. However, additional research is necessary to better understand how healthcare access and utilization practices changed, comparing pre-COVID-19 to during COVID-19, as well as what factors may have driven forgone care, such as lack of access to transportation or lack of insurance. Moving forward, it is imperative that health systems work to address gaps in care experienced during the COVID-19 pandemic, to reduce both its short and long-term health impacts. Additionally, incorporating health systems strengthening efforts into broader GHS-related policy and planning can help ensure continuity of care during future PHEs.

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APPENDIX

A.1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for chapter 2

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Title Page
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2,3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	3
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4,5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	3,4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	S2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5,6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	7
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	7

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	8,9 Tables I-III, supp 3
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	7, Tables I-III
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	9-14, Table IV, supp 3
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	14-18
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	17
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	18
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Title page

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

A.2 Search strategy for chapter 2: Review of the literature

Search Dates	Search Engine	Search Terms
01/01/20-11/05/21	PubMed	"COVID-19"[Mesh] OR "SARS-CoV-2"[Mesh] OR "COVID-19"[tw] OR "COVID 19"[tw] OR "COVID19"[tw] OR "COVID2019"[tw] OR "COVID 2019"[tw] OR "COVID-2019"[tw] OR "novel coronavirus"[tw] OR "new coronavirus"[tw] OR "novel corona virus"[tw] OR "new corona virus"[tw] OR "SARS-CoV-2"[tw] OR "SARSCoV2"[tw] OR "SARS-CoV2"[tw] OR "2019nCoV"[tw] OR "2019-nCoV"[tw] OR "2019 coronavirus"[tw] OR "2019 corona virus"[tw] OR "coronavirus disease 2019"[tw] OR "severe acute respiratory syndrome coronavirus 2"[nm] OR "severe acute respiratory syndrome coronavirus 2"[tw] OR "sars-coronavirus-2"[tw] OR "coronavirus disease 2019"[tw] OR "corona virus disease 2019"[tw] AND (hiv infections[mh] OR hiv[mh] OR hiv[tw] OR hiv-1[tw] OR hiv-2[tw] OR hiv1[tw] OR hiv2[tw] OR "hiv infect*"[tw] OR "human immunodeficiency virus"[tw] OR "human immunodeficiency virus"[tw] OR "human immune-deficiency virus"[tw] OR "human immune-deficiency virus"[tw] OR (("human immun*") AND ("deficiency virus"[tw])) OR "acquired immunodeficiency syndrome"[tw] OR "acquired immunodeficiency syndrome"[tw] OR "acquired immuno-deficiency syndrome"[tw] OR "acquired immune-deficiency syndrome"[tw] OR (("acquired immun*") AND ("deficiency syndrome"[tw]))) AND (Impact[tiab] OR Impacts[tiab] OR Reduction[tiab] OR Reductions[tiab] OR Decrease[tiab] OR Decreases[tiab] OR Decreased[tiab] OR Decline[tiab] OR Declines[tiab] OR Changes[tiab] OR Increase[tiab] OR Increases[tiab] OR Increased[tiab]) AND ("United States" [mh] OR "united states" [tiab] OR "usa" [tiab] OR "united states" [ad] OR "usa" [ad] OR "Alabama" [tiab] OR "Alabama" [tiab] OR "Alaska" [tiab] OR "Arizona" [tiab] OR "Arkansas" [tiab] OR "California " [tiab] OR "Colorado" [tiab] OR "Connecticut" [tiab] OR "Delaware" [tiab] OR "District of Columbia" [tiab] OR "Florida" [tiab] OR "Georgia" [tiab] OR "Georgia" [tiab] OR "Hawaii" [tiab] OR "Idaho" [tiab] OR "Illinois " [tiab] OR "Indiana" [tiab] OR "Iowa" [tiab] OR "Kansas" [tiab] OR "Kentucky" [tiab] OR "Louisiana " [tiab] OR "Maine" [tiab] OR "Maryland" [tiab] OR "Massachusetts " [tiab] OR "Michigan" [tiab] OR "Minnesota" [tiab] OR "Mississippi" [tiab] OR "Missouri" [tiab] OR "Montana" [tiab] OR "Nebraska" [tiab] OR "Nevada" [tiab] OR "New Hampshire" [tiab] OR "New Jersey" [tiab] OR "New Mexico" [tiab] OR "New York" [tiab] OR "North Carolina" [tiab] OR "North Dakota" [tiab] OR "Ohio" [tiab] OR "Oklahoma" [tiab] OR "Oregon" [tiab] OR "Pennsylvania" [tiab] OR "Rhode Island" [tiab] OR "South Carolina" [tiab] OR "South Dakota" [tiab] OR "Tennessee" [tiab] OR "Texas" [tiab] OR "Utah" [tiab] OR "Vermont" [tiab] OR "Virginia" [tiab] OR "Washington" [tiab] OR "West Virginia" [tiab] OR "Wisconsin" [tiab] OR "Wyoming" [tiab])
01/01/20-11/05/21	CINAHL	(MH "COVID-19") OR TI "COVID-19" OR TI "COVID 19" OR TI "COVID19" OR TI "COVID2019" OR TI "COVID 2019" OR TI "COVID-2019" OR TI "novel coronavirus" OR TI "new coronavirus" OR TI "novel corona virus" OR TI "new corona virus" OR TI "SARS-CoV-2" OR TI "SARSCoV2" OR TI "SARS-CoV2" OR TI "2019nCoV" OR TI "2019-nCoV" OR TI "2019 coronavirus" OR TI "2019 corona virus" OR TI "coronavirus disease 2019" OR TI "severe acute respiratory syndrome coronavirus 2" OR TI "severe acute respiratory syndrome coronavirus 2" OR TI "sars-coronavirus-2" OR TI "coronavirus disease 2019" OR TI "corona virus disease 2019" OR AB "COVID-19" OR AB "COVID 19" OR AB "COVID19" OR AB "COVID2019" OR AB "COVID 2019" OR AB "COVID-2019" OR AB "novel coronavirus" OR AB "new coronavirus" OR AB "novel corona virus" OR AB "new corona virus" OR AB "SARS-CoV-2" OR AB "SARSCoV2" OR AB "SARS-CoV2" OR AB "2019nCoV" OR AB "2019-nCoV" OR AB "2019 coronavirus" OR AB "2019 corona virus" OR AB "coronavirus disease 2019" OR AB "severe acute respiratory syndrome coronavirus 2" OR AB "severe acute respiratory syndrome coronavirus 2" OR AB "sars-coronavirus-2" OR AB "coronavirus disease 2019" OR AB "corona virus disease 2019" AND ((MH "HIV Infections+") OR "hiv" OR (MH "Human Immunodeficiency Virus+") OR hiv*) OR (human immunodeficiency virus OR humanimmunedeficiency virus oR human immuno-deficiency virus OR human immune-deficiency virus OR (human immun*) N3 (deficiency

		virus)) OR (acquired immunodeficiency syndrome OR acquired immune-deficiency syndrome OR acquired immunedeficiency syndrome OR acquired immuno-deficiency syndrome OR (acquired immune) N3 (deficiency syndrome)) AND TI impact OR TI impacts OR TI reduction OR TI reductions OR TI decrease OR TI decreases OR TI decreased OR TI decline OR TI declines OR TI changes OR TI increase OR TI increases OR TI increased AB impact OR AB impacts OR AB reduction OR AB reductions OR AB decrease OR AB decreases OR AB decreased OR AB decline OR AB declines OR AB changes OR AB increase OR AB increases OR AB increased AND (MH "United States+") OR TI "united states" OR TI usa OR TI alabama OR TI al OR TI alaska OR TI ak OR TI arizona OR TI az OR TI arkansas OR TI ar OR TI california OR TI ca OR TI colorado OR TI co OR TI connecticut OR TI ct OR TI delaware OR TI de OR TI florida OR TI fl OR TI georgia OR TI ga OR TI hawaii OR TI hi OR TI idaho OR TI id OR TI illinois OR TI il OR TI indiana OR TI iowa OR TI ia OR TI kansas OR TI ks OR TI kentucky OR TI ky OR TI louisiana OR TI la OR TI maine OR TI me OR TI maryland OR TI massachusetts OR TI ma OR TI michigan OR TI mi OR TI minnesota OR TI mn OR TI mississippi OR TI ms OR TI missouri OR TI mo OR TI montana OR TI mt OR TI nebraska OR TI neOR TI nevada OR TI nv OR TI "new hampshire" OR TI nh OR TI "new jersey" OR TI nj OR TI "new mexico" OR TI nm OR TI "new york" OR TI ny OR TI "north carolina" OR TI nc OR TI "north dakota" OR TI nd OR TI ohio OR TI oh OR TI oklahoma OR TI ok OR TI oregon OR TI pennsylvania OR TI pa OR TI "rhode island" OR TI ri OR TI "south carolina" OR TI sc OR TI "south dakota" OR TI sd OR TI tennessee OR TI tn OR TI texas OR TI tx OR TI utah OR TI ut OR TI vermont OR TI vt OR TI virginia OR TI va OR TI washington OR TI wa OR TI "west virginia" OR TI wv OR TI wisconsin OR TI wi OR TI wyoming OR TI wy OR (MH "United States+") OR AB "united states" OR AB usa OR AB alabama OR AB al OR AB alaska OR AB ak OR AB arizona OR AB az OR AB arkansas OR AB ar OR AB california OR AB ca OR AB colorado OR AB co OR AB connecABcut OR AB ct OR AB delaware OR AB de OR AB florida OR AB fl OR AB georgia OR AB ga OR AB hawaii OR AB hi OR AB idaho OR AB id OR AB illinois OR AB il OR AB indiana OR AB iowa OR AB ia OR AB kansas OR AB ks OR AB kentucky OR AB ky OR AB louisiana OR AB la OR AB maine OR AB me OR AB maryland OR AB massachusetts OR AB ma OR AB michigan OR AB mi OR AB minnesota OR AB mn OR AB mississippi OR AB ms OR AB missouri OR AB mo OR AB montana OR AB mt OR AB nebraska OR AB neOR AB nevada OR AB nv OR AB "new hampshire" OR AB nh OR AB "new jersey" OR AB nj OR AB "new mexico" OR AB nm OR AB "new york" OR AB ny OR AB "north carolina" OR AB nc OR AB "north dakota" OR AB nd OR AB ohio OR AB oh OR AB oklahoma OR AB ok OR AB oregon OR AB pennsylvania OR AB pa OR AB "rhode island" OR AB ri OR AB "south carolina" OR AB sc OR AB "south dakota" OR AB sd OR AB tennessee OR AB tn OR AB texas OR AB tx OR AB utah OR AB ut OR AB vermont OR AB vt OR AB virginia OR AB va OR AB washington OR AB wa OR AB "west virginia" OR AB wv OR AB wisconsin OR AB wi OR AB wyoming OR AB wy
01/01/20-11/05/21	Embase	'coronavirus disease 2019'/exp OR 'COVID-19':ti,ab OR 'COVID 19':ti,ab OR 'COVID19':ti,ab OR 'COVID2019':ti,ab OR 'COVID 2019':ti,ab OR 'COVID-2019':ti,ab OR 'novel coronavirus':ti,ab OR 'new coronavirus':ti,ab OR 'novel corona virus':ti,ab OR 'new corona virus':ti,ab OR 'SARS-CoV-2':ti,ab OR 'SARSCoV2':ti,ab OR 'SARS-CoV2':ti,ab OR '2019nCoV':ti,ab OR '2019-nCoV':ti,ab OR '2019 coronavirus':ti,ab OR '2019 corona virus':ti,ab OR 'coronavirus disease 2019':ti,ab OR 'severe acute respiratory syndrome coronavirus 2':ti,ab OR 'severe acute respiratory syndrome coronavirus 2':ti,ab OR 'sars-coronavirus-2':ti,ab OR 'coronavirus disease 2019':ti,ab OR 'corona virus disease 2019':ti,ab AND 'human immunodeficiency virus infection'/exp OR 'human immunodeficiency virus infection' OR 'human immunodeficiency virus'/exp OR 'human immunodeficiency virus' OR 'acquired immune deficiency syndrome'/exp OR 'acquired immune deficiency syndrome' OR 'hiv':ab,ti OR 'hiv-1':ab,ti OR 'hiv-2':ab,ti OR 'hiv1':ab,ti OR 'hiv2':ab,ti OR 'human immunodeficiency virus':ab,ti OR 'human immunedeficiency virus':ab,ti OR 'human immuno-deficiency virus':ab,ti OR 'human immune-deficiency virus':ab,ti OR ((human NEAR/4 immune*) AND (deficiency NEAR/4 virus)) OR 'acquired immunodeficiency syndrome':ab,ti OR 'acquired immunedeficiency syndrome':ab,ti OR 'acquired immuno-deficiency syndrome':ab,ti OR 'acquired immune-deficiency syndrome'/exp OR 'acquired immune-deficiency syndrome' OR ((acquired NEAR/4 immun*) AND (deficiency NEAR/4 syndrome)) AND

		(impact:ti,ab OR impacts:ti,ab OR reduction:ti,ab OR reductions:ti,ab OR decrease:ti,ab OR decreases:ti,ab OR decreased:ti,ab OR decline:ti,ab OR declines:ti,ab OR changes:ti,ab OR increase:ti,ab OR increases:ti,ab OR increased:ti,ab) NOT ('juvenile'/exp NOT 'adult'/exp) AND ('united states'/exp OR 'united states':ti,ab OR 'usa':ti,ab OR 'alabama':ti,ab OR 'al':ti,ab OR 'alaska':ti,ab OR 'ak':ti,ab OR 'arizona':ti,ab OR 'az':ti,ab OR 'arkansas':ti,ab OR 'ar':ti,ab OR 'california':ti,ab OR 'ca':ti,ab OR 'colorado':ti,ab OR 'co':ti,ab OR 'connecticut':ti,ab OR 'ct':ti,ab OR 'delaware':ti,ab OR 'de':ti,ab OR 'florida':ti,ab OR 'fl':ti,ab OR 'georgia':ti,ab OR 'ga':ti,ab OR 'hawaii':ti,ab OR 'hi':ti,ab OR 'idaho':ti,ab OR 'id':ti,ab OR 'illinois':ti,ab OR 'il':ti,ab OR 'indiana':ad OR 'iowa':ti,ab OR 'ia':ti,ab OR 'kansas':ti,ab OR 'ks':ti,ab OR 'kentucky':ti,ab OR 'ky':ti,ab OR 'louisiana':ti,ab OR 'la':ti,ab OR 'maine':ti,ab OR 'me':ti,ab OR 'maryland':ti,ab OR 'massachusetts':ti,ab OR 'ma':ti,ab OR 'michigan':ti,ab OR 'mi':ti,ab OR 'minnesota':ti,ab OR 'mn':ti,ab OR 'mississippi':ti,ab OR 'ms':ti,ab OR 'missouri':ti,ab OR 'mo':ti,ab OR 'montana':ti,ab OR 'mt':ti,ab OR 'nebraska':ti,ab OR 'ne':ti,ab OR 'nevada':ti,ab OR 'nv':ti,ab OR 'new hampshire':ti,ab OR 'nh':ti,ab OR 'new jersey':ti,ab OR 'nj':ti,ab OR 'new mexico':ti,ab OR 'nm':ti,ab OR 'new york':ti,ab OR 'ny':ti,ab OR 'north carolina':ti,ab OR 'nc':ti,ab OR 'north dakota':ti,ab OR 'nd':ti,ab OR 'ohio':ti,ab OR 'oh':ti,ab OR 'oklahoma':ti,ab OR 'ok':ti,ab OR 'oregon':ti,ab OR 'pennsylvania':ti,ab OR 'pa':ti,ab OR 'rhode island':ti,ab OR 'ri':ti,ab OR 'south carolina':ti,ab OR 'sc':ti,ab OR 'south dakota':ti,ab OR 'sd':ti,ab OR 'tennessee':ti,ab OR 'tn':ti,ab OR 'texas':ti,ab OR 'tx':ti,ab OR 'utah':ti,ab OR 'ut':ti,ab OR 'vermont':ti,ab OR 'vt':ti,ab OR 'virginia':ti,ab OR 'va':ti,ab OR 'washington':ti,ab OR 'wa':ti,ab OR 'west virginia':ti,ab OR 'wv':ti,ab OR 'wisconsin':ti,ab OR 'wi':ti,ab OR 'wyoming':ti,ab OR 'wy':ti,ab)
01/01/20-11/05/21	PsycINFO	DE "COVID-19" OR SARS-CoV-2 OR COVID-19 OR "COVID 19" OR COVID19 OR COVID2019 OR "COVID 2019" OR COVID-2019 OR "novel coronavirus" OR "new coronavirus" OR "novel corona virus" OR "new corona virus" OR SARS-CoV-2 OR SARSCoV2 OR SARS-CoV2 OR 2019nCoV OR 2019-nCoV OR "2019 coronavirus" OR "2019 corona virus" OR "coronavirus disease 2019" OR "severe acute respiratory syndrome coronavirus 2" OR "severe acute respiratory syndrome coronavirus 2" OR sars-coronavirus-2 OR "coronavirus disease 2019" OR "corona virus disease 2019" AND DE "HIV" OR DE "AIDS" OR hiv OR hiv-1 OR hiv-2 OR hiv1 OR hiv2 OR "hiv infect*" OR "human immunodeficiency virus" OR "human immunodeficiency virus" OR "human immune-deficiency virus" OR "human immune-deficiency virus" OR (("human immun*") AND ("deficiency virus")) OR "acquired immunodeficiency syndrome" OR "acquired immunodeficiency syndrome" OR "acquired immuno-deficiency syndrome" OR "acquired immune-deficiency syndrome" OR (("acquired immun*") AND ("deficiency syndrome")) AND Impact OR Impacts OR Reduction OR Reductions OR Decrease OR Decreases OR Decreased OR Decline OR Declines OR Changes OR Increase OR Increases OR Increased AND "United States" OR "united states" OR usa OR "united states" OR usa OR Alabama OR Alabama OR Alaska OR Arizona OR Arkansas OR California OR Colorado OR Connecticut OR Delaware OR "District of Columbia" OR Florida OR Georgia OR Georgia OR Hawaii OR Idaho OR Illinois OR Indiana OR Iowa OR Kansas OR Kentucky OR Louisiana OR Maine OR Maryland OR Massachusetts OR Michigan OR Minnesota OR Mississippi OR Missouri OR Montana OR Nebraska OR Nevada OR "New Hampshire" OR "New Jersey" OR "New Mexico" OR "New York" OR "North Carolina" OR "North Dakota" OR Ohio OR Oklahoma OR Oregon OR Pennsylvania OR "Rhode Island" OR "South Carolina" OR "South Dakota" OR Tennessee OR Texas OR Utah OR Vermont OR Virginia OR Washington OR "West Virginia" OR Wisconsin OR Wyoming
01/01/20-11/05/21	Web of Science	(COVID-19 OR SARS-CoV-2 OR COVID-19 OR "COVID 19" OR COVID19 OR covid019 OR "COVID 2019" OR COVID-2019 OR "novel coronavirus" OR "new coronavirus" OR "novel corona virus" OR "new corona virus" OR SARS-CoV-2 OR sarscov OR SARS-CoV2 OR 2019ncovr OR 2019-nCoV OR "2019 coronavirus" OR "2019 corona virus" OR "coronavirus disease 2019" OR "severe acute respiratory syndrome coronavirus 2" OR "severe acute respiratory syndrome coronavirus 2" OR sars-coronavirus-2 OR "coronavirus disease 2019" OR "corona virus disease 2019") AND ("hiv infections" OR hiv OR hiv OR hiv-1 OR hiv-2 OR hiv1 OR hiv2 OR "hiv infect*" OR "human immunodeficiency virus" OR "human immunodeficiency virus" OR "human immune-deficiency virus" OR "human immune-deficiency virus" OR (("human immun*") AND

		("deficiency virus")) OR "acquired immunodeficiency syndrome" OR "acquired immunodeficiency syndrome" OR "acquired immuno-deficiency syndrome" OR "acquired immune-deficiency syndrome" OR (("acquired immun*") AND ("deficiency syndrome"))) AND (Impact OR Impacts OR Reduction OR Reductions OR Decrease OR Decreases OR Decreased OR Decline OR Declines OR Changes OR Increase OR Increases OR Increased) AND ("United States" OR "united states" OR usa OR "united states" OR usa OR Alabama OR Alabama OR Alaska OR Arizona OR Arkansas OR California OR Colorado OR Connecticut OR Delaware OR "District of Columbia" OR Florida OR Georgia OR Georgia OR Hawaii OR Idaho OR Illinois OR Indiana OR Iowa OR Kansas OR Kentucky OR Louisiana OR Maine OR Maryland OR Massachusetts OR Michigan OR Minnesota OR Mississippi OR Missouri OR Montana OR Nebraska OR Nevada OR "New Hampshire" OR "New Jersey" OR "New Mexico" OR "New York" OR "North Carolina" OR "North Dakota" OR Ohio OR Oklahoma OR Oregon OR Pennsylvania OR "Rhode Island" OR "South Carolina" OR "South Dakota" OR Tennessee OR Texas OR Utah OR Vermont OR Virginia OR Washington OR "West Virginia" OR Wisconsin OR Wyoming)

A.3 In-depth reporting of study findings for chapter 2: Review of the literature

Reference	Study Design	Sample & Location	Observable Measure & Sample Size	Time Period (s)	Study Data	Statistical Test[1]
Algarin et al. (2020)	CS	-Older adults enrolled in a clinical trial -Miami, FL	-Response to survey questions on the effects of C19 on HIV care (n=16 PWH)	- After Mar 13, 2020 (exact dates not specified)	**Retention/Engagement** -83.3% (10 of 12 who had a scheduled visit) kept HIV care visits after start of social distancing -83.3% (10 of 12 who had a case manager) maintained contact with case manager after start of social distancing **ART Prescriptions** -100% (16/16) received ART	
Auchus et al. (2021)	MM	-Patients at a HIV primary care clinic -San Francisco, CA	-Compared telehealth and in-person visits and non-attendance rates using patient records (n=966 records) -Perceptions around telehealth via multiple-choice and open-ended survey questions (n=202 participants)	-Pre-C19: Oct 1, 2019 to Mar 16, 2020 -During C19: Mar 17 to Jun 30, 2020	**Retention/Engagement** Pre-C19: -In-person and telehealth nonattendance rates: 16.5%, 0% -Telehealth: 5.3% of all visits During C19: -In-person and telehealth nonattendance rates: 6.1%, 13.7% -Telehealth: 86.9% of all visits -46.9% preferred in-person visits (vs. telehealth); 41.8% had no preference -20.5% more likely to attend visits in-person -Advantages of telehealth: convenience, safety from exposure to C19, privacy benefits -Disadvantages: communication/ technical issues, lack of familiarity, lack of trust and human connection	
Bogart et al. (2021)	CS	- Black Americans participating in an RCT -Los Angeles County, CA	-ART adherence from Medication Event Monitoring System data and survey questions (n=101 PWH)	- May to Jul, 2020	**Retention/Engagement** -22% reported negative health consequences because of C19 -18% cancelled/avoided medical care **ART Prescriptions** -53% (26 of 49 with adherence data) were adherent to ART (>80% of doses taken in past month) -6% unable to get HIV medications -Reporting more negative impacts of the pandemic (e.g., decreased work, decreased access to transportation) was associated with lower odds of ART adherence[a]	[a]OR=0.59**
Campbell et al. (2021)	MM	-Message exchanges between PositiveLink (PL) members and their care team -Virginia	-Percent change in messages exchanged (n=497 PL members) -Challenges seeking HIV care via message content thematic analysis (n=6,668 message exchanges)	-Pre-C19: Jan 13 to Mar 1, 2020 -During C19: Mar 2 to Apr 19, 2020	**Retention/Engagement** Comparing during C19 to pre-C19: -25% increase in messages exchanged -Increase in mean weekly member message rate from 0.55 to 0.68[a] -Increase in mean weekly provider message rate from 4.32 to 5.91[b] -Change in weekly administrator message rate not significant C19-related messages (n=591)	[a]β=0.211** [b]β=0.31**

					-Functions included: information exchange (82%), rapport building (50%) -Message topics included: medical (58%), social (26%), app-related issues/challenges (64%) - C19 related topics: care coordination (43%), risk/precautions (22%), social impacts (22%), concern for others (17%), mental health (15%), physical symptoms (5%)	
Chen et al. (2021)	CS	-Black MSM and transgender women enrolled in an existing study -Chicago, IL	-Response to telephone survey on the impacts of C19 (n=90 HIV+, n=132 HIV-)	-Early C19: Apr 20 to Jun 2, 2020 -Later C19: Jun 3-Jul 31, 2020	**ART Prescriptions** -Of those PWH on ART (n=78), 21.8% reported that it was harder to access ART during C19. 62.8% reported no change, and 15.4% reported that it was easier -Those who experienced greater travel-related financial burden[a], were exposed to IPV[b], or who lost insurance[c] during the pandemic had increased perceived difficulty in accessing ART	[a]PR=6.2** [b]PR=2.7* [c]PR=3.5*
Cooley et al. (2021)	CS	- Patients who were previous study enrollees -St. Louis, MO	- Responses to telephone/email survey on impacts of C19 (n=133 HIV+, 54 HIV-)	-Apr to May, 2020	**Retention/Engagement** -13.5% of PWH reported changes/loss in medical care, compared to 3.7% of HIV negative participants[a] -No difference between groups in rate of job/income loss **Viral Suppression** -96% of PWH had undetectable VL	[a]13.5% PWH vs. 3.7% HIV-**
Dawson & Kates (2020)	MM	- Directly funded Ryan White medical provider grantees -National	-Percentage of providers (n=161) reporting changes in the provision of services	- Aug 18 to Sept 4, 2020	**Retention/Engagement** -30% reported an increase in new patients -40% saw a change in payer mix; 49% saw increase in uninsured patients -24% reported no change in how well clients' needs were being met -25% reported slightly improved retention; 38% reported no change; 28% reported a slight decline in retention in care -92% reduced on-site staff -99% reported offering telehealth (compared to 22% pre-C19) -47% of visits completed using telehealth -66% reduced laboratory visit frequency **ART Prescriptions** -89% offered multi-month ART prescription services; others offered home delivery or used mail order prescription services	
El-Nahal et al. (2021)	RR	-Patients enrolled in an HIV clinical cohort with a scheduled visit -Baltimore, MD	-Proportion of patients from pre-C19 (n=2,010) and during C19 (n=1,929) time periods that completed 1 or more scheduled visits	-Pre-C19: Sept 1, 2019 to Mar 15, 2020 -During C19: Mar 16 to Sept 30, 2020	**Retention/Engagement** Pre-C19: -88% completed at least 1 visit -Older (>60 years) individuals, men, and those VS more likely to complete visit During C19:	[a]Pre-C19 prevalence=88%; During C19 prevalence=91%** [b]Pre-C19 prevalence=86%;

					-91% completed at least 1 visit (in-person or telemedicine) -84% had at least one scheduled telemedicine visit; 99% completed at least one visit -16% scheduled for in-person visit only; 48% completed at least one visit <u>Comparing pre-C19 to during C19:</u> -Increase in visit completion (in-person or telemedicine) during C19 compared to pre-C19[a] -Increase in visit completion during C19 (compared to pre-C19) for women[b] and Black individuals[c]	During C19 prevalence=93%** [c]Pre-C19 prevalence=88%; During C19 prevalence=91%**
Ennis et al. (2021)	RR	-Patients from Community Healthcare clinics living with or at risk for HIV -Florida	- Descriptive statistics and adjusted odds of completing a telehealth visit via video using attendance and EMR data (n=4,280 HIV+, 593 HIV-; 11,006 encounters)	- Apr 1 to Oct 31, 2020	**<u>Retention/Engagement</u>** -89.9% of PWH or at risk for HIV with at least one scheduled video visit did not miss it -Patients who identified as Black[a] or Latinx[b], were on public insurance[c], had detectable VL[d], identified as heterosexual[e], or were older[f] had lower odds of completing video telehealth visits -Odds of completing a video telehealth visit did not differ between PWH and those without HIV **<u>Viral Suppression</u>** -93.8% had undetectable VL	[a]OR=0.30** [b]OR=0.67* [c]OR=0.25** [d]OR=0.49** [e]OR=0.40** [f]OR=0.96**
Fadul et al. (2021)	QI, RR	- Visits to an HIV clinic -Nebraska	- Telehealth attendance and VS rates using patient charts (n=1,559 scheduled clinic visits, including new patients; 1,167 established patient visits)	-Apr 1 to Oct 30, 2020	**<u>Retention/Engagement</u>** -21% of all scheduled visits missed -35% of established patient visits conducted via telephone <u>At end of Oct 2020</u> -53 patients out of care compared to 34 at baseline (pre-C19) -Decrease in medical visit frequency to 55% (compared to 69% at baseline); medical visit frequency defined as "the percentage of patients who had one visit in each 6 months of the preceding 24 months with at least 60 days between visits" -Increase in gap in care to 24% (compared to 14% at baseline); gaps in care defined as "the percentage of patients who had no visit in the preceding 6 months" -Successful telehealth implementation strategies: review of barriers/facilitators, identification/education of telehealth champions, organization of clinician meetings, staff training **<u>Viral Suppression</u>** -93.1% of established patients were VS; higher VS rates found in those who received a telemedicine vs. in-person visit[a]	[a]Telemedicine visit: 97% VS; in-person visit: 91% VS**
Genberg et al. (2021)	CS	- Members of the AIDS Linked to the IntraVenous Experience cohort	- Survey responses (n=144 HIC+, 295 HIV-) on C19 related interruptions in healthcare	- Apr to Jun, 2020	**<u>Retention/Engagement</u>** -6% of all participants reported challenges accessing healthcare in the previous month; no difference between PWH and those not living with HIV	

		-Baltimore, MD			**ART Prescriptions** -86% of PWH who were on ART (n=130) reported having a month's supply -94% of PWH who were on ART (n=130) reported receiving information about how to get ART during lockdowns	
Gwadz et al. (2021)	MM	- Black or Latino PWH from low-SES background participating in an existing study -New York City, NY	-Survey (n=96) that measured the impacts of C19 on ability to get medication, attend clinic visits, and effects on HIV management -Semi-structured interviews (n=26)	-Apr 16 to Aug 7, 2020	**Retention/Engagement** -69.8% reported cancellations of visits and closures of HCP office -60.4% reported cancellation/closure of social worker provider visit -41.7% cancelled clinic/doctor's visit due to fear of contagion -Telehealth challenges included lack of access to smartphones (especially for those experiencing homelessness), computers, and the internet, and lack of interaction -Strong preference for telehealth due to lack of travel required **ART Prescriptions** -13.5%/9.4% were unable to go to the pharmacy/unable to obtain their medications -2.3% of participants on ART (n=86) stopped taking their medications -39.5% of participants on ART increased how often they took their medications -55.8% reported that the pandemic increased their desire to adhere to ART regimen -21.8% reported that the C19 interrupted how they took their ART	
Hickey et al. (2021)	TSA	- Patients enrolled in POP-UP, a care model for PWH experiencing homelessness -San Francisco, CA	- Comparison of mean number of visits, VS rates, and proportion with a monthly visit (n=85 patients) using POP-UP data	-Pre-C19: Oct 17, 2019 to Mar 16, 2020 -During C19: Mar 17 to Aug 16, 2020	**Retention/Engagement** Pre-C19: -1.6 mean visits per patient-month -64% patients had monthly visit During C19: -1.7 mean visits per patient-month -58% patients had monthly visit -No significant difference in odds of having a monthly visit when comparing during C19 to pre-C19 **Viral Suppression** Pre-C19: -48% of patients VS During C19: -47% of patients VS -No significant difference in odds of viral suppression when comparing pre-C19 to during C19	

Hochstatter et al. (2020)	LS	- PWH and substance use disorder at HIV clinics -Wisconsin	-Survey responses on impacts of C19 comparing pre-C19 (n=194 weekly surveys, 60 individuals) to during C19 (n=148 weekly surveys, 43 individuals)	-Pre-C19: Jan 31 to Mar 12, 2020 -During C19: Mar 24 to May 4, 2020	**Retention/Engagement** -Decreased incidence in reporting ability to keep next appointment with HIV provider during C19 compared to pre-C19[a] **ART Prescriptions** -Higher odds of missed ART dose at least 2 days of the week during C19 compared to pre-C19	[a]IRR=0.92* [b]OR=2.81*
Kalichman et al. (2020)	LS	- PWH (ages 20-37 years) who were also positive for active substance use -Atlanta, GA	-Percentage of survey participants (n=162) who reported data on HIV treatment status	-Began in Mar 2020	**Retention/Engagement** -19% of participants missed HIV clinic visit within the past 30 days; 45% reported these cancellations were related to C19 -45% reported having visits cancelled by their provider during the pandemic **ART Prescriptions** -Practicing greater C19 protective behaviors was associated with greater difficulty in accessing medications[a] and getting to a pharmacy[b] -ART adherence improved significantly the month after the beginning of COVID-19 protective actions[c]	[a]X^2=10.8** [b]X^2=7.0** [c]t=17.2**
Kalichman et al. (2021)	CS	- African American/Black men who reported having one male sex partner, recruited through social media and snowball sampling -Atlanta, GA	- Survey responses (n=148 HIV+, 338 HIV-) to questions on C19 related disruptions in healthcare	- Apr 13 to Jul 2, 2020	**Retention/Engagement** -45% of men living w/HIV cancelled clinic visits due to C19 (compared to 30% of men living w/o HIV)[a] -63% of men living w/HIV's clinic closed or cancelled visits due to C19 (compared to 33% of men living w/o HIV)[b] **ART Prescriptions** -96% of men living w/HIV reported taking ART currently -No reported significant difference between men living w/ vs. w/o HIV in getting to the pharmacy or getting their medications **Viral Suppression** -88% of men living w/HIV reported undetectable VL	[a]X^2=11.2** [b]X^2=38.9**
McGinnis et al. (2021)	RR	- Members of the Veterans Aging Cohort Study living with HIV with at least one outpatient visit -National	- Comparison of clinic visits, VL tests, ART medication refill length, and ART coverage comparing 2019 to 2020 (n=27,674 records)	-March 1, 2019 to February 29, 2020 ("2019") -March 1, 2020 to February 28, 2021 ("2020")	**Retention/Engagement** 2019: -96% had at least one general medicine or infectious disease (GM/ID) visit (virtual or in-person) -27% of all visits virtual -In-person visits: men (95%), women (91%) -Virtual visits: men (57%), women (62%) 2020: -95% had at least one GM/ID visit (virtual or in-person) -64% of all visits virtual -In-person visits: men (80%), women (77%) -Virtual visits: men (89%), women (92%)	

					ART Prescriptions 2019: -85% taking ART -39% had ART refills for greater than 90 days 2020: -84% taking ART -51% had ART refills for greater than 90 days -ART coverage similar for both 2019 and 2020 **Viral Suppression** 2019: -82% had VLs measured -92% of those measured were VS -VLs measured: men (82%), women (73%) 2020: -74% had VLs measured -91% of those measured were VS -VLs measured: men (74%), women (67%)	
McKay et al. (2021)	CS	- LGBTQ individuals (age 18+) recruited on social media -National	- Survey responses (n=728 gay/bisexual men) on impacts of C19	-Apr 10 to May 10, 2020	**Retention/Engagement** -HIV positive men 55% more likely to report difficulty in accessing healthcare compared to HIV negative men	
Nguyen et al. (2021)	CS	- Individuals (>50 years of age) who identified as being HIV positive -Palm Springs, CA	- Percentage of participants (n=100) who reported interruptions in healthcare and medications during C19	-May to Jul, 2020	**Retention/Engagement** -46% reported an inability to attend clinic visits due to C19 **ART Prescriptions** -24% reported missing ART medications -Younger (age 51-63) group more likely to miss a dose of HIV medication than those 64 years and older[a] -Inability to attend visits was associated with increased odds of missing a dose of HIV medication[b] **Viral Suppression** -90.8% self-reported undetectable VL	[a]Two-sided Fisher's exact test=6.7** [b]OR=3.70*
Qiao et al. (2021)	MM	- Ryan White clinics -South Carolina	-Data included country level indicators (social economic status, COVID-19 cases, HIV cases) -Service interruptions reported in clinic program process reports (n=27 clinics)	-Mar, 2020	**Retention/Engagement** -Clinics reported widespread adoption of telehealth -55.6% reported partial interruptions in services, 25.9% reported complete interruptions, 11.1% reported minimal interruptions, and 7.4% reported no interruptions -Severity of service disruption did not correspond to density of C19 cases -Areas with no HIV service interruptions had higher percentage of insured individuals (in post-hoc analysis) -Two clinics stopped home visits and support groups -Two clinics helped patients pick up their medications	
Rhodes et al. (2021)	QL	-Participants of the *weCare* intervention	-Participant experiences during C19 via semi-	-Apr 23 to May 23, 2020	**Retention/Engagement**	

		-North Carolina	structured interviews (n=15)		-Reported no interruptions in HIV care, but did experience challenges accessing other types of medical care (e.g., dentist, etc.) **ART Prescriptions** -Reported successfully obtaining HIV prescriptions -Challenges in adherence noted, specifically due to interruptions in daily routines	
Sanchez et al. (2020)	CS	- Responses from the American Men's Internet Survey -National	-Percentage of respondents (n=1,051; 122 identified as HIV+) replying to questions on HIV treatment impacts	Apr 2-13, 2020	**Retention/Engagement** -27% of PWH reported decreased HIV care visits -19.7% reported trouble making or keeping HIV care visits -23.8% reported decreased access to getting VLs taken **ART Prescriptions** -8.2% and 6.6% reported challenges getting or filling ART prescriptions -4.9% reported decreased medication adherence	
Sorbera et al. (2021)	RR	- PWH who needed ART renewals or follow-up during C19 -Brooklyn, NY	- Comparison of pre-C19 and post-C19 VS rates via clinic data (n=211 patients)	-Pre-C19: 1 year prior to Mar 13, 2020 -Post-C19: Mar 13 to Jul 20, 2020	**ART Prescriptions** -Clinical pharmacists in the treatment center helped to assess ART adherence and need for laboratory work **Viral Suppression** -No difference was found in those VS comparing pre- (88.6%) and post-C19 (85.3%) - No difference was found in those with an undetectable VL comparing pre- (81.5%) and post-C19 (74.4%) -Percentage with CD4 cell count >200 cells/mm^3 decreased[a]	[a]Pre-C19 prevalence=92.6%; During C19 prevalence=78.3%**
Spinelli et al. (2020)	RR	- PWH on publicly funded insurance who attend a safety-net clinic -San Francisco, CA	- OR of viral nonsuppression and no-show visits comparing pre-C19 (n=4,153 visits) to during C19 (n=1,997 visits) using clinic data	-Pre-C19: Dec 1, 2019 to Feb 29, 2020 -During C19: Apr 1 to 30, 2020	**Retention/Engagement** -31% of visits were no-shows pre-C19; 30% were no-shows during C19 -Odds of no-shows comparing during C19 to pre-C19 were not significantly different -Those experiencing homelessness had reduced odds for no-show visit during C19[a] -Those who had telehealth visits had reduced odds for no-show visit during C19 compared to in-person visits[b] **Viral Suppression** -Increased odds for unsuppressed VL comparing during C19 to pre-C19[c] -Viral nonsuppression higher in those experiencing homelessness during C19[d] -Younger individuals (<35 years)[e] and Black individuals[f] had increased odds of viral nonsuppression both pre- and during C19	[a]OR=0.64 [95% CI 0.48-0.85] [b]OR=0.56 [95% CI 0.36-0.86] [c] OR=1.31 [95% CI 1.08-1.53] [d] OR=3.36 [95% CI 2.74-4.12] [e]1.29 [95% CI 1.11-1.51] [f]1.60 [95% CI 1.30-1.91]
Tamargo et al. (2021)	CS, RR	- Participants from the Miami Adult Studies on HIV cohort	- Comparison of ART adherence and visit attendance using survey	Jul to Aug, 2020	**Retention/Engagement** -PWH had a higher odds of having a visit to a HCP within the last 6 months compared to those without HIV[a]	[a]OR=4.11** [b]OR=0.52*

		-Miami, FL	responses and clinic data (n=183 HIV+, 116 HIV-)		-PWH had a lower odds of avoiding healthcare within the last month compared to those without HIV[b] -6% of PWH reported missing an HIV-related visit in the last month (54.6% were cancelled) -No significant change in healthcare utilization among PWH comparing during to before C19 **ART Prescriptions** -99.5% of PWH on ART -13.2% avoided picking up their HIV medication -No significant change in the percentage reporting missing doses of ART in the last week during C19 (8.2%) compared to 10.4% before C19	
Wion & Miller (2021)	CS	- PWH (ages 18+) recruited via social media platforms -National	- Participant responses (n=85) to rating of C19 pandemic factors and to the HIV Self-Management Scale	-Apr 23-30, 2020	**Retention/Engagement** -50% of those who reported attending HIV support groups (n=14) could no longer attend due to C19 -Reported low to moderate difficulty in communicating with their provider about HIV concerns during C19 -Reported moderate to high confidence in getting assistance from HIV provider or pharmacy -Comparing during C19 to pre-C19: decrease in Social Support domain mean score[a] and overall self-management mean score[b] on the HIV Self-Management Scale **Viral Suppression** -94.1% self-reported being VS	[a]Mean score difference = -0.45** [b]Mean score difference = -1.27**

*P ≤0.05; **P ≤0.01

[1]Statistical test left blank if it is not applicable (e.g., no statistical test was completed) or if the specific test performed or resulting p-value was not provided by the study authors

Legend: MM-mixed methods, RR-retrospective review of existing data, CS-cross-sectional survey, LS-longitudinal survey, TSA-interrupted time series analysis, QI-quality improvement study, QL-qualitative stydt, C19-COVID-19, ART-anti-retroviral therapy, HIV-human immunodeficiency virus, VL-viral load, VS-virally suppressed, PWH-people living with HIV, RCT-randomized controlled trial, OR-odds ratio, CI-confidence interval, SES-socio-economic status, HCP-healthcare provider, EMR-electronic medical record, PR-prevalence ratio

A.4 Parent study questionnaire (C-FORWARD)

Date: ___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

For many of the questions in this survey, we will ask about the time prior to when the COVID-19 pandemic started. The date that we will use for this is March 1, 2020. We would like to first ask some questions about yourself and your background. Remember there are no right or wrong answers and your answers are completely confidential.

SECTION 1: DEMOGRAPHICS

1. What was your biological sex assigned at birth?
   - ☐ Male
   - ☐ Female
   - ☐ Non-binary
   - ☐ None of these describe me
   - ☐ Prefer not to answer

2. What terms best express how you describe your gender identity?
   - ☐ Male/Man
   - ☐ Female/Woman
   - ☐ Non-binary
   - ☐ Transgender man/Female-to-Male (FTM)
   - ☐ Transgender woman/Male-to-Female (MTF)
   - ☐ Gender non-binary/Genderqueer/Gender nonconforming
   - ☐ Agender
   - ☐ Bigender
   - ☐ None of these describe me
   - ☐ Prefer not to answer

3. Which of the following best describe your marital status?
   - ☐ Single
   - ☐ Monogamous, in a relationship
   - ☐ In more than one relationship
   - ☐ Engaged
   - ☐ Married
   - ☐ Other (Specify_____)

4. What is your highest level of education you have achieved outside or in the United States? Grades are roughly equivalent to years of school.
   - ☐ Have never gone to school
   - ☐ 5th grade or less
   - ☐ 6th to 8th grade
   - ☐ 9th to 12th grade, no diploma
   - ☐ High school graduate or GED completed
   - ☐ Some college level/technical/vocational/associate's degree
   - ☐ Bachelor's degree
   - ☐ Other advanced degree (Master's, doctoral degree)
   - ☐ Prefer not to answer
   - ☐ Don't know

5. We would like to know about what you do- Are you working now, looking for work, retired, keeping house, a student or what? ***CHECK ALL THAT APPLY***
   - ☐ Working full-time (40 hours per week)
   - ☐ Working part-time (Less than 40 hours per week)
   - ☐ Retired
   - ☐ Keeping house
   - ☐ Student
   - ☐ Other (Specify: _____)
   - ☐ Only temporarily laid off, sick leave or maternity leave
   - ☐ Looking for work, unemployed
   - ☐ Disabled, permanently or temporarily
   - ☐ Prefer not to say
   - ☐ Don't Know

6. Are you considered an essential worker? An essential worker is someone who was required to go to work even when stay at home orders were in place in Maryland.
   - ☐ Yes
   - ☐ No
   - ☐ Don't Know

7. Would any of these describe where you work?
   - ☐ Nursing care facilities
   - ☐ Visiting nurse or home health aide service
   - ☐ Building cleaning services
   - ☐ Public transportation
   - ☐ Corrections facility
   - ☐ EMT or paramedic services
   - ☐ Meat packing farm facility
   - ☐ Agriculture and food production facility
   - ☐ Grocery Store
   - ☐ Construction
   - ☐ No

8. Are you currently a caregiver for a dependent/dependents in your home? A dependent is anyone who relies on you for help with activities of daily living, including children under the age of 18 years or an older adult with chronic disease or disability.
☐ Yes ☐ No ☐ Don't Know

9. What was your household annual income in 2019 from all sources before taxes? This includes all income from both formal and informal employment.
☐ less than $15,000
☐ $15,000 - $19,999
☐ $20,000 – $24,999
☐ $25,000 - $34,999
☐ $35,000 - $49,999
☐ $50,000 - $74,999
☐ $75,000 - $99,999
☐ $100,000 and above
☐ Don't know
☐ Refuse to Answer

10. Including yourself, how many people depend on this income? This can include people who don't live with you now.
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 or more ☐ Don't know ☐ Refuse to answer

11. Prior to the COVID-19 pandemic (March 1, 2020), was your household paying lower rent because the Federal, State or Local government was paying part of the cost?
☐ Yes ☐ No ☐ Don't Know ☐ Refuse to Answer

12. Were you born in the United States?
☐ Yes ☐ No ☐ Don't Know ☐ Refuse to Answer

13. Do you speak a language other than English at home?
☐ Yes ☐ No (***GO TO Q14***)

→ 13a. What Language(s): **CHECK ALL THAT APPLY**
☐ Spanish ☐ Vietnamese ☐ Mandarin ☐ Cantonese ☐ Tagalog ☐ Hawaiian ☐ Ilokano ☐ Navajo ☐ Other (Specify:_____)

14. Which of the following best represents how you think of yourself at this time?
☐ Straight; that is, not gay or lesbian, etc.
☐ Gay
☐ Lesbian
☐ Bisexual
☐ None of these describe me
☐ Prefer not to answer

SECTION 2: COVID-19 SYMPTOMS, TESTING AND TREATMENT EXPERIENCE

1. Since February 1, 2020, have you thought you had COVID-19?
☐ Yes ☐ No ☐ I'm not sure/Don't know

2. Since February 1, 2020, have you had….?

		Yes	No	Don't remember
a.	Fever or chills	☐	☐	☐
b.	Cough	☐	☐	☐
c.	Shortness of breath or difficulty breathing	☐	☐	☐
d.	Lack of energy or general tired feeling	☐	☐	☐
e.	Muscle or body aches	☐	☐	☐
f.	Headache	☐	☐	☐
g.	New loss of taste or smell	☐	☐	☐
h.	Sore throat, congestion, or runny nose	☐	☐	☐
i.	Feeling sick to your stomach or vomiting, diarrhea	☐	☐	☐
j.	Abdominal pain	☐	☐	☐
k.	Skin rash	☐	☐	☐
l.	Other symptom (describe:_____ _____	☐	☐	☐

If you said NO to QUESTION 1 and you said No/Don't Know to all symptoms (QUESTION 2), GO TO QUESTION 10

3. In the past 7 days, have you thought you had COVID-19?
☐ Yes ☐ No ☐ I'm not sure/Don't know

	4. In the past 7 days, have you had any of the following symptoms?		5. *If you had this symptom*, did the symptom affect your ability to do your normal activities? [***Only answer this question for the symptoms you have had in the past 7 days***]		
	NO	YES	I had the symptom, but I could still do normal activities	The symptom really bothered me. It was hard to do normal activities	The symptom was very bad. I was not able to do activities that I usually do
a. Fever or chills	☐ ***(GO TO Q4b)***	☐	☐	☐	☐
b. Cough	☐ ***(GO TO Q4c)***	☐	☐	☐	☐
c. Shortness of breath or difficulty breathing	☐ ***(GO TO Q4d)***	☐	☐	☐	☐
d. Lack of energy or general tired feeling	☐ ***(GO TO Q4e)***	☐	☐	☐	☐
e. Muscle or body aches	☐ ***(GO TO Q4f)***	☐	☐	☐	☐
f. Headache	☐ ***(GO TO Q4g)***	☐	☐	☐	☐
g. New loss of taste or smell	☐ ***(GO TO Q4h)***	☐	☐	☐	☐
h. Sore throat, congestion or runny nose	☐ ***(GO TO Q4i)***	☐	☐	☐	☐
i. Feeling sick to your stomach or vomiting, diarrhea	☐ ***(GO TO Q4j)***	☐	☐	☐	☐
j. Abdominal Pain	☐ ***(GO TO Q4k)***	☐	☐	☐	☐
k. Skin rash	☐ ***(GO TO Q4l)***	☐	☐	☐	☐
l. Other symptom (describe:_____ _____)	☐	☐	☐	☐	☐

Now think about the two weeks prior to your most recent symptoms.

6. In the two weeks prior to developing your most recent symptoms, had anyone in your household including yourself traveled outside of Baltimore, Maryland or the US? ***CHECK ALL THAT APPLY***
☐ Yes, outside of Baltimore City
☐ Yes, outside of Maryland
☐ Yes, outside of the US
☐ No
☐ Don't Know/remember

7. In the two weeks prior to developing your most recent symptoms, did you do any of the following? ***CHECK ALL THAT APPLY***
☐ Left the house for work
☐ Left the house for school
☐ Visited with friends and or/family (who don't live with you) outside of the home
☐ Visited with friends and/or family (that don't live with you) at your home
☐ None of the above
☐ Don't know /Unsure

8. In the two weeks prior to developing your most recent symptoms, did you have contact with someone who tested positive for COVID-19?
☐ No
☐ Yes, someone in my home
☐ Yes, someone outside my home
☐ Yes, someone in my home and someone outside my home
☐ Don't know/Unsure

9. In the two weeks prior to developing your most recent symptoms, did you have contact with someone who had symptoms of COVID-19, but who had not yet tested positive or had not yet had a test?
☐ No
☐ Yes, someone in my home
☐ Yes, someone outside my home
☐ Yes, someone in my home and someone outside my home
☐ Don't know/Unsure

10. Do you have allergies (such as seasonal or non-seasonal)?
☐ Yes ☐ No ☐ I'm not sure/Don't know

11. Have you ever wanted or needed to get a test for COVID-19?

☐ Yes ☐ No (***GO TO Q12***)

→ 11a. Why did you want or need to get tested for COVID-19? *If you have been tested multiple times, think about all of the reasons why you were tested each time.* (***CHECK ALL THAT APPLY***)

- ☐ You had symptoms
- ☐ Someone else in your household had symptoms
- ☐ Someone else in your household tested positive for COVID-19
- ☐ Someone else you had close contact with had symptoms
- ☐ Someone else you had close contact with tested positive for COVID-19
- ☐ You needed to get a test before a medical procedure
- ☐ You wanted to get tested before visiting an elderly relative
- ☐ You were required to get tested for school
- ☐ You went to an event/large gathering
- ☐ You were curious and wanted to know status
- ☐ Other (describe: _____ _____)

12. Have you ever been tested for COVID-19? Here we are asking about whether you have been tested for the virus itself. This is typically done with a swab that goes into your nose.

☐ Yes (***GO TO Q12b***) ☐ Don't Know (***GO TO Q21***)

☐ No ☐ Prefer not to answer (***GO TO Q21***)

→ 12a. What is the main reason you have you not been tested for COVID-19? ***CHECK ALL THAT APPLY***

- ☐ You haven't felt sick
- ☐ You have felt sick, but didn't feel sick enough to get tested
- ☐ You felt sick but didn't think you had COVID-19
- ☐ You felt sick but weren't aware of COVID-19 until after you felt better
- ☐ You were told by a healthcare provider to self-quarantine instead of getting tested
- ☐ Testing was not available to you
- ☐ You were afraid to get tested
- ☐ You were afraid of how people would treat you if you tested positive
- ☐ You were concerned about not being able to work if you tested positive
- ☐ You thought by going to a testing center you would be exposed to/infected with COVID-19
- ☐ You haven't had transportation to or from a testing location
- ☐ You were worried about not being able to pay
- ☐ You didn't know where to go for testing
- ☐ You didn't have someone to watch your children/other people in your care while you went
- ☐ You haven't been able to take time off of work for testing
- ☐ Don't know/unsure
- ☐ Other (Specify: _____)

AFTER ANSWERING Q12a, GO TO Q21

Please tell us more about your experience with COVID-19 testing. Here we are interested in testing for the virus which is typically done with a swab that goes into your nose.

→ 12b. How many times have you been tested for COVID-19? ☐☐ *times*

(Enter 97 if you don't know)

12c. In which month were you first tested for COVID-19

- ☐ January
- ☐ February
- ☐ March
- ☐ April
- ☐ May
- ☐ June
- ☐ July
- ☐ August
- ☐ September
- ☐ October
- ☐ November
- ☐ December

12d. In which year did you first have a COVID-19 test?

☐ 2019 ☐ 2020 ☐ 2021

12e. Thinking about that first COVID-19 test, how would you rate your experience from knowing where to call, scheduling the test, going to the testing site and receiving the results.

- ☐ Very Easy
- ☐ Easy
- ☐ Somewhat difficult
- ☐ Very difficult
- ☐ Prefer not to say

13. Have you ever tested positive for COVID-19?

- ☐ Yes
- ☐ No (***GO TO Q14***)
- ☐ Don't Know (***GO TO Q14***)
- ☐ Prefer not to Answer (***GO TO Q14***)

13a. What month did you first test positive for COVID-19

- ☐ January
- ☐ February
- ☐ March
- ☐ April
- ☐ May
- ☐ June
- ☐ July
- ☐ August
- ☐ September
- ☐ October
- ☐ November
- ☐ December

13b. What year did you first test positive for COVID-19?

- ☐ 2019
- ☐ 2020
- ☐ 2021

13c. After you tested positive for COVID-19, were you asked by someone to give the names of people who you had spent time with so they could be notified that they might have been exposed to COVID-19?

- ☐ No
- ☐ Yes
- ☐ Don't Know/Unsure

The next 6 questions are about your most recent COVID-19 test whether it was positive or negative.

14. What month did you have your most recent test for COVID-19?

- ☐ January
- ☐ February
- ☐ March
- ☐ April
- ☐ May
- ☐ June
- ☐ July
- ☐ August
- ☐ September
- ☐ October
- ☐ November
- ☐ December

15. What year did you have your most recent test for COVID-19?

- ☐ 2019
- ☐ 2020
- ☐ 2021

16. When you were tested most recently, why did you get tested for COVID-19? ***CHECK ALL THAT APPLY***

- ☐ You had symptoms
- ☐ Someone else in your household had symptoms
- ☐ Someone else in your household tested positive for COVID-19
- ☐ Someone else you had close contact with had symptoms
- ☐ Someone else you had close contact with tested positive for COVID-19
- ☐ You needed to get a test before a medical procedure.
- ☐ You needed to get tested before travel/visiting an elderly relative
- ☐ You were required to get tested for school/work
- ☐ You went to an event/large gathering
- ☐ You were curious and wanted to know your status
- ☐ Other (Describe: _____ _____)

17. What was the result of your most recent COVID-19 test?

- ☐ Negative
- ☐ Positive
- ☐ Never obtained my results
- ☐ Indeterminate
- ☐ Don't Know
- ☐ Prefer not to Answer

18. How were you tested for your most recent result?

- ☐ Nasal Swab
- ☐ Throat Swab
- ☐ Blood sample
- ☐ Saliva
- ☐ Don't Know/Unsure

19. <u>When you had your most recent COVID-19 test</u>, how long (like hours/days/weeks) did it take you to get a test for COVID-19?

- ☐ Same day
- ☐ Within 48 hours
- ☐ 3-4 days
- ☐ 5-7 days
- ☐ More than a week
- ☐ Don't Know/Unsure

20. <u>After your most recent COVID-19 test</u>, how long did it take you to get your test results back (once you were tested)?

- ☐ Same day
- ☐ Within 48 hours
- ☐ 3-4 days
- ☐ 5-7 days
- ☐ More than a week
- ☐ Don't Know/Unsure

21. There are also tests that can tell us whether you have antibodies to COVID-19. These antibodies tell us whether you have been previously infected with COVID-19. This is usually a blood test. Have you ever had an antibody test for COVID-19?

☐ Yes ☐ No (***GO TO Q22***) ☐ I'm not sure (***GO TO Q22***)

21a. Have you ever tested positive for COVID-19 antibodies?

☐ Yes ☐ No (***GO TO Q22***) ☐ I'm not sure (***GO TO Q22***)

21b. What month did you most recently test positive for antibodies to COVID-19?

☐ January ☐ April ☐ July ☐ October
☐ February ☐ May ☐ August ☐ November
☐ March ☐ June ☐ September ☐ December

21c. What year did you have your most recent positive test for COVID-19 antibodies?

☐ 2019 ☐ 2020 ☐ 2021

22. Have you ever taken any medications for the treatment of COVID-19?

☐ Yes ☐ No (***GO TO Q23***) ☐ I'm not sure (***Go TO Q23***)

22a. Were they prescribed to you by a health care provider?

☐ Yes
☐ Yes, I took both medications that were and were not prescribed by a health care provider
☐ No

23. Since February 1, 2020, did you go to the emergency room or were you admitted to the hospital because of COVID-19 related symptoms?

☐ Yes ☐ No (***GO TO Q24***)

23a. How long were you hospitalized? ☐☐☐ *days*

(Write 000 if you went to the Emergency Room only and didn't get admitted)
(Write 997 if you are not sure)

The next two questions are about COVID-19 testing in your community

24. I know where I can get COVID-19 testing in my community.

☐ Strongly disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither disagree or agree

25. It is easy to get tested for COVID-19.

☐ Strongly disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither disagree or agree

SECTION 3: ADOPTION OF PREVENTIVE BEHAVIORS INCLUDING IN THE WORKPLACE

The next questions are about the actions you have taken to keep you and your family safe from COVID-19. First, think about your household.

1. In the past 2 weeks, has everyone in your household including yourself practiced social distancing (i.e., reduced your physical contact with people outside of your home in social, work, or school settings by avoiding groups of 10 or more and staying 6 feet away from other people when out in public and wearing a face mask)?

- ☐ No
- ☐ Yes, some but not all household members practiced social distancing
- ☐ Yes, all household members practiced social distancing ***(GO TO Q2)***
- ☐ I don't know ***(GO TO Q2)***

→ 1a. What is the main reason everyone in your household did not practice social distancing?

CHECK ALL THAT APPLY

- ☐ People have been vaccinated
- ☐ Don't feel that social distancing was helping to reduce virus spread
- ☐ Too difficult to maintain social distancing
- ☐ Tired of social distancing
- ☐ Someone in your household is working in a setting where they cannot maintain social distance
- ☐ Not worried about getting COVID-19
- ☐ Not under stay at home orders
- ☐ Don't feel like it is necessary because we are wearing masks
- ☐ I can't always control my children's behavior and the context of their activities (such as a sports practice, get together with friends, etc.)
- ☐ Don't Know/Unsure
- ☐ Other, describe why:_____
  _____

Now please think about things you have been doing in the past 2 weeks to protect yourself and your family from COVID-19

2. Please tell me which of the following things you have been doing in the past 2 weeks. Are you:

CHECK ALL THAT APPLY

- ☐ Washing hands/using hand sanitizer every time you enter your home
- ☐ Disinfecting surfaces in your household with bleach/alcohol
- ☐ Disinfecting or wiping down groceries
- ☐ Disinfecting or wiping down mail or packages
- ☐ Reducing how often you go to the store for groceries/supplies
- ☐ Not going to stores for reasons other than groceries/medication
- ☐ Avoiding or cancelling travel or vacation plans
- ☐ Not ordering food from restaurants/ordering less
- ☐ Not visiting restaurants even those with outdoor seating
- ☐ Wearing a mask when out in public
- ☐ Avoiding gatherings with people outside of your home
- ☐ Keeping my children home as much as possible
- ☐ Avoiding public places/crowds
- ☐ Staying home as much as you can

3. Please tell me which of the following things you have been doing in the past 2 weeks

Have you ...	Yes	No	Don't Remember
a. **Gone to a place of worship (ex. church, mosque, temple) for an indoor service**	☐	☐	☐
b. **Gone to a place of worship (ex. church, mosque, temple) for an outdoor service**	☐	☐	☐
c. **Gone to a place of worship (ex. church, mosque, temple) for some other reason (e.g., food bank, meeting)**	☐	☐	☐
d. **Visited with friends, neighbors or relatives at your home or theirs and spent time outdoors**	☐	☐	☐
e. **Visited with friends, neighbors or relatives at your home or theirs and spent time indoors**	☐	☐	☐
f. **Spent time at the beach**	☐	☐	☐
g. **Spent time at an outdoor pool**	☐	☐	☐
h. **Participated in a group outdoor fitness activity**	☐	☐	☐
i. **Gone to a bar and spent time outdoors**	☐	☐	☐
j. **Gone to a bar and spent time indoors**	☐	☐	☐
k. **Eaten outdoors at a restaurant**	☐	☐	☐
l. **Eaten indoors at a restaurant**	☐	☐	☐
m. **Gone to a grocery store or pharmacy**	☐	☐	☐
n. **Gone to a store other than a grocery store or pharmacy**	☐	☐	☐
o. **Worked out in an indoor gym**	☐	☐	☐
p. **Gone to a salon, spa, barber shop or tattoo parlor**	☐	☐	☐
q. **Gone to a movie theatre, auditorium or stadium**	☐	☐	☐
r. **Gone to a social gathering or event outside of your home where there were more than 10 people**	☐	☐	☐
s. **Gone to a social gathering or event outside of your home where there were more than 100 people**	☐	☐	☐
t. **Used public transportation**	☐	☐	☐

4. Thinking about all of the times in the past 2 weeks that you interacted with people inside (like at a friend's home, store, restaurant or bar…

	Never	Sometimes	Always	Not applicable
a. How often did you practice social distancing (e.g., maintain 6-foot distance)?	☐	☐	☐	☐
b. How often did you wear a mask?	☐	☐	☐	☐

5. Thinking about all of the times in the past 2 weeks that you interacted with people in outdoor activity (like at an outdoor bar/restaurant or pool)…

	Never	Sometimes	Always	Not applicable
a. How often did you practice social distancing (e.g., maintain 6 foot distance)?	☐	☐	☐	☐
b. How often did you wear a mask ?	☐	☐	☐	☐

6. In your workplace, do you have access to necessary facilities to wash?
   - ☐ Yes, all of the time
   - ☐ Yes, most of the time
   - ☐ Some of the time
   - ☐ Rarely
   - ☐ Not at all
   - ☐ Not applicable (if not working for any reason)

7. Does your work require you to be in close contact (i.e., within 6 feet) with others?
   - ☐ Yes, all of the time
   - ☐ Yes, most of the time
   - ☐ Some of the time
   - ☐ Rarely
   - ☐ Not at all
   - ☐ Not applicable (if not working for any reason)

8. In your workplace, do you have access to necessary personal protective equipment (PPE)?
   - ☐ Yes, all of the time
   - ☐ Yes, most of the time
   - ☐ Some of the time
   - ☐ Rarely
   - ☐ Not at all
   - ☐ Not applicable (if not working for any reason)

SECTION 4: COMORBIDITIES AND HEALTH CARE ACCESS

The next questions are about health conditions you may have and how your health care has been impacted by the COVID-19 pandemic.

1. Are you currently pregnant?
   ☐ Yes ☐ No ☐ Not applicable

2. How tall are you without shoes? *Please choose the units you would like to use for height.*

   ☐ *Feet* ☐☐ *Inches* ☐ *Meters* ☐☐ *Centimeters*

3. How much do you weigh without clothes or shoes? *Please choose the units you would like to use for weight. If you are currently pregnant, how much did you weigh before your pregnancy?*

   ☐☐☐ *Pounds* ☐☐ *Kilograms*

4. Do you have any of the following health conditions? ***CHECK ALL THAT APPLY***

	Yes	No	Don't Know/ Unsure
a. Diabetes	☐	☐	☐
b. Cardiovascular disease (CVD or heart disease)	☐	☐	☐
c. Hypertension (HTN, high blood pressure)	☐	☐	☐
d. Immunocompromised condition	☐	☐	☐
e. Autoimmune disease	☐	☐	☐
f. Cancer diagnosis and/or treatment within past 12 months	☐	☐	☐
g. Chronic kidney disease	☐	☐	☐
h. Asthma	☐	☐	☐
i. Chronic obstructive pulmonary disease (COPD)	☐	☐	☐
j. Other chronic lung disease	☐	☐	☐
k. Sickle cell anemia	☐	☐	☐
l. Depression	☐	☐	☐
m. Alcohol or substance use disorder	☐	☐	☐
n. Injection drug use	☐	☐	☐
o. Other mental health disorder	☐	☐	☐
p. Other chronic condition	☐	☐	☐

4a1. If you said YES to Cardiovascular disease (***Q4b***), which of the following cardiovascular conditions do you have?

	Yes	No
a. Congestive heart failure	☐	☐
b. Myocarditis/pericarditis	☐	☐
c. History of stroke(s)	☐	☐
d. History of heart attack(s)	☐	☐
e. Other	☐	☐

Describe: _____

4a2. If you said YES to Immunocompromised condition (***Q4d***), which of the following immune disorders do you have?

	Yes	No
a. Transplant recipient	☐	☐
b. HIV positive	☐	☐
c. Other	☐	☐

Describe: _____

5. Do you take chronic medication for any of the conditions listed above?
☐ Yes ☐ No *(**GO TO Q6**)* ☐ Don't know *(**GO TO Q6**)*

5a. Since the COVID-19 pandemic, (March 1, 2020), have you experienced any delays or interruptions of treatment as a result of COVID-19?
☐ Yes ☐ No ☐ I'm not sure/Don't know

6. Since the COVID-19 pandemic (March 1, 2020), did you…

		Yes	No	Don't Know/ Unsure
a.	Need to see a health care provider for a routine follow-up visit or a new health or mental health concern that was not related to COVID-19	☐	☐	☐
b.	Skip/miss any in person or video/phone appointments with a health care provider because of COVID-19	☐	☐	☐
c.	Go to any appointment with a health care provider in person	☐	☐	☐
d.	Have an appointment with a health care provider by phone or video	☐	☐	☐

7. Since the COVID-19 pandemic (March 1, 2020), did you need to go to the emergency room/hospital for a condition that was not related to COVID-19?
☐ Yes ☐ No *(**GO TO Q8**)* ☐ Don't Know *(**GO TO Q8**)*

7a. Did you go to the emergency room/hospital when you needed to?
☐ Yes ☐ No ☐ Don't Know

8. Since the COVID-19 pandemic (March 1, 2020), did you need to have a major medical or dental procedure such as surgery?
☐ Yes ☐ No *(**GO TO Q9**)* ☐ Don't Know *(**GO TO Q9**)*

8a. Did you postpone this medical or dental procedure because of COVID-19?
☐ Yes ☐ No ☐ Don't Know

8b. Have you now had this medical or dental procedure?
☐ Yes ☐ No ☐ Don't Know

9. Would you say your health in general is excellent, very good, good, fair, or poor?
☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Prefer not to answer
☐ Don't know

10. The next questions are about limitations that you might have.

		Yes	No	Prefer not to say
a.	Do you have a disability that interferes with your ability to carry out daily activities? Examples of daily activities include walking, climbing stairs, shopping, balancing a checkbook, bathing or dressing.	☐	☐	☐
b.	Are you limited in any way in any activities because of physical, mental, or emotional problems	☐	☐	☐
c.	Do you have serious difficulty concentrating, remembering things, or making decisions	☐	☐	☐
d.	Do you have difficulty doing errands alone, such as visiting a doctor's office or shopping	☐	☐	☐
e.	Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone (*Include occasional use or use in certain circumstances)*	☐	☐	☐
f.	Do you have serious difficulty walking or climbing stairs	☐	☐	☐
g.	Are you blind or do you have serious difficulty seeing even when wearing glasses	☐	☐	☐
h.	Do you have difficulty dressing or bathing	☐	☐	☐

11. Are you deaf or do you have serious difficulty hearing?
☐ Yes ☐ No *(GO TO SECTION 5)* ☐ Prefer not to say *(GO TO SECTION 5)*

11a. Do you wear a hearing aid or have a cochlear implant?
☐ Yes ☐ No ☐ Prefer not to say

SECTION 5: CORONAVIRUS IMPACT AND PANDEMIC STRESS

The next questions are about how COVID-19 has impacted you and your household. For the next several questions, think about whether any of these things have happened to your household after March 1, 2020 as a result of COVID-19 even if this is not happening currently.

1. Have you, or has anyone in your household, experienced a loss of employment income since the start of the COVID-19 pandemic (March 2020)?
☐ Yes ☐ No *(GO TO Q2)*

1b. Have you or your household member requested unemployment benefits?
☐ Yes ☐ No *(GO TO Q2)* ☐ Don't know *(GO TO Q2)*

1c. Have you or your household member received unemployment benefits?
☐ No
☐ Yes, but not everyone who requested have received benefits
☐ Yes, everyone who requested received benefits
☐ Don't Know/Unsure

2. What is your primary kind of health insurance or health care plan that you have now?
☐ I do NOT have health insurance *(GO TO Q4)*
☐ Public (Medicare, Medicaid, Tricare)
☐ Private (purchased directly or through Employment)
☐ Don't know
☐ Prefer not to answer

3. Did you lose health coverage because of the COVID-19 pandemic?
☐ Yes
☐ Prefer not to answer
☐ No
☐ Don't know

4. At any time since March 1, 2020,

		No	Yes	Not applicable	Don't Know/Unsure
a.	Have you or someone in your household had to spend time taking care of your children because of school cancellation, loss of daycare, nanny, changes in childcare, etc.	☐	☐	☐	☐
b.	Have you or someone in your household to spend more time taking care of elders because you lost caregivers, removed someone from a facility, etc.	☐	☐	☐	☐
c.	Have you or anyone in your household lost housing or become homeless	☐	☐	☐	☐
d.	Has your household been unable to pay your rent/mortgage	☐	☐	☐	☐
e.	Has your household had difficulty paying for any basic needs including food, housing, clothing, electricity	☐	☐	☐	☐

5. At any time since March 1, 2020, have you or someone in your household been told to self-isolate or quarantine because you or they were infected, exposed or had symptoms? *By quarantine, I mean separating yourself from other people, even those in the household, to prevent others from getting sick.*

- ☐ Yes
- ☐ No ***(GO TO Q6)***
- ☐ Don't Know ***(GO TO Q6)***

5a. When you or your household members were told to self-isolate or quarantine, were you or they able to maintain the self-isolation/quarantine for the entire time that was recommended?

- ☐ Yes
- ☐ No
- ☐ Don't Know

5b. Why were you/the household member not able to self-isolate/quarantine or maintain it for the whole time that was recommended?

		Yes	No	Don't Know
a.	Not enough bedrooms to isolate in own bedroom	☐	☐	☐
b.	Had to share a bathroom with others in household	☐	☐	☐
c.	Meal preparation/eating	☐	☐	☐
d.	Had to care for young children	☐	☐	☐
e.	Had to care for an elderly family member	☐	☐	☐
f.	Had to continue working even though I was sick	☐	☐	☐
g.	Was tired of being indoors	☐	☐	☐
h.	Too much of a hassle	☐	☐	☐

6. If you were to test positive for COVID-19, would you be able to isolate without losing your job?
☐ Yes ☐ No ☐ Don't Know ☐ Not applicable

7. If you would be exposed to someone with COVID-19, would you be able to quarantine without losing your job?
☐ Yes ☐ No ☐ Don't Know ☐ Not applicable

8. Has anyone in your family died that you suspected or knew had COVID-19?
☐ Yes ☐ No ***(GO TO Q9)*** ☐ Don't know ***(GO TO Q9)***

8a. How many family members died that you knew or suspected had COVID-19? ☐☐ ***[Write 97 if Unsure]***

8b. Did any of your family members die alone either in their home or in a nursing home?
☐ Yes ☐ No ☐ Don't Know ☐ Refuse to Answer

9. The COVID-19 Pandemic may cause challenges for some people, whether they get COVID-19 or not. In the past 6 months have you or your family experienced any of the below changes?

		No, not a challenge	Yes, a minor challenge	Yes, a major challenge
a.	Getting the healthcare I need (including for mental health)	☐	☐	☐
b.	Having a place to stay/live	☐	☐	☐
c.	Getting enough food to eat	☐	☐	☐
d.	Having clean water to drink	☐	☐	☐
e.	Getting the medicine I need	☐	☐	☐
f.	Getting where I need to go	☐	☐	☐

Now think about things that might have happened in the past month

10. In the past month, have you earned income? By income I mean both formal and informal income.
- ☐ Yes
- ☐ No (**GO TO 10A**)
- ☐ Don't know (***GO TO Q10C***

10a. In the past month, what is the main reason you have not earned income?
- ☐ I lost my job
- ☐ I had to quit my job because I was concerned about COVID-19 risk
- ☐ I had to quit my job to care for children or elders
- ☐ I am not able to find a job
- ☐ Not enough business or clients
- ☐ I don't regularly earn income because I am retired or for some other reason
- ☐ My choice
- ☐ Don't Know/Unsure
- ☐ Other (Specify: _____)

GO TO Q11 after answering this question

10b. In the past month, have you left your home for work?
- ☐ Yes
- ☐ No
- ☐ I'm not sure/Don't know

10c. In the past month, have you been working for fewer hours, the same number of hours, or more hours than you were working before COVID-19?
- ☐ Fewer hours
- ☐ The same
- ☐ More hours
- ☐ Don't Know/Unsure

11. In the past month, has your household income changed relative to what your household was earning prior to COVID-19?
- ☐ Yes
- ☐ No *(**GO TO Q12**)*
- ☐ Don't know *(**GO TO Q12**)*

11a. How has your income changed in the past month?
- ☐ Increased
- ☐ Decreased
- ☐ Don't Know/Unsure

12. In the past month, did you or any household member have to eat fewer meals in a day or smaller meals than usual because there was not enough food?
- ☐ Yes
- ☐ No *(**GO TO SECTION 6**)*
- ☐ Don't know *(**GO TO SECTION 6**)*

12a. Is this happening more or less often than the time before the COVID-10 pandemic (March 1, 2020)?
- ☐ It is worse now, compared to before the pandemic
- ☐ It is about the same now
- ☐ It is better now, compared to before the pandemic
- ☐ Don't Know/Unsure

SECTION 6: MENTAL HEALTH

The next questions are about how you have been feeling.

1. In the past 2 weeks, how often...

	Not at all or less than 1 day	1-2 days	3-4 days	5-7 days
a. Have you felt nervous, anxious, or on edge?	☐	☐	☐	☐
b. Have you felt depressed?	☐	☐	☐	☐
c. Have you felt lonely?	☐	☐	☐	☐
d. Have you felt hopeful about the future?	☐	☐	☐	☐
e. Have you had physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart, when thinking about your experience with the COVID-19 pandemic?	☐	☐	☐	☐

2. Please tell me if you agree or disagree with the following statements:

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
g.	I am worried about getting COVID-19	☐	☐	☐	☐	☐
h.	I am very worried about my family/friends getting COVID-19.	☐	☐	☐	☐	☐
i.	I am very worried about giving someone else COVID-19.	☐	☐	☐	☐	☐
j.	I have a hard time sleeping because of COVID-19	☐	☐	☐	☐	☐
k.	I have had difficulties concentrating because of COVID-19	☐	☐	☐	☐	☐
l.	Thinking about COVID-19 makes me very anxious.	☐	☐	☐	☐	☐
m.	I am feeling overwhelmed by COVID-19	☐	☐	☐	☐	☐
n.	I am worried about money because of COVID-19.	☐	☐	☐	☐	☐
o.	I am worried about having enough food because of COVID-19.	☐	☐	☐	☐	☐
p.	I am worried about loss of income if I get sick from COVID-19.	☐	☐	☐	☐	☐
q.	I am spending more money because of COVID-19	☐	☐	☐	☐	☐
r.	I am worried about medical bills if I get sick from COVID-19.	☐	☐	☐	☐	☐

Think about your experiences with your neighbors and in your neighborhood since the COVID-19 pandemic (March 1, 2020). Do you agree or disagree with the following statements?

		Agree	Disagree	Don't Know/ Not Sure
3.	I can count on people in my neighborhood to help me if I'm sick.	☐	☐	☐
4.	My neighbors would go to the store for me if I'm sick.	☐	☐	☐

SECTION 7: SUBSTANCE USE

The next questions about whether you have used any substances like cigarettes or alcohol in the past month. Please remember that all of your responses are confidential.

1. Have you ever smoked cigarettes or used an electronic nicotine product (e-cigarette, vape, juul)?
☐ Yes ☐ No *(**GO TO Q2**)* ☐ Don't Know *(**GO TO Q2**)* ☐ Refuse to Answer *(**GO TO Q2**)*

→1a. Do you now smoke cigarettes?
☐ Every day
☐ Some days (***GO TO Q1C***)
☐ Not at all (***GO TO Q1C***)
☐ Refuse to answer (***GO TO Q1C***)
☐ Don't know (***GO TO Q1C***)

→1b. If you smoke every day, on average, how many cigarettes per day do you smoke? ☐☐ *Cigarettes per day* **[*Write 97 if Unsure*]**

1c. Since the COVID-19 pandemic (March 1, 2020), have you smoked cigarettes more or less than usual?
☐ Less than usual
☐ The same amount
☐ More than usual
☐ Don't Know/Unsure

1d. Do you now use electronic cigarettes every day, some days, rarely, or not at all?
☐ Every day
☐ Some days
☐ Rarely
☐ Not at all *(**GO TO Q2**)*
☐ Refuse to answer *(**GO TO Q2**)*
☐ Don't know *(**GO TO Q2**)*

→1e. On average on the days that you used electronic cigarettes in the past month, how many times each day did you use your electronic nicotine product (e-cigarette, vape, juul), whether you took one puff or several?

☐☐ *Times per day* **[*Write 97 if Unsure*]**

1f. Since the COVID-19 pandemic (March 1, 2020), have you used electronic nicotine products more or less than usual?

- ☐ Less than usual
- ☐ The same amount
- ☐ More than usual
- ☐ Don't Know/Unsure

2. In your entire life, have you had at least 1 drink of any kind of alcohol, not counting small tastes or sips?

- ☐ Yes
- ☐ No (***GO TO Q3***)
- ☐ Refuse to Answer (***GO TO Q3***)

2a. How often do you have a drink containing alcohol?

- ☐ Never
- ☐ Monthly or less
- ☐ 2-4 times a month
- ☐ 2-3 times a week
- ☐ 4 or more times a week
- ☐ Don't know or refuse to answer

2b. Since the COVID-19 pandemic (March 1, 2020), have you drank alcohol more or less than usual?

- ☐ Less than usual
- ☐ The same amount
- ☐ More than usual
- ☐ Don't Know/Unsure

3. Have you ever used marijuana?

- ☐ Yes
- ☐ No ***(GO TO SECTION 8)***
- ☐ Don't Know ***(GO TO SECTION 8)***
- ☐ Refuse to Answer ***(GO TO SECTION 8)***

3a. In the past month, how often did you use marijuana?

- ☐ Never
- ☐ Monthly or less
- ☐ 2-4 times a month
- ☐ 2-3 times a week
- ☐ 4 or more times a week
- ☐ Don't know or refuse to answer

3b. Since the COVID-19 pandemic (March 1, 2020), have you used marijuana more or less than usual?

- ☐ Less than usual
- ☐ The same amount
- ☐ More than usual
- ☐ Don't Know/Unsure

SECTION 8: KNOWLEDGE AND ATTITUDES TOWARDS COVID-19

1. Please tell me whether you agree or disagree with the following statements:

		Agree	Disagree	Don't Know
a.	Using a hand dryer on high heat will kill COVID-19	☐	☐	☐
b.	Spraying alcohol or chlorine all over your body will kill viruses that have entered your body	☐	☐	☐
c.	Regularly rinsing the nose with saline has protected people from getting COVID-19	☐	☐	☐
d.	COVID-19 was manufactured in a lab	☐	☐	☐
e.	People of all ages can get COVID-19	☐	☐	☐
f.	COVID-19 can be transmitted by people even when they aren't showing signs of infection	☐	☐	☐
g.	Hot weather and humidity will kill COVID-19	☐	☐	☐
h.	COVID-19 can be spread by contact with surfaces an infected person has touched	☐	☐	☐

2. In the past 2 weeks, have you used any sources (e.g., people, news, social media) to get information about COVID-19?

☐ Yes ☐ No ***(GO TO Q3)*** ☐ Don't Know ***(GO TO Q3)***

→2a. In the past 2 weeks, which of the following sources have you used to get information about COVID-19?
CHECK ALL THAT APPLY

☐ Twitter
☐ Facebook
☐ Newspaper
☐ Friends or family members
☐ Coworkers or classmates
☐ Doctors or health care providers
☐ President Trump
☐ President Biden
☐ State Governor
☐ Mayor
☐ World Health Organization (WHO)
☐ Centers for Disease Control (CDC)
☐ State, county or City Health Department
☐ CNN
☐ Fox News
☐ MSNBC
☐ Local news station (e.g., CBS, ABC, NBC)
☐ Official government websites
☐ Other website or online news source
☐ YouTube
☐ NPR
☐ Other podcast
☐ Other (describe:_____
_____)

3. Generally speaking, do you think of yourself as a Republican, Democrat, Independent or something else?

☐ Republican
☐ Democrat
☐ Independent
☐ Something else
☐ Don't Know/Unsure
☐ Refused

SECTION 9: VACCINES

1. Have you ever received a flu vaccination?

☐ Yes ☐ No ☐ Do not remember

2. Did you receive a flu vaccine during the 2020/2021 flu season?

☐ Yes ☐ No ☐ Do not remember

3. Have you searched for information on where to get a COVID-19 vaccine?

☐ Yes ☐ No ☐ Do not remember

4. Have you tried to sign up for or schedule an appointment for your COVID-19 vaccine?
   - ☐ Yes
   - ☐ No ***(GO TO Q5)***
   - ☐ Do not remember ***(GO TO Q5)***

4a. Were you able to make an appointment for your COVID-19 vaccine?
   - ☐ Yes
   - ☐ No
   - ☐ Do not remember

4b. How would you rate your experience with setting up/scheduling an appointment for a COVID-19 vaccine?
   - ☐ Very difficult
   - ☐ Somewhat difficult
   - ☐ Not too bad
   - ☐ Very easy

5. Have any of your friends and family members been vaccinated for COVID-19?
   - ☐ Yes
   - ☐ No
   - ☐ Do not remember

6. Have you received a COVID-19 vaccine?
   - ☐ Yes
   - ☐ No (***GO TO Q8***)
   - ☐ Don't know ***(GO TO Q8)***
   - ☐ Refuse to answer ***(GO TO Q8)***

6a. Which vaccine did you receive?
   - ☐ Moderna (two shots)
   - ☐ Pfizer (two shots)
   - ☐ Johnson and Johnson (one shot)
   - ☐ Don't know but I got two shots
   - ☐ Don't know but I got one shot only
   - ☐ Don't know and don't remember if I got one or two shots
   - ☐ Other, specify(_____)

7. What was the date of your first COVID-19 vaccination (i.e. your first shot)?
If you are unsure of the exact date, answer your best guess.

__ __/ __ __/ __ __ __ __
M M D D Y Y Y Y

7b. What is the date of your second COVID-19 vaccination (i.e. your second shot)?
If your vaccine only requires one shot, select "Not applicable"
If you are unsure of the exact date, answer your best guess.

__ __/ __ __/ __ __ __ __
M M D D Y Y Y Y

   - ☐ I haven't received my second shot yet
   - ☐ Not applicable (N/A) because I received the Johnson and Johnson, which is only one shot
   - ☐ Don't know
   - ☐ Other, specify (_____)

A.5 Parent study questionnaire (CoVPN 5002)

CoVPN 5002 Participant Questionnaire – 13 Years Old and Older

Participant ID: _____ **Date of Enrollment:** _____

Date of Questionnaire Administration: _____

Interviewer (read aloud): We're conducting this study to estimate the number of people who have or have had SARS-CoV-2 or COVID-19 in the United States and better understand how the COVID-19 pandemic affected peoples' lives. We'd like to ask you some questions about you, your health, your household, possible exposure to COVID-19 and your thoughts and feelings about COVID-19.

The questionnaire will take about 15-20 minutes to complete. Your participation is completely voluntary, and please be assured that your answers will remain strictly confidential.

Do you have any questions before we begin?

Interviewer please check one of the following:

- o Participant is completing the questionnaire for themselves
- o Legally authorized representative is completing this questionnaire on behalf of the participant

MEDICAL HISTORY

Interviewer (read aloud): We are now going to ask about your medical conditions and how they may have been affected by the COVID-19 pandemic. Please answer these questions to the best of your ability.

1. **Did you receive an influenza vaccine ("flu shot") during last year's (2019-2020) flu season?**
   - o Yes
   - o No
   - o Don't Know/ Not sure

2. **Have you ever been diagnosed by a healthcare professional with any of the following medical conditions?** Pick all that apply

Asthma	Yes	No
Other chronic lung disease	Yes	No
Heart disease	Yes	No
Hypertension (high blood pressure)	Yes	No
Cancer chemotherapy in the last 12 months	Yes	No
Other immunosuppressive condition	Yes	No
HIV	Yes	No
Diabetes	Yes	No
Kidney or renal disease	Yes	No
Liver Disease	Yes	No
Sickle cell disease	Yes	No
Obesity	Yes	No
Mental health condition	Yes	No
Substance use disorder	Yes	No
Other chronic medical conditions that have not already been mentioned	Yes	No

3. **Are you limited in any way in your daily activities because of a physical, mental, or emotional disability?** (Check all that apply)

- Physical disability
- Mental disability
- Emotional disability

4. **Are you currently pregnant?**
   - Yes
   - No
   - Don't know/Not sure
   - Prefer not to answer
   - Not applicable

5. **Do you have any medical conditions that require medication or routine visits to the doctor?**
   - Yes
   - No *(Skip to next section)*

6. **Because of the COVID-19 pandemic, were you unable or unwilling to attend scheduled appointments with your health care provider?**
   - Yes, I did miss appointments
   - No, I did not miss an appointment *(Skip to Q8)*
   - No, I did not have any appointments to miss *(Skip to Q8)*
   - Don't Know/ Not sure *(Skip to Q8)*

7. **What is the main reason you missed these appointments with your healthcare provider?**
   - My clinic cancelled my appointment because of COVID-19
   - I had symptoms of COVID-19 so did not go
   - I felt good, I did not need to go
   - I did not have money or insurance
   - Inconvenient (location/hours/times, etc.)
   - Forgot to go/missed appointment
   - Disrespected by the office or medical staff
   - I could not attend telemedicine visit
   - Did not have transportation
   - I postponed my appointment until it was safe to go
   - Other

8. **Because of the COVID-19 pandemic, were you unable to take any of your medications?**
   - Yes, I could not get a refill from the pharmacy
   - Yes, I did not get my refill from the pharmacy because I was concerned about social distancing, interacting with others, or exposure to coronavirus
   - Yes, I have medication in my possession, but I forgot to take them
   - Yes, I could no longer afford them because of lost employment or insurance.
   - No
   - Don't Know

- Prefer not to answer

COVID-19 INFECTION HISTORY, RISK, AND EXPOSURE

Interviewer (read aloud): We are now going to ask about any history of COVID-19 symptoms, testing, and illness in you or your household.

1. **Do you think you ever had COVID-19?**
    a. Yes – tested positive via diagnostic or antibody test
    b. Yes – did not get tested
    c. No
    d. Don't Know/ Not sure

Note to interviewer: diagnostic tests are usually collected through swabs in the nose, mouth, and throat and antibody tests are usually blood tests.

2. **Have you received a COVID-19 diagnostic test in the past? A diagnostic test is usually a swab in the nose, mouth, or throat.**
    - Yes – tested positive *(Skip to Q4)*
    - Yes – tested negative *(Skip to Q5)*
    - Never been tested
    - Don't Know/Not Sure *(Skip to Q13)*

3. **What were the reasons you have not gotten a COVID-19 diagnostic test: Pick all that apply**

Insurance/ could not afford the test	Yes	No
Fear of the test	Yes	No
Fear of the results	Yes	No
I did not know where to get tested	Yes	No
I did not have a reason to get tested	Yes	No
I was sure I already had COVID-19 (had symptoms or was exposed)	Yes	No
CDC recommended not testing if you have mild symptoms	Yes	No
The test was not available near where I live	Yes	No
I was quarantining/socially distancing	Yes	No
I was avoiding healthcare facilities	Yes	No

Note to interviewer: Skip Q4 - Q12 if participant has never had a COVID-19 diagnostic test.

4. **What was the date of the positive diagnostic test**? MM/YYYY

5. **How many days did it take to receive your results?** _____ Days

Note to interviewer: Skip Q6 - Q12 if participant had a negative COVID-19 diagnostic test.

6. **Have you tested positive for COVID-19 via a diagnostic test more than once?**
    - Yes
    - No
    - Prefer not to answer

7. **Did you seek care after testing positive via diagnostic test?**
    - Yes

- o No *(Skip to Q12)*
- o Prefer not to answer *(Skip to Q12)*

8. **Where did you seek medical care?**
   - o Visited a primary care provider's office or another doctor's office
   - o Telephone call to a primary care provider's office or doctor's office
   - o Telemedicine such as an electronic consultation or video call with a health care provider
   - o Retail clinic or pharmacy
   - o Urgent care
   - o Emergency room
   - o Hospital, not in the emergency room
   - o Other

9. **How many days after testing positive did you first seek care?**
   - o Same day
   - o 1-2 days
   - o 3-5 days
   - o More than 5 days
   - o Don't know/ Not sure

10. **Did you spend at least one night in a hospital after testing positive?**
    - o Yes
    - o No *(Skip to Q12)*
    - o Don't know/ Not sure *(Skip to Q12)*

11. **How many nights were you hospitalized?**
    - o 1-2 nights
    - o 3-5 nights
    - o More than 5 nights
    - o Don't know/Not sure

12. **Have you received a COVID-19 antibody test in the past? An antibody test is usually a blood test.**
    - o Yes – I tested positive
    - o Yes – I tested negative *(Skip to Q14)*
    - o Never been tested *(Skip to Q16)*
    - o Don't Know/Not Sure *(Skip to Q16)*

13. **What is the date of the positive antibody test**? MM/YYYY

14. **How many days did it take to receive the results of your antibody test?** ___ days

Note to interviewer: only ask Q15 to people who tested positive for COVID-19 through diagnostic and/or antibody test.

15. **Did you experience any discrimination (such as being treated badly, harassed, threatened) from anyone because you were diagnosed with COVID-19 or had a positive antibody test?**
    - o Yes
    - o No
    - o Not Applicable
    - o Don't Know/ Not sure

16. **In the past 14 days, have you had any of the following symptoms?**

Fever or chills	Yes	No
Cough with phlegm or mucus	Yes	No
Dry cough with no phlegm or mucus	Yes	No
Shortness of breath or difficulty breathing	Yes	No
Fatigue/ Feeling tired	Yes	No
Muscle or body aches	Yes	No
Headache	Yes	No
Sudden loss of taste or smell	Yes	No
Sore throat	Yes	No
Congestion or runny nose	Yes	No
Nausea or vomiting	Yes	No
Diarrhea	Yes	No
Abdominal/ stomach pain	Yes	No

Note to interviewer: Skip to Q22 if respondent says "No" to all symptoms.

17. **Are you currently experiencing any of these symptoms?**
    - o Yes
    - o No
    - o Don't Know/ Not sure

18. **In the past 14 days prior to developing these symptoms, had you traveled within your state, outside your state, or outside the country?**
    - o No
    - o Yes, within the state
    - o Yes, outside the state
    - o Yes, outside the country

19. **While you were experiencing these symptoms, did you seek care from a healthcare professional? (seeking care includes a getting a test)**
    - o Yes
    - o No *(Skip to Q22)*
    - o Don't Know/ Not sure *(Skip to Q22)*

20. **Where did you seek medical care?**
    - o Visited a primary care provider's office or another doctor's office
    - o Telephone call to a primary care provider's office or doctor's office

- Telemedicine such as an electronic consultation or video call with a health care provider
- Retail clinic or pharmacy
- Urgent care
- Emergency room
- Hospital, not in the emergency room
- Other

21. How many days after your symptoms started did you first seek care?

- Same day
- 1-2 days
- 3-5 days
- More than 5 days
- Don't know/ Not sure

22. In the past month, have you interacted in person or through direct physical contact, such as touching, hugging, or shaking hands, with someone who recently tested positive for COVID-19?

- Yes
- No
- Don't Know/ Not sure

Note to interviewer: If participant asks, recently refers to the last 2 months.

Note to interviewer: Skip Q23 – Q24, if participant lives alone.

23. Has anyone in your household tested positive for COVID-19?

- Yes
- No
- Don't Know/ Not sure

24. In the past month, has a member of your household other than you experienced any symptoms of COVID-19?

- Yes
- No
- Don't Know/ Not sure

KNOWLEDGE, ATTITUDES, AND BEHAVIOR ABOUT COVID-19

Interviewer (read aloud): We would like to ask about your knowledge, attitudes, and behavior about COVID-19. Please answer to the best your ability.

1. On a scale of 1 to 5, 1 being never, 3 being some of the time, and 5 being all of the time, in the last 7 days, how often did you do the following actions?

	Never	Almost never	Some of the time	Most of the time	All of the time

Wear a face mask in public	1	2	3	4	5
Wash your hands with soap and water after coming home from a public place	1	2	3	4	5
See a health care provider because you felt sick	1	2	3	4	5
See a health care provider if you felt healthy but worried that you were exposed to COVID-19	1	2	3	4	5
Keep a 6 ft distance between you and others when outside your home	1	2	3	4	5
Sanitize any items coming into the house (i.e. packages, groceries)	1	2	3	4	5
Spend time in public spaces, gatherings, and crowds	1	2	3	4	5
Have physical contact with people who could be high-risk (I.e. essential workers, health care workers, elderly individuals, small children, or students who are in institutional/group setting on a daily or near daily basis)	1	2	3	4	5
Go to restaurants for in-person dining	1	2	3	4	5
Go to bars for in-person service	1	2	3	4	5
Use public transportation	1	2	3	4	5
Increase daily intake of fluid, electrolytes, and vitamins	1	2	3	4	5
Increase daily intake of herbal, holistic, or homeopathic medicine	1	2	3	4	5
Take an anti-malarial drug (hydroxychloroquine)	1	2	3	4	5
Attend indoor religious service	1	2	3	4	5

2. **Do you personally know someone who was diagnosed with COVID-19?**
   - o Yes
   - o No
   - o Don't Know/ Not Sure

- Prefer not to answer

3. **Do you personally know someone who has died in 2020?**
   - Yes
   - No *(Skip to next section)*
   - Don't Know/ Not sure *(Skip to next section)*
   - Prefer not to answer *(Skip to next section)*

4. **Did they die from COVID-19?**
   - Yes
   - No
   - Don't Know/ Not sure
   - Prefer not to answer

VIOLENCE DURING COVID-19

Note to interviewer: Skip this section for participants who are under 18 years old, over 65 years old or who have a mental or disability.
Interviewer (read loud): We would like to ask you some questions about any instances of physical violence you may have experienced in your relationship or household in the time you were engaged in social distancing, quarantining, or staying at home because of the COVID-19 pandemic. When we say partner, we mean intimate partner, boyfriend, girlfriend, or spouse, and a member of your household is someone who lives in your primary residence most of the time.

1. **Since March 2020, have you experienced an increase of physical violence such as slapping, shoving, kicking, punching, and burning from a partner or someone in your household?**
   - Yes
   - No
   - Not Applicable
   - Prefer not to answer

2. **Since March 2020, have you experienced an increase of verbal violence such as yelling and threats of physical violence, and insults, from a partner or someone in your household?**
   - Yes
   - No
   - Not Applicable
   - Prefer not to answer

3. **Since March 2020, have you experienced an increase of sexual violence such as unwanted sexual comments, advances, or coercion from a partner or someone in your household?**
   - Yes
   - No
   - Not Applicable
   - Prefer not to answer

COVID-19 IMPACT

Interviewer (read aloud): We would like to ask you about the impact COVID-19 has had on your daily life, your household, and how you feel. If no experiences apply to you, please respond with not applicable. Some of these questions may be very personal. Please be assured that your answers will remain completely confidential.

1. Did you experience any of the following because of the COVID-19 pandemic?

Financial			
Working or studying from home	Yes	No	N/A
Not working	Yes	No	N/A
Reduced work hours	Yes	No	N/A
Worrying about paying rent/mortgage	Yes	No	N/A
Personal financial loss	Yes	No	N/A
Loss of housing	Yes	No	N/A
Getting financial support from family, friends, partners, an organization, or someone else	Yes	No	N/A
Not having enough basic supplies like toilet paper, paper towels, bottled water, or soap	Yes	No	N/A
Emotional			
Worrying about friends, family, partners, etc.	Yes	No	N/A
More anxiety than usual	Yes	No	N/A
More depression than usual	Yes	No	N/A
Frustration or boredom	Yes	No	N/A
Getting emotional or social support from family, friends, partner, a counselor, or someone else	Yes	No	N/A
Loneliness	Yes	No	N/A
Feeling that you are contributing to the greater good by preventing yourself or others from getting COVID-19	Yes	No	N/A
Fear of getting COVID-19	Yes	No	N/A
Fear of giving COVID-19 to someone else	Yes	No	N/A
Confusion about what COVID-19 is, how to prevent it, or why physical distancing/isolation/quarantines are needed	Yes	No	N/A
Interpersonal			
Caring for someone at home	Yes	No	N/A
Spending more time with your family or loved ones	Yes	No	N/A
Not being able to receive visitors	Yes	No	N/A
Not being able to visit elderly or sick relatives because they were not allowed visitors	Yes	No	N/A
Other			
Switched to alternative travel methods (e.g. driving instead of flying, driving instead of public transportation, etc.)	Yes	No	N/A
Released from being incarcerated due to COVID-19 (reduce jail or prison time)	Yes	No	N/A

2. **What changes, if any, have you noticed regarding your normal sleep pattern during the COVID-19 pandemic?**
   - o I sleep a lot more
   - o I sleep more
   - o About the same
   - o I sleep less
   - o I sleep a lot less

3. **What changes, if any, have you noticed regarding your sexual activity during the COVID-19 pandemic?**
   - o A lot more sexual encounters
   - o More sexual encounters
   - o About the same
   - o Less sexual encounters
   - o A lot less sexual encounters

4. **What changes, if any, have you noticed regarding your travel habits during the COVID-19 pandemic?**
   - o I travel a lot more
   - o I travel more
   - o About the same
   - o I travel less
   - o I travel a lot less

5. **Have you had any alcoholic drinks in the last 6 months?**
   - o Yes
   - o No *(Skip to Q7)*
   - o Prefer not to answer *(Skip to Q7)*

6. **What changes, if any, have you noticed regarding your use of alcohol during the COVID-19 pandemic?**

   - o I use a lot more
   - o I use more
   - o About the same
   - o I use less
   - o I use a lot less

7. **Have you smoked or vaped tobacco (including cigarettes and e-cigarettes) in the last 6 months?**
   - o Yes
   - o No (*Skip to Q9)*
   - o Prefer not to answer *(Skip to Q9)*

8. **What changes, if any, have you noticed regarding your use of tobacco during the COVID-19 pandemic?**

   - o I use a lot more
   - o I use more
   - o About the same
   - o I use less
   - o I use a lot less

9. **Have you smoked or vaped cannabis/marijuana in the last 6 months?**
   - o Yes
   - o No *(Skip to Q10)*
   - o Prefer not to answer *(Skip to Q10)*

10. **What changes, if any, have you noticed regarding your use of cannabis/marijuana during the COVID-19 pandemic?**

    - o I use a lot more
    - o I use more
    - o About the same
    - o I use less
    - o I use a lot less

11. **Have you used opioids such as heroin, fentanyl, or painkillers in the last 6 months?**
    - o Yes
    - o No *(Skip to Q13)*
    - o Prefer not to answer *(Skip to Q13)*

12. **What changes, if any, have you noticed regarding your use of these substances during the COVID-19 pandemic?**

    - o I use a lot more
    - o I use more
    - o About the same
    - o I use less
    - o I use a lot less

13. **Have you used other substances such as cocaine, crystal meth, LSD, or steroids in the last 6 months?**
    - o Yes
    - o No *(Skip to next section)*
    - o Prefer not to answer *(Skip to next section)*

14. **What changes, if any, have you noticed regarding your use of these substances during the COVID-19 pandemic?**

    - I use a lot more
    - I use more
    - About the same
    - I use less
    - I use a lot less

WILLINGNESS TO PARTICIPATE IN COVID-19 VACCINE TRIAL

Interviewer (read aloud): Thank you for responses so far. We are now going to ask about your experience and willingness to participate in a vaccine trial and get a COVID-19 vaccine in the future.

1. **Have you ever participated in a vaccine clinical trial?**
    - Yes
    - No

2. **On a scale of 1 to 5, 1 being very unlikely, 3 being neutral, and 5 being very likely, how likely are you to enroll in a COVID-19 vaccine trial in the future?**
    1. Very Unlikely
    2. Unlikely
    3. Neutral
    4. Likely
    5. Very Likely

3. **On a scale of 1 to 5, 1 being very likely, 2 being neutral, and 5 being very likely, how are likely are you to get an approved COVID-19 vaccine in the future?**
    - Very Unlikely
    - Unlikely
    - Neutral
    - Likely
    - Very Likely

Interviewer (read aloud): Thank you for taking the time to participate in our study and to complete this questionnaire. The responses your provided are extremely valuable. Do you have any questions for me?

A.6 CoVPN 5002 sub-study questionnaire

CoVPN 5002 Participant Questionnaire – 18 Years Old and Older

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Participant ID: _____

Date of Questionnaire Administration: ___ ___ / ___ ___ / ___ ___ ___ ___

9. On a scale of 1 to 5, 1 being never, 3 being some of the time, and 5 being all of the time, before the COVID-19 pandemic, how often did you do the following actions?

	Never	Almost never	Some of the time	Most of the time	All of the time	N/A
a) Miss an appointment with a health care provider (such as for health screenings, vaccinations, regular check-up)?	1	2	3	4	5	N/A
b) Miss an appointment with your dentist?	1	2	3	4	5	N/A
c) Miss or postpone an elective procedure (such as a biopsy)?	1	2	3	4	5	N/A
d) Experience difficulties or delays in obtaining health care?	1	2	3	4	5	N/A
e) Experience difficulties or delays in obtaining prescription medications?	1	2	3	4	5	N/A
f) Go to a health care provider because you felt sick?	1	2	3	4	5	N/A
g) Seek urgent care or emergency health care services when you needed to?	1	2	3	4	5	N/A

10. If you compare how often you have utilized health care services during the COVID-19 pandemic vs. before the pandemic, how would you describe the change in utilization? This would include use of preventive services, routine care, emergency services, dental care, etc.

a. My use of health care services has **not changed at all** during the COVID-19 pandemic (e.g., I have gone to all of my scheduled appointments and have not postponed care)
b. My use of health care services has **somewhat changed** during the COVID-19 pandemic (e.g., Some of my appointments have been cancelled or postponed)
c. My use of health care services **has changed substantially** during the COVID-19 pandemic (e.g., I have not used health care services at all during the pandemic)

11. Since the COVID-19 pandemic (March 1, 2020), did you need to see a health care provider for a routine follow-up visit or a new health or mental health concern that was not related to COVID-19?

a. Yes

b. No
c. Don't know

12. Since the COVID-19 pandemic, (March 1, 2020), have you experienced any difficulties or delays in obtaining health care as a result of COVID-19?

a. Yes
b. No
c. Don't know
d. Not applicable

13. Since the COVID-19 pandemic, did you have an appointment with a health care provider by phone or video?

a. Yes
b. No
c. Don't know

14. Since the COVID-19 pandemic (March 1, 2020), did you need to go to the emergency room/hospital for a condition that was not related to COVID-19?

a. Yes
b. No (*Skip to Q8*)
c. Don't know *(Skip to Q8*)

15. Did you go to the emergency room/hospital when you needed to?

a. Yes
b. No
c. Don't know

16. Since the COVID-19 pandemic (March 1, 2020), did you need to have a major medical or dental procedure such as a surgery?

a. Yes
b. No *(skip to Q11)*
c. Don't know *(skip to Q11)*

17. Did you postpone this medical or dental procedure because of COVID-19?

a. Yes
b. No *(skip to Q11)*
c. Don't know *(skip to Q11)*

18. Have you now had this medical or dental procedure?

a. Yes
b. No
c. Don't know

19. At any time since March 1, 2020, have you experienced a change in your health insurance coverage?

a. No
b. Yes, loss of health insurance
c. Yes, gaining insurance as part of emergency coverage/Medicaid expansion
d. Experienced both loss and gaining of new health insurance
e. Don't know/unsure

Interviewer (read aloud): Thank you for taking the time to complete this survey. We are looking to conduct additional interviews with those participants who reported interruptions or changes in health service utilization during the pandemic. This would involve a 30-minute interview with a study team member. If you are selected, this interview would occur over the telephone. Would you be interested in participating?

a) Yes
b) No
c) Not applicable

A.7 Variable codebook

Variable Name	Variable Type	Variable Description	Variable Coding
Participant Information			
parent_ID	numeric	parent study ID code	CoVPN 5002: 9-digit number CF: 1-5 digit number
substudy_ID	numeric	sub-study ID code	1-4 digit number
study	binary	indicates what study data came from	1=CoVPN 5002 2=CF
subsurvey_yn	categorical	indicates whether they took the CoVPN sub-study	0=no 1=yes 99=N/A
survey_date_2	date	date of survey completion	mm/dd/yy
person_days	numeric	person-days since start of the pandemic (3/1/20)	3-4 digit number
person_years	numeric	person-years since start of pandemic (3/1/20)	3-digit number (2 decimal places)
csa_id	numeric	assigned Baltimore community statistical area (CSA)	2-digit number
Demographic Information			
age_cat	ordinal	age category of participant	1=18-34 years 2=35-49 years 3=50-64 years 4=≥65 years
age	continuous	age of participant	2-digit number
sex	binary	sex at birth of participant	0=male 1=female
race_cat	categorical	race of participant	1=White 2=Black/African American 3=Other 97=unknown
afram_yn	binary	race of participant	0=no (not African American/Black) 1=yes (African American/Black)
married_yn	binary	relationship status (married or partnered)	0=no 1=yes
employed_yn	binary	employment status (full or part-time)	0=no 1=yes
disabled_yn	binary	disability status	0=no 1=yes
edulvl_cat	binary	highest education level achieved	0= high school or less 1=some college or more
income_cat3	ordinal	income level (3 categories)	1=<$25,000 2=$25,000-$49,999 3=$50,000 and above
income_cat2	binary	income level (2 categories)	0= <$25,000 1=≥$25,000
lost_house	binary	participant reported loss of housing during COVID-19	0=no 1=yes

worry_rent	binary	participant reported worrying about paying rent/mortgage during COVID-19	0=no 1=yes
funct_limit	binary	participant report of functional limitations (includes physical, mental or emotional disability)	0=no 1=yes
mental_illness	binary	participant reported presence of mental health condition (includes depression, other mental health disorder)	0=no 1=yes
substance_abuse	binary	participant reported presence of substance abuse disorder (includes alcohol or substance use disorder, injection drug use)	0=no 1=yes
comorbid_num	ordinal	number of comorbidities reported (included: cancer, diabetes, renal disease, sickle cell disease, respiratory disease, cardiac disease, immune disease, other)	0=none 1=one condition 2=two +
Healthcare Needs and Forgone Care			
need_anycare	binary	participant report of needing any care (routine, emergent, dental/surgical)	0=no 1=yes
forgo_anycare	binary	reported forgoing any care	0=no 1=yes 97=unknown
need_routine	binary	participant report of needing routine care	0=no 1=yes
forgo_routine	binary	reported forgoing routine care	0=no 1=yes 97=unknown
need_emergent	binary	participant report of needing emergent care	0=no 1=yes
forgo_emergent	binary	reported forgoing emergent care	0=no 1=yes 97=unknown
need_elective	binary	participant report of needing elective care (e.g., surgical or dental procedure)	0=no 1=yes
forgo_elective	binary	reported forgoing elective care (e.g., surgical or dental procedure)	0=no 1=yes 97=unknown
elective_postponed	binary	report of continued forgone elective care (e.g., the participant still had not had the procedure at time of survey completion)	0=no 1=yes 97=unknown
Community-Level Variables			
crime_rate	binary	crime rate per 1,000 residents	0=low crime (<50 crimes per 1,000) 1=high crime (≥50 crimes per 1,000)
no_internet	binary	percent of households with no internet	0=good access (<20% of HH don't have internet) 1=poor access (≥20% of HH don't have internet)
rely_transport	binary	percent of population that uses public transport to get to work	0=low reliance on public transport (<20% of population uses public transport for work) 1=high reliance on public transport (≥20% of population uses public transport for work)

walk_score	binary	walk score	0=low to medium walkability (score of 0-69) 1=better walkability (score 70+)
percent_black	binary	percent of population that is Black/African American	0=majority other race (<50% Black) 1=majority Black/AA (≥50% Black)
percent_hispanic	binary	percentage of population that is Hispanic	0=low Hispanic (<10% Hispanic) 1=higher Hispanic (≥10%Hispanic)
life_exp	binary	population life expectancy	0=lower life expectancy (<76.8 years) 1=higher life expectancy (≥76.8 years)
afford_rent	binary	The percentage of households that pay more than 30% of their total household income on rent and related expenses out of all households in an area.	0=better affordability (<50% of HH pay 30% of income on rent) 1=lower affordability (≥50% of HH pay 30% of income on rent)
hs_complete	binary	The percentage of 12th graders in a school year that successfully completed high school out of all 12th graders within an area	0=low completion (<80% of 12th graders graduate) 1=high completion (≥80% of 12th graders graduate)
hh_poverty	binary	the percentage of households whose income fell below the poverty threshold out of all households in an area	0=low poverty (<20% HH live in poverty) 1=high poverty (≥20% HH live in poverty)
unemployed	binary	The percent of persons who are not in the labor force out of all persons between the ages of 16 and 64 in the area.	0=low unemployment (<30% of population not employed) 1=high unemployment (≥30% of population not employed)
Other Variables			
delta	binary	Captures whether the participant experienced the delta wave	0=enrolled before August 1, 2021 1=enrolled on or after August 1, 2021
omicron	binary	Captures whether the participant experienced the omicron wave	0=enrolled before December 1, 2021 1=enrolled on or after December 1, 2021
missing_anyvariable	binary	calculates how many participants are missing at least one of the study variables	0=none 1=at least one
missing_impute	binary	calculates how many participants are missing at least one of the variables to be imputed	0=none 1=at least one
gender	categorical	gender of participant	0=male 1=female 2=other (including: gender NC, TGF, TGM, non-binary, other) 97= unknown, PNA
sexorient	categorical	sexual orientation of participant	1=straight 2=gay/lesbian 3=bisexual 97=unknown

race	categorical	race of participant	1=White 2=Black/African American 3=Asian 4=American Indian or Native Alaskan 5=Native Hawaiian or Pacific Islander 6=more than one race 97=unknown
ethnicity	binary	ethnicity of participant	1=Hispanic 2=not Hispanic
edulvl	ordinal	highest education level achieved	1=high school or less 2=some college 3=college degree or higher 97=unknown
income1	ordinal	income level (multiple categories)	1=<15,000 2=15,000-24,999 3=25,000-34,999 4=35,000-49,999 5=50,000-74,999 6=75,000-99,999 7=100,000 and above 8=don't know 97=unknown 98=PNA
income_cat4	ordinal	income level (4 categories)	1=<25,000 2=25,000-49,999 3=50,000-99,999 4=100,000 and above
comorbid_number	ordinal	number of comorbidities reported	0=none 1=one condition 2=two conditions 3=three+ conditions
_mi_miss	binary	marks the observations in the original dataset that have missing values.	0=no missing values 1=missing value
_mi_m	categorical	indicates the imputation number.	0=original dataset 1=imputation dataset 1 2= imputation dataset 2 3= imputation dataset 3 4= imputation dataset 4 5= imputation dataset 5
_mi_id	numeric	indicator for the observations in the original dataset and is repeated across imputed dataset to mark the imputed observations.	N/A

CF: C-Forward; HH: household; AA: African American; NC: non-conforming; TGM: transgender male; TGF: transgender female; PNA: prefer not to answer

A.8 Stata Code

Variable Generation

```
generate delta = 0 if person_years < 1.42
replace delta = 1 if person_years >=1.42
tab delta

generate omicron = 0 if person_years < 1.75
replace omicron = 1 if person_years >=1.75
tab omicron

generate age_cat = 1 if age<=34
repace age_cat =2 if age>34 & age<=49
replace age_cat =2 if age>34 & age<=49
replace age_cat = 3 if age>49 & age<=64
replace age_cat = 4 if age>=65
tab age_cat
```

Missing Data Exploration and Imputation

```
generate missing_impute = 1 if sex == . | afram_yn == . | married_yn == . |
employed_yn == . | disabled_yn == . | edulvl_cat == . | income_mi == . | lost_house ==
. | worry_rent == . | funct_limit == . | mental_illness == . | substance_abuse == .
[Creates a new variable (missing_impute) that calculates how many of the 2,003
participants are missing at least one of the variables that will be imputed ]

replace missing_impute = 0 if missing_impute == .

mdesc
[this describes the amount of missing data per variable]

mvdecode age sex gender sexorient afram_yn ethnicity married_yn employed_yn
disabled_yn edulvl lost_house worry_rent funct_limit mental_illness substance_abuse
comorbid_number edulvl_cat age_cat race race_cat income1 income_cat2, mv(97)
[this recodes "97" as missing]

egen missing=rmiss(sex race_cat ethnicity married_yn employed_yn disabled_yn
edulvl_cat income_cat2 lost_house worry_rent funct_limit mental_illness
substance_abuse)
[this generates a new variable that defines how many missing variables there are per
person]

mvpatterns
[shows patterns of missing data]

misstable summarize, all
[provides the number of missing observations per variables]

generate missing_anyvariable = 1 if missing == 1 | missing == 2 | missing == 3 |
missing == 4 | missing == 5 | missing == 6
replace missing_anyvariable = 0 if missing == 0
tab missing_anyvariable
[creates a new variable that displays whether or not each participant is missing any
amount of data]

mi set mlong

mi register imputed sex afram_yn married_yn employed_yn disabled_yn edulvl_cat
income_cat2 lost_house worry_rent funct_limit mental_illness substance_abuse
(550 m=0 obs. now marked as incomplete)
```

```
mi impute chained (logit, include(age comorbid_num forgo_anycare sex afram_yn
married_yn employed_yn disabled_yn edulvl_cat income_cat2 lost_house worry_rent
funct_limit mental_illness substance_abuse study) noimputed augment) sex afram_yn
married_yn employed_yn disabled_yn edulvl_cat income_cat2 lost_house worry_rent
funct_limit mental_illness substance_abuse, add(5)
```

Summary Statistics for Sample Demographics

```
tab age_cat if _mi_m == 0, mi
tab sex if _mi_m == 0, mi
tab race_cat if _mi_m == 0, mi
tab afram_yn if _mi_m == 0, mi
tab married_yn if _mi_m == 0, mi
tab employed_yn if _mi_m == 0, mi
tab disabled_yn if _mi_m == 0, mi
tab edulvl_cat if _mi_m == 0, mi
tab income_cat3 if _mi_m == 0, mi
tab income_cat2 if _mi_m == 0, mi
tab income_cat4 if _mi_m == 0, mi
tab lost_house if _mi_m == 0, mi
tab worry_rent if _mi_m == 0, mi
tab funct_limit if _mi_m == 0, mi
tab mental_illness if _mi_m == 0, mi
tab substance_abuse if _mi_m == 0, mi
tab comorbid_num if _mi_m == 0, mi
sum age if _mi_m == 0
total person_years if _mi_m == 0
sum person_years if _mi_m == 0
tab csa_id if _mi_m == 0, mi
sum csa_id if _mi_m == 0
total person_years if _mi_m == 0
total csa_id if _mi_m == 0
```

Individual level correlates (any type of forgone care)

```
mi estimate : logistic forgo_anycare sex [iweight = person_years]
mi estimate : logistic forgo_anycare i.age_cat [iweight = person_years]
mi estimate : logistic forgo_anycare age [iweight = person_years]
mi estimate : logistic forgo_anycare afram_yn [iweight = person_years]
mi estimate : logistic forgo_anycare married_yn [iweight = person_years]
mi estimate : logistic forgo_anycare employed_yn [iweight = person_years]
mi estimate : logistic forgo_anycare disabled_yn [iweight = person_years]
mi estimate : logistic forgo_anycare edulvl_cat [iweight = person_years]
mi estimate : logistic forgo_anycare income_cat2 [iweight = person_years]
mi estimate : logistic forgo_anycare lost_house [iweight = person_years]
mi estimate : logistic forgo_anycare worry_rent [iweight = person_years]
mi estimate : logistic forgo_anycare funct_limit [iweight = person_years]
mi estimate : logistic forgo_anycare mental_illness [iweight = person_years]
mi estimate : logistic forgo_anycare substance_abuse [iweight = person_years]
mi estimate : logistic forgo_anycare comorbid_num [iweight = person_years]
mi estimate : logistic forgo_anycare i.comorbid_num [iweight = person_years]
```

Final Base Model (any type of forgone care)

```
mi estimate : logistic forgo_anycare study delta omicron i.age_cat sex afram_yn
disabled_yn lost_house worry_rent funct_limit mental_illness substance_abuse
i.comorbid_num [iweight = person_years]
```

Community level correlates (any type of forgone care)

```
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
crime_rate [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
no_internet [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
rely_transport [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
walk_score [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
percent_black [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
percent_hispanic [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron life_exp
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
afford_rent [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
hs_complete [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
hh_poverty [iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn lost_house worry_rent
funct_limit mental_illness substance_abuse i.comorbid_num study delta omicron
unemployed [iweight = person_years] || csa_id:
```

Individual level correlates (surgical/dental procedure)

```
tab age_cat if forgo_elective == 0, mi
tab sex if forgo_elective == 0, mi
tab race_cat if forgo_elective == 0, mi
tab afram_yn if forgo_elective == 0, mi
tab married_yn if forgo_elective == 0, mi
tab employed_yn if forgo_elective == 0, mi
tab disabled_yn if forgo_elective == 0, mi
tab edulvl_cat if forgo_elective == 0, mi
tab income_cat3 if forgo_elective == 0, mi
tab income_cat2 if forgo_elective == 0, mi
tab income_cat4 if forgo_elective == 0, mi
tab lost_house if forgo_elective == 0, mi
tab worry_rent if forgo_elective == 0, mi
tab funct_limit if forgo_elective == 0, mi
tab mental_illness if forgo_elective == 0, mi
tab substance_abuse if forgo_elective == 0, mi
tab comorbid_num if forgo_elective == 0, mi
tab gender if forgo_elective == 0, mi
tab ethnicity if forgo_elective == 0, mi

mi estimate : logistic forgo_elective sex [iweight = person_years]
mi estimate : logistic forgo_elective i.age_cat [iweight = person_years]
mi estimate : logistic forgo_elective age [iweight = person_years]
mi estimate : logistic forgo_elective afram_yn [iweight = person_years]
mi estimate : logistic forgo_elective married_yn [iweight = person_years]
mi estimate : logistic forgo_elective employed_yn [iweight = person_years]
```

```
mi estimate : logistic forgo_elective disabled_yn [iweight = person_years]
mi estimate : logistic forgo_elective edulvl_cat [iweight = person_years]
mi estimate : logistic forgo_elective income_cat2 [iweight = person_years]
mi estimate : logistic forgo_elective lost_house [iweight = person_years]
mi estimate : logistic forgo_elective worry_rent [iweight = person_years]
mi estimate : logistic forgo_elective funct_limit [iweight = person_years]
mi estimate : logistic forgo_elective mental_illness [iweight = person_years]
mi estimate : logistic forgo_elective substance_abuse [iweight = person_years]
mi estimate : logistic forgo_elective comorbid_num [iweight = person_years]
mi estimate : logistic forgo_elective i.comorbid_num [iweight = person_years]

mi estimate : logistic forgo_elective study delta omicron sex income_cat2 lost_house
worry_rent funct_limit mental_illness i.comorbid_num [iweight = person_years]
```

Individual level correlates (emergent care)

```
tab age_cat if forgo_emergent == 0, mi
tab sex if forgo_emergent == 0, mi
tab race_cat if forgo_emergent == 0, mi
tab afram_yn if forgo_emergent == 0, mi
tab married_yn if forgo_emergent == 0, mi
tab employed_yn if forgo_emergent == 0, mi
tab disabled_yn if forgo_emergent == 0, mi
tab edulvl_cat if forgo_emergent == 0, mi
tab income_cat3 if forgo_emergent == 0, mi
tab income_cat2 if forgo_emergent == 0, mi
tab income_cat4 if forgo_emergent == 0, mi
tab lost_house if forgo_emergent == 0, mi
tab worry_rent if forgo_emergent == 0, mi
tab funct_limit if forgo_emergent == 0, mi
tab mental_illness if forgo_emergent == 0, mi
tab substance_abuse if forgo_emergent == 0, mi
tab comorbid_num if forgo_emergent == 0, mi
tab gender if forgo_emergent == 0, mi
tab ethnicity if forgo_emergent == 0, mi

mi estimate : logistic forgo_emergent sex [iweight = person_years]
mi estimate : logistic forgo_emergent i.age_cat [iweight = person_years]
mi estimate : logistic forgo_emergent age [iweight = person_years]
mi estimate : logistic forgo_emergent afram_yn [iweight = person_years]
mi estimate : logistic forgo_emergent married_yn [iweight = person_years]
mi estimate : logistic forgo_emergent employed_yn [iweight = person_years]
mi estimate : logistic forgo_emergent disabled_yn [iweight = person_years]
mi estimate : logistic forgo_emergent edulvl_cat [iweight = person_years]
mi estimate : logistic forgo_emergent income_cat2 [iweight = person_years]
mi estimate : logistic forgo_emergent lost_house [iweight = person_years]
mi estimate : logistic forgo_emergent worry_rent [iweight = person_years]
mi estimate : logistic forgo_emergent funct_limit [iweight = person_years]
mi estimate : logistic forgo_emergent mental_illness [iweight = person_years]
mi estimate : logistic forgo_emergent substance_abuse [iweight = person_years]
mi estimate : logistic forgo_emergent comorbid_num [iweight = person_years]
mi estimate : logistic forgo_emergent i.comorbid_num [iweight = person_years]

mi estimate : logistic forgo_emergent study delta omicron sex afram_yn lost_house
i.comorbid_num [iweight = person_years]
```

Sensitivity Analysis

```
Create a new variable that displays whether or not each participant is missing any
amount of data

egen missing=rmiss(sex afram_yn married_yn employed_yn disabled_yn edulvl_cat
income_cat2 lost_house worry_rent funct_limit mental_illness substance_abuse)
```

```
generate missing_anyvariable = 1 if missing == 1 | missing == 2 | missing == 3 |
missing == 4 | missing == 5 | missing == 6
replace missing_anyvariable = 0 if missing == 0
tab missing_anyvariable

Drop those participants missing data (n=550)
drop if missing_anyvariable == 1


Build Level One Model
logistic forgo_anycare sex [iweight = person_years]
logistic forgo_anycare i.age_cat [iweight = person_years]
logistic forgo_anycare age [iweight = person_years]
logistic forgo_anycare afram_yn [iweight = person_years]
logistic forgo_anycare married_yn [iweight = person_years]
logistic forgo_anycare employed_yn [iweight = person_years]
logistic forgo_anycare disabled_yn [iweight = person_years]
logistic forgo_anycare edulvl_cat [iweight = person_years]
logistic forgo_anycare income_cat2 [iweight = person_years]
logistic forgo_anycare lost_house [iweight = person_years]
logistic forgo_anycare worry_rent [iweight = person_years]
logistic forgo_anycare funct_limit [iweight = person_years]
logistic forgo_anycare mental_illness [iweight = person_years]
logistic forgo_anycare substance_abuse [iweight = person_years]
logistic forgo_anycare comorbid_num [iweight = person_years]
logistic forgo_anycare i.comorbid_num [iweight = person_years]

Final level one base model:
logistic forgo_anycare study delta omicron i.age_cat sex disabled_yn lost_house
worry_rent funct_limit mental_illness substance_abuse i.comorbid_num [iweight =
person_years]

Level two model building:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron crime_rate [iweight
= person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron no_internet [iweight
= person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron rely_transport
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron walk_score [iweight
= person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron percent_black
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron percent_hispanic
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron life_exp [iweight =
person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron afford_rent [iweight
= person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron hs_complete [iweight
= person_years] || csa_id:
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron hh_poverty [iweight
= person_years] || csa_id:
```

```
melogit forgo_anycare i.age_cat sex disabled_yn lost_house worry_rent funct_limit
mental_illness substance_abuse i.comorbid_num study delta omicron unemployed [iweight
= person_years] || csa_id:
```

Sensitivity Analysis Using Only C-Forward Dataset

```
Level One Model
mi estimate : logistic forgo_anycare sex [iweight = person_years]
mi estimate : logistic forgo_anycare i.age_cat [iweight = person_years]
mi estimate : logistic forgo_anycare age [iweight = person_years]
mi estimate : logistic forgo_anycare afram_yn [iweight = person_years]
mi estimate : logistic forgo_anycare married_yn [iweight = person_years]
mi estimate : logistic forgo_anycare employed_yn [iweight = person_years]
mi estimate : logistic forgo_anycare disabled_yn [iweight = person_years]
mi estimate : logistic forgo_anycare edulvl_cat [iweight = person_years]
mi estimate : logistic forgo_anycare income_cat2 [iweight = person_years]
mi estimate : logistic forgo_anycare lost_house [iweight = person_years]
mi estimate : logistic forgo_anycare worry_rent [iweight = person_years]
mi estimate : logistic forgo_anycare funct_limit [iweight = person_years]
mi estimate : logistic forgo_anycare mental_illness [iweight = person_years]
mi estimate : logistic forgo_anycare substance_abuse [iweight = person_years]
mi estimate : logistic forgo_anycare comorbid_num [iweight = person_years]
mi estimate : logistic forgo_anycare i.comorbid_num [iweight = person_years]

Final Level One Model
mi estimate : logistic forgo_anycare delta omicron i.age_cat sex afram_yn disabled_yn
edulvl_cat lost_house worry_rent funct_limit mental_illness substance_abuse [iweight =
person_years]


Level Two Model (run these for each of the 5 imputed datasets)

melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron crime_rate
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron no_internet
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron rely_transport
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron walk_score
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron percent_black
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron percent_hispanic
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron life_exp [iweight
= person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron afford_rent
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron hs_complete
[iweight = person_years] || csa_id:
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron hh_poverty
[iweight = person_years] || csa_id:
```

```
melogit forgo_anycare i.age_cat sex afram_yn disabled_yn edulvl_cat lost_house
worry_rent funct_limit mental_illness substance_abuse delta omicron unemployed
[iweight = person_years] || csa_id:
```

CURRICULUM VITAE

CURRICULUM VITAE
(DIANE MEYER, RN, MPH, PhD-candidate)

PROFESSIONAL DATA

700 East Pratt Street, Suite 900 Baltimore MD 21202
dmeyer10@jhmi.edu
She, her, hers

EDUCATION AND TRAINING

PhD/2023 (Anticipated) Johns Hopkins University Nursing
Master of Public Health/2016 Johns Hopkins University Infectious Diseases
Bachelor of Science/2011 Georgetown University Nursing
Bachelor of Arts/2010 Carroll College Biology
2016 Johns Hopkins University Certificate in Public Health Preparedness
2015 Maryland Registered Nurse Licensure
2012 District of Columbia Registered Nurse Licensure

PROFESSIONAL EXPERIENCE

Johns Hopkins University

Research Associate/Associate Scholar, Department of Environmental Health and Engineering, Johns Hopkins Bloomberg School of Public Health, August 2022-present

- *Co-Principal Investigator on project looking at improving the availability of training and educational materials for nurses interested in pandemic and disaster nursing*
- *Co-Principal Investigator on project assessing health system capacities for Kitsap Public Health District (WA)*
- *Responsible for growing the Center's nursing workforce project portfolio*
- *Co-Investigator on two projects related to improving national preparedness for pandemics (Next Generation Masks, Building Resilience in Critical Infrastructure)*

Research Associate/Senior Analyst, Department of Environmental Health and Engineering, Johns Hopkins Bloomberg School of Public Health, May 2018-August 2022

- *Project manager for four separate projects that focused on global health security and health systems strengthening. Managerial responsibilities include completing institutional review board (IRB) packages, tracking deadlines, acting as the main point-of-contact for the research team, organizing data collection and analysis, organizing meetings, leading manuscript and report writing, and presenting results at conferences.*

Research Associate/Senior Managing Analyst, Department of Environmental Health and Engineering, Johns Hopkins Bloomberg School of Public Health, June 2019-September 2021

- *Managing Senior Analyst responsibilities included coordinating a team of 10 Analyst's workloads and responsibilities, coordinating with leadership and senior staff to ensure that Analysts are fulfilling all roles and responsibilities adequately, and providing guidance and mentorship to Analysts on project-related challenges.*

Research Associate/Analyst, Department of Environmental Health and Engineering, Johns Hopkins Bloomberg School of Public Health, January 2017-May 2018

Research Assistant, Department of Infectious Diseases, Johns Hopkins School of Medicine, December 2015-May 2016

UPMC Center for Health Security
Research Assistant, University of Pittsburgh Medical Center, May 2016-January 2017

Medstar Washington Hospital Center
Registered Nurse, February 2012-June 2015
- *Took care of critically ill patients who had sustained severe burns, traumatic injuries, or were in the critical post-operative period at a Level I trauma center in Washington, DC.*

PROFESSIONAL ACTIVITIES
Member, Global Health Security Network (2020-present)
Sigma Theta Tau International Honor Society of Nursing, Tau Chapter (2011-present)
Intensive Care Unit Infection Control Committee, Medstar Washington Hospital Center (2014-2015)

EDITORIAL AND OTHER PEER REVIEW ACTIVITIES [include past and present with dates of affiliation, list most current first]
Associate Editor, Health Security
Editor, National Association of County and City Health Officials (NACCHO) special issue in journal Health Security on Improving Public Health Communication in Response to Large-Scale Health Threats (published in 2023)
Editor, National Emerging Special Pathogens Training and Education Center (NETEC) special issue in journal Health Security on lessons learned during the COVID-19 pandemic (published in 2022)
Editor, CDC Special Issue in journal Health Security: "What Works? Lessons Learned in Global Health Security Implementation" (2019)
Peer reviewer: BMC Public Health, Health Security, American Journal of Public Health, AIDS and Behavior

HONORS AND AWARDS
Nurse Faculty Loan Program, Health Resource and Services Administration (2020-2021)
Johns Hopkins University School of Nursing Merit Scholarship (2020, 2021, 2022)
Georgetown University Scholar at Washington Hospital Center (2010-2015)
Presidential Scholarship, Carroll College (2006-2010)

PUBLICATIONS
Journal Articles
1. Adalja A, McQuillen D, & **Meyer D**. How Infectious Diseases Experts Impacted the COVID-19 Response: Lessons from the Front Lines. *Clinical Infectious Diseases*. Accepted 1 March, 2023.

2. **Meyer D**, Guillaume D, Adalja A. Mpox Considerations for the Radiology Nurse. *Radiology Nursing*. Accepted 1 March, 2023.

3. Heidari O, O'Conor KJ, **Meyer D**, Cargill V, Lowensen K, Farley JE. High Primary COVID-19 Vaccine Series Completion by People Who Inject Drugs When Colocating Services at a Syringe Services Van [published online ahead of print, 2023 Mar 10]. J Addict Med. 2023;10.1097/ADM.0000000000001164. doi:10.1097/ADM.0000000000001164

4. McKneely JAB, **Meyer D**, Veenema TG, & Sell TK. (2022). In-home healthcare worker COVID-19 vaccination awareness, access, and acceptability—An online focus group study. *Journal of the American Geriatrics Society*. 1-5. doi: 10.1111/jgs.18183

5. Guillaume D, **Meyer D**, Waheed DE, Schlieff M, Muralidharan K, Chou VB, & Limaye R. (2022). Factors influencing the prioritization of vaccines by policymakers in low and middle income countries: A scoping review. *Health Policy Plan*. doi:10.1093/heapol/czac092

6. **Meyer D**, Slone SE, Ogungbe O, Duroseau B, Farley JE. (2022). Impact of the COVID-19 pandemic on HIV healthcare service engagement, treatment adherence, and viral suppression in the United States: A Systematic Literature Review. *AIDS Behav*. 1-14. doi:10.1007/s10461-022-03771-w

7. Veenema TG, **Meyer D**[2], Rushton CH, et al. (2022). The COVID-19 nursing workforce crisis: Implications for national health security. *Health Secur*. 20(3), 264-269. doi:10.1089/hs.2022.0022

8. Ogungbe O, Kumbe B, Fadodun O, Latha T, **Meyer D**, Asala A, Davidson PM, Dennison Himmelfarb CR, Post WS, Commodore-Mensah Y. (2021). Subclinical myocardial injury, fibrosis, coagulopathy, and inflammation in COVID-19: A meta-analysis of 41,013 hospitalized patients. J Vasc Surg. 40 (2022). https://doi.org/10.1016/j.ijcha.2021.100950

9. Heidari, O., **Meyer, D**., O'Conor, K.J., Vargill, V., Patch, M., & Farley, J. (2022). COVID-19 vaccination and communicable disease testing services integration within a syringe services program. A program brief. *Journal of the Association of Nurses in AIDS Care*. Accepted December 2021.

10. **Meyer, D**., Martin, E., Madad, S., Dhagat, P., & Nuzzo, J. (2021). Preparedness and response to an emerging health threat—Lessons learned from Candida auris outbreaks in the United States. *Infection Control & Hospital Epidemiology,* 1-6. doi:10.1017/ice.2021.12

11. **Meyer, D**., Trotochaud, M., Ferguson, L., Vines, J., Barlow, R., & Nuzzo, J.B. (2020). A US Metropolitan County Health Department's Response to a Measles Outbreak in a Childcare Facility—Challenges Faced and Lessons Learned. *Perspectives in Public Health.* https://pubmed.ncbi.nlm.nih.gov/33200687/

12. Ravi, S. J., Warmbrod, K. L., Mullen, L., **Meyer, D**., Cameron, E., Bell, J., Bapat, P., Paterra, M., Machalaba, C., Nath, I., Gostin, L. O., James, W., George, D., Nikkari, S., Gozzer, E., Tomori, O., Makumbi, I., & Nuzzo, J. B. (2020). The value proposition of the Global Health Security Index. *BMJ Global Health*, *5*(10), e003648. https://doi.org/10.1136/bmjgh-2020-003648

13. Shearer, M.P., **Meyer, D**., Hosangadi, D., Snyder, M.R., Trotochaud, M., Madad, S. & Nuzzo, J.B. (2020). Operational Stresses on New York City Health+Hospitals Health System Frontline Hospitals During the 2017-18 Influenza Season. *Journal of Emergency Management,* 18(3), 191-203. https://pubmed.ncbi.nlm.nih.gov/32441036/

14. **Meyer, D**., Bishai, D., Ravi, S.J., Rashid, H., Mahmood, S.S., Toner, E., & Nuzzo, J.B. (2020). A Checklist to Improve Health System Resilience to Infectious Disease Outbreaks and Natural Hazards. *BMJ Global Health*, 5(8). https://pubmed.ncbi.nlm.nih.gov/32759184/

[2] Denotes shared first authorship

15. Shearer, M. P., Meyer, D., Hosangadi, D., Snyder, M. R., Trotochaud, M., Madad, S., & Nuzzo, J. B. (2020). Operational stresses on New York City Health+Hospitals Health System frontline hospitals during the 2017-18 influenza season. *Journal of emergency management (Weston, Mass.)*, *18*(3), 191–203. https://doi.org/10.5055/jem.2020.0465

16. Kirk Sell, T., Watson, C., **Meyer, D**., Snyder, M.R., Ravi, S., McGinty, E.E., Pechta, L.E., Lubell, K.M., Podgornik, M.N. & Rose, D.A. (2020). Zika Inquiries Made to the CDC-INFO System, December 2015-Septemeber 2017. ***Emerging Infectious Diseases***. 26(5), 1022-1024. https://www.ncbi.nlm.nih.gov/pubmed/32310059

17. Kirk Sell, T., Shearer, M.P., **Meyer, D**., Thomas, E., & Carbone, E.G. (2020). Public Health Implementation Considerations for State-level Ebola Monitoring and Movement Restrictions. ***Disaster Medicine and Public Health Preparedness***. Epub ahead of print. https://www.ncbi.nlm.nih.gov/pubmed/32308182

18. Sell, T.K., Ravi, S.J., Watson, C., **Meyer, D**., Pechta L.E., Rose, D.A., Lubell, K.M., Podgornik, M.N. & Shoch-Spana, M. (2020). A Public Health Systems View of Risk Communication About Zika. ***Public Health Reports***. Epub ahead of print. https://www.ncbi.nlm.nih.gov/pubmed/32243762

19. Schoch-Spana, M., Watson, C., Ravi, S., **Meyer, D**., Pechta, L.E., Rose, D.A., Lubell, K.M., Podgornik, M.N. & Sell, T.K. (2020). Vector Control in Zika-affected Communities: Local Views on Community Engagement and Public Health Ethics during Outbreaks. ***Preventive Medicine Reports***, eCollection https://www.sciencedirect.com/science/article/pii/S221133552030019X?via%3Dihub

20. **Meyer, D**., Cameron, E.E., Bell, J. & Nuzzo, J.B. (2020). The Road to Achieving Global Health Security: Accelerating Progress and Spurring Urgency to Fill Remaining Gaps. ***Health Security,*** 18(S1), S1-S3. https://www.liebertpub.com/doi/10.1089/hs.2019.0147

21. Nuzzo, J.B., **Meyer, D**., Snyder, M., Ravi, S.J., Lapascu, A., Souleles, J., Andrada, C.I., & Bishai, D. (2019). What Makes Health Systems Resilient Against Infectious Disease Outbreaks and Natural Hazards? Results from a Scoping Review. ***BMC Public Health,*** 19(1). https://www.ncbi.nlm.nih.gov/pubmed/31623594

22. Watson, C., Toner, E.S., Shearer, M.P., Rivers, C., **Meyer, D**., Hurtado, C., Waton, M., Gronvall, G.K., Adalja, A.A., Sell, T.K., Inglesby, T. & Cicero, A. (2019). Clade X: A Pandemic Exercise. ***Health Security,*** 17(5), 410-417. https://www.ncbi.nlm.nih.gov/pubmed/31593508

23. Sell, T.K., Shearer, M.P., **Meyer, D.**, Leinhos, M., Carbone, E.G. & Thomas, E. (2019). Influencing Factors in the Development of State-Level Movement Restriction and Monitoring Policies in Response to Ebola, United States, 2014-15. ***Health Security,*** 17(5), 364-371. https://www.ncbi.nlm.nih.gov/pubmed/31593507
    a. Finalist, US CDC Center for Preparedness and Response publication award (subcategory of Interventions and Prevention Effectiveness)

24. Koeller, S., **Meyer, D.**, Shearer, M.P., Hosangadi, D., Snyder, M. & Nuzzo, J.B. (2019). Responding to a Mumps Outbreak Impacting Immigrants and Low-English Proficiency Populations. ***Journal of Public Health Management and Practice.*** https://www.ncbi.nlm.nih.gov/pubmed/31592985

25. Snyder, M.R., McGinty, M.D., Shearer, M.P., **Meyer, D.**, Hurtado, C. & Nuzzo. J.B. (2019). Outbreaks of Hepatitis A in US Communities, 2017-2018. Firsthand Experiences and Operational Lessons from Public Health Responses. *American Journal of Public Health,* 109(S4), S297-S302. https://www.ncbi.nlm.nih.gov/pubmed/31505154

26. Ravi, S.J., **Meyer, D.**, Cameron, E., Nalabandian, M., Pervaiz, B. & Nuzzo, J.B. (2019). Establishing a theoretical foundation for measuring global health security: a scoping review. *BMC Public Health,* 10(1), 954. https://www.ncbi.nlm.nih.gov/pubmed/31315597

27. Rivers, C., Chretien, J.P., Riley, S., Pavlin, J.A., Woodward, A., Brett-Major, D., Maljkovic Berry, I., Morton, L., Jarman, R.G., Biggerstaff, M., Johansson, M.A., Reich, N.G., **Meyer, D.**, Snyder, M.R. & Pollett, S. (2019). Using "outbreak science" to strengthen the use of models during epidemics. *Nature Communications,* 10(1), 3102. https://www.ncbi.nlm.nih.gov/pubmed/31308372

28. Cicero, A.[3], **Meyer, D.**[1], Shearer, M.P.[1], AbuBakar, S., Bernard, K., Carus, W.S., Chong, C.K., Fischer, J., Hynes, N., Inglesby, T., Kwa ,C.G., Makalinao, I., Pangestu, T., Sitompul, R., Soebandrio, A., Sudarmono, P., Tjen, D., Wibulpolprasert, S. & Yunus, Z. (2019). Southeast Asia Strategic Dialogue on Biosecurity. *Emerging Infectious Diseases,* 25(5). https://www.ncbi.nlm.nih.gov/pubmed/31002062

29. Hurtado, C,. **Meyer, D.**, Snyder, M. & Nuzzo, J.B. (2018). Evaluating the frequency of operational research conducted during the 2014-2016 West Africa Ebola epidemic. *International Journal of Infectious Diseases,* 77, 29-33. https://www.ncbi.nlm.nih.gov/pubmed/30296574

30. **Meyer, D.**, Shearer, M.P., Chih, Y.C., Hsu, Y.C., Lin, Y.C., & Nuzzo, J.B. (2018). Taiwan's Annual Seasonal Influenza Mass Vaccination Program—Lessons for Pandemic Planning. *American Journal of Public Health*, 108(S3), S188. https://www.ncbi.nlm.nih.gov/pubmed/30192663

31. Sell, T.K., Shearer, M.P., **Meyer, D.**, Schoch-Spana, M., Echols, E., Rose, D.A., Carbone, E.G. & Toner, E. (2018). Public health resilience checklist for high consequence infectious diseases—informed by the domestic ebola response in the United States. *Journal of Public Health Management and Practice,* 24(6), 510. https://www.ncbi.nlm.nih.gov/pubmed/29595573

32. Sell, T.K., Watson, C., **Meyer, D.**, Kronk, M., Ravi, S., Pechta, L.E., Lubell, K.M. & Rose, D.A. (2018). Frequency of Risk-Related News Media Messages in 2016 Coverage of Zika Virus. *Risk Analysis*, 38(12), 2514. https://www.ncbi.nlm.nih.gov/pubmed/29314118

33. **Meyer, D.**, Kirk Sell, T., Schoch-Spana, M., Shearer, M.P., Chandler, H., Thomas, E., Rose, D.A., Carbone, E.G. & Toner, E. (2017). Lessons from the domestic Ebola response: Improving health care system resilience to high consequence infectious diseases. *American Journal of Infection Control*, 46(5), 533-537. https://www.ncbi.nlm.nih.gov/pubmed/29249609

34. Schoch-Spana, M., Ravi, S., **Meyer, D.**, Biesiadecki, L. & Mwaungulu, G. (2017). High-Performing Local Health Departments Relate Their Experiences at Community Engagement in Emergency Preparedness. *Journal of Public Health Management and Practice*, 24(4), 360. https://www.ncbi.nlm.nih.gov/pubmed/29084119

[3] Denotes shared first authorship

35. Schoch-Spana, M., Cicero, A., Adalja, A., Gronvall, G., Kirk Sell, T., **Meyer, D**., Nuzzo, J.B., Ravi, S., Shearer, M.P, Toner, E., Watson, C., Watson, M. & Inglesby, T. (2017). Global Catastrophic Biological Risks: Toward a Working Definition. *Health Security*, 15(4), 323. https://www.ncbi.nlm.nih.gov/pubmed/28745924

36. Watson, M., Nuzzo, J.B., Shearer, M.P. & **Meyer, D**. (2017). Strengthening US Public Health Preparedness and Response Operations. *Health Security*, 15(1), 20. https://www.ncbi.nlm.nih.gov/pubmed/28092487

Chapters

1. Hynes, N.A. and Meyer, D. (2020). Agents of Infection and Principles of Transmission. Maxy-Rosenau-Last Public Health and Preventive Medicine, Mc-Graw Hill Publishers, New York, NY.

Reports (not peer reviewed)

1. Adalja A, Jezek A, & **Meyer D.** (2022). Infectious diseases experts: America's link back to everyday life. *Infectious Diseases Society of America & the Johns Hopkins Bloomberg School of Public Health Center for Health Security*. https://www.idsociety.org/globalassets/value-of-id/our-response-to-covid-19/final-covid-action-brief-9.26.22.pdf

2. Bell, J., Nuzzo, J.B., Bristol, N., Essix., C., Kobokovich, A., Meyer, D., Mullen, L., & Rose, S. (2021). Global Health Security Index 2021: Advancing Collective Action and Accountability Amid Global Crisis. Nuclear Threat Initiative, *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. https://www.centerforhealthsecurity.org/our-work/publications/GHSindex2021

3. Rivers, C., Martin, E., **Meyer, D**., Inglesby, T.V. & Cicero, A. (2020). Modernizing and Expanding Outbreak Science to Support Better Decision Making During Public Health Crisis: Lessons for COVID-19 and Beyond. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. https://www.centerforhealthsecurity.org/our-work/publications/modernizing-and-expanding-outbreak-science-to-support-better-decision-making-during-public-health-crises

4. Gronvall, G., **Meyer, D.**, Ingelsby, T. & Cicero, A. (2019). US-India Strategic Dialogue on Biosecurity: Report on the Sixth Dialogue Session. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. http://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2019/190619-US-India-Report.pdf

5. Schoch Spana, M., Hurtado, C., **Meyer, D.**, Moore-Sheeley, K., Ravi, S., & Snyder, M. (2019). Risk Communication Strategies for the Very Worst of Cases. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. http://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2019/190304-Risk-Comm-Strategies.pdf

6. Preparedness for a High-Impact Respiratory Pathogen Pandemic. (2019). *Johns Hopkins Center for Health Security*. Prepared for the Global Preparedness Monitoring Board. https://apps.who.int/gpmb/assets/thematic_papers/tr-6.pdf

7. Gronvall, G., **Meyer, D.**, Ingelsby, T. & Cicero, A. (2018). US-India Strategic Dialogue on Biosecurity: Report on the Fifth Dialogue Session. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. http://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2018/181030-US-India-dialogue-report.pdf

8. Ingelsby, T., Cicero, A., Gronvall, G., Shearer, M. & **Meyer, D**. (2018). Strategic Biosecurity Dialogue Among Singapore, Malaysia, Indonesia, and the United States with Participating Observers from Thailand and Philippines: Meeting Report from the 2018 Dialogue Session. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. http://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2017/Meeting_Report_07.07.2017_FINAL.pdf

9. Ingelsby, T., Cicero, A., Gronvall, G., Shearer, M. & **Meyer, D**. (2017). Strategic Biosecurity Dialogue Among Singapore, Malaysia, Indonesia, and the United States with Participating Observers from Thailand and Philippines. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. http://www.centerforhealthsecurity.org/our-work/current-projects/multilateral-biosecurity-dialogue.html

10. Toner, E., Shearer, M.P., Sell, T.K., **Meyer, D.**, Chandler, H., Schoch-Spana, M., Echols, E.T., Rose, D. & Carbone, E. (2017). Health Sector Resilience Checklist for High-Consequence Infectious Diseases—Informed by the Domestic US Ebola Response. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. http://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2017/HCID_Final_Report_05.23.2017.pdf

Opinion Pieces

1. Veenema, T.G. & Meyer, D. (2020, June 4). Why America's Nurses were not Prepared for the Coronavirus Pandemic. *Forbes*. https://www.forbes.com/sites/coronavirusfrontlines/2020/06/04/why-americas-nurses-were-not-prepared-for-the-coronavirus-pandemic/#497ea0be164b

2. Nuzzo, J.B. and **Meyer, D**. (2018). Rise in tuberculosis highlights broader global health security concerns. *The Hill*. https://thehill.com/opinion/healthcare/379843-rise-in-tuberculosis-highlights-broader-global-health-security-concerns

3. **Meyer, D.**, Nuzzo, J.B. & Shearer, M. (2017). The danger of delaying vaccination. *Baltimore Sun*. http://www.baltimoresun.com/news/opinion/oped/bs-ed-op-0825-vaccination-delay-20170824-story.html

PRACTICE ACTIVITIES

Practice-Related Reports

1. Veenema, T.G., Closser, S., Thrul, J., et al. (2021). Mental Health and Social Support for Healthcare and Hospital Workers During the COVID-19 Pandemic. Baltimore, MD: *Johns Hopkins Center for Health Security*. https://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2021/20210923-C19-mental-health.pdf

2. Veenema, T.G., **Meyer, D**., Bell, S.A., Couig, M.P., Friese, C.R., Lavin, R., Stanley, J., Martin, E., Montague, M., Toner, E., Schoch-Spana, M., & Cicero, A. (2020, June 10). Recommendations for Improving National Nurse Preparedness for Pandemic Response: Early Lessons from COVID-19. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*. https://www.centerforhealthsecurity.org/our-work/publications/recommendations-for-improving-national-nurse-preparedness-for-pandemic-response--early-lessons-from-covid-19

3. Toner, E., Waldhorn, R., Veenema, T., Adalja, A., **Meyer, D**., Martin, E., Sauer, L., Watson, M., Daughtry Biddison, L., Cicero, A. & Inglesby, T. (2020). National Action Plan for Expanding and Adapting the Healthcare System for the Duration of the COVID Pandemic. *Johns Hopkins Bloomberg School of Public Health Center for Health Security*.

https://www.centerforhealthsecurity.org/our-work/publications/national-action-plan-for-expanding-and-adapting-the-healthcare-system-for-the-duration-of-the-covid-pandemic

4. Toner, E,. Barnill, A., Krubiner, C., et al. (2020). Interim Framework for COVID-19 Vaccine Allocation and Distribution in the United States. *Johns Hopkins Center for Health Security*. https://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2020/200819-vaccine-allocation.pdf

5. **Meyer, D**., LaFave, S., Hart, A.A., Martin, E. & Nuzzo, J. (2020). Recommendations for a Metropolitan COVID-19 Response—Special Area of Emphasis: Guidance on Protecting Individuals Residing in Long-Term Care Facilities. *Johns Hopkins Bloomberg School of Public Health*. https://www.centerforhealthsecurity.org/our-work/publications/recommendations-for-a-metropolitan-covid-19-responsespecial-area-of-emphasis

6. Filling in the Blanks: National Research Needs to Guide Decisions about Reopening Schools in the United States. *Johns Hopkins Center for Health Security*. https://www.centerforhealthsecurity.org/our-work/pubs_archive/pubs-pdfs/2020/200515-reopening-schools.pdf

COVID-19 Related Community Research

1. August 2021-Current, Syringe Service COVID-19 Mobile Vaccine, Jason Farley (PI), research assistant (role), PhD research residency

2. January 2021-Current, Community Collaboration to Combat Coronavirus, Jason Farley (PI), research assistant (role), PhD research residency

3. January 2021-July 2021, SARS-COV-2 Prevalence Study (CoVPN-5002), Jason Farley (PI), research assistant (role), PhD research residency

PART II

RESEARCH GRANT PARTICIPATON

Associations of Social and Structural Determinants of Health with Forgone Care during the COVID-19 Pandemic in Baltimore, Maryland, March 2023 to August 2024, National Institute for Nursing Research F31 Predoctoral Training Grant

Principal Investigator: Diane Meyer; Funding Level: $77,000

Grant Objective: Pre-doctoral training grant awarded to support dissertation research.

Kitsap County Healthcare System Needs Assessment and Recommendations, April to December 2023, Kitsap Public Health District

Principal Investigators: Tener Veenema, Diane Meyer, Sanjana Ravi; Funding Level: $200,000

Grant Objective: To conduct a comprehensive assessment and evaluation of Kitsap County's healthcare system and workforce to better understand strengths and weaknesses within its healthcare system infrastructure.

International Resource Center for Pandemic and Disaster Nursing Education, October-December 2022, Aronson Family Foundation

Principal Investigators: Tener Veenema, Diane Meyer; Funding Level: $30,000

Grant Objective: To continue to develop an online resource library with relevant and reliable educational resources and training materials to prepare nurses for disaster and pandemic response.

International Resource Center for Pandemic and Disaster Nursing Education, July 2021-October 2022, Aronson Family Foundation

Principal Investigators: Tener Veenema, Diane Meyer; Funding Level: $100,000

Grant Objective: To develop an online resource library with relevant and reliable educational resources and training materials to prepare nurses for disaster and pandemic response.

Southeast Asia Multilateral Dialogue on Biosecurity—With Participation from Indonesia, Malaysia, Singapore, Thailand, and the United States; March 1, 2019 to February 28, 2020; Project on Advanced Systems and Concepts for Countering Weapons of Mass Destruction, US Air force Institute for National Security Studies, Defense Threat Reduction Agency

Principal Investigator: Anita Cicero, Funding Level: $272,082

Grant Objective: To address health and security risks related to emerging infectious diseases, including those with pandemic potential; the deliberate and accidental misuse of high-

consequence pathogens, including Select Agents; and potential risks related to advanced biology and biotechnology in the Southeast Asia region.

Role: Co-investigator

Synthetic Biology and High-Consequence Pathogen Research in the Russian Federation, August 15, 2019 to August 14, 2020, Project on Advanced Systems and Concepts for Countering Weapons of Mass Destruction, US Air force Institute for National Security Studies, Defense Threat Reduction Agency

Principal Investigator: Gigi Kwik Gronvall, Funding Level: $130,000

Grant Objective: To increase understanding of the Russian life sciences landscape, their relative emphasis on synthetic biology and high consequence pathogen research, concentration of expertise, and identify other descriptive factors useful in contextualizing biosecurity concerns. Responsibilities: Acting project manager. Will help lead subject matter expert interviews, an open-source analysis of scientific publications, and a Delphi study.

Role: Co-investigator

Creating a New Vision and Strategy to Enhance Disaster Response, December 1, 2017 to February 28, 2019, The Rockefeller Foundation

Principal Investigator: Dr. Jennifer Nuzzo, Funding Level: $398,191

Grant Objective: To develop a Health System Resilience Checklist and Implementation Guide that health systems in a broad set of countries can use to ensure an effective response to health emergencies.

Role: Co-investigator

PRESENTATIONS

Scientific Meetings

Nurses, Midwives, and the Mental Health Burden of Disasters and Pandemics. Webinar. WHO Nursing and Midwifery Global Community of Practice. Virtual. 2022.

Creating an International Resource Center for Pandemic Nursing Education and Training. Panel Presentation. Global Health Security 2022 Conference. Singapore. 2022.

COVID-19 and the Nursing Workforce: Impacts and Implications for Building Resilient Communities. Poster Presentation (virtual). Preparedness Summit. 2022.

Sub-clinical Myocardia Injury, Coagulopathy, and Inflammation in COVID-19: A Meta-analysis. Oral presentation (co-author). American Heart Association EPI Lifestyle. 2022.

Creating an International Resource Center for Pandemic and Disaster Nursing Education. Panel Presentation (panelist; virtual). International Council of Nurses 2021 Congress. 2021.

Development of a Mobile COVID-19 Vaccination Clinic Co-located with a Syringe Support Services Van for People who Inject Drugs. Panel Presentation (co-author). Association of Nurses in AIDS Care conference. Washington DC. 2021.

A Checklist to Improve Health System Resilience to Infectious Disease Outbreaks and Natural Hazards. Panel Presentation (panelist). International Preparedness and Response for Emergencies and Disasters Conference. Tel Aviv, Israel. 2020.

Global Health Security Index. Global Health Security Agenda Steering Committee Meeting (presenter). Brussels, Belgium. 2019.

A Checklist to Improve Health System Resilience to Infectious Disease Outbreaks and Natural Hazards. Panel Presentation (panelist). Global Health Security 2019 Conference. Sydney, Australia. 2019.

Outbreak Observatory: Improving Preparedness for Infectious Disease Outbreaks Through the Conduct of Operational Research. Poster Presentation. Global Health Security 2019 Conference. Sydney, Australia. 2019.

Outbreak Observatory: Two Jurisdictions Experiences Working with Outbreak Observatory. Panel Presentation (moderator). Preparedness Summit. St. Louis, MO, 2019.

A Checklist to Improve Health System Resilience to Infectious Disease Outbreaks and Natural Hazards. Poster Presentation. Preparedness Summit. St. Louis, MO, 2019.

A Checklist to Improve Health System Resilience to Infectious Disease Outbreaks and Natural Hazards. Poster Presentation. National Healthcare Coalition Preparedness Conference. New Orleans, LA, 2018.

Gastrointestinal Anthrax: A Global Public Health Perspective. Presented at the Bloomberg School of Public Health Capstone Symposium. Baltimore, MD, 2016.

ADDITIONAL INFORMATION

My research goals are to better understand how the fields of health security and health systems strengthening intersect to improve resilience during public health emergencies, including natural, accidental, and deliberate events. I am interested specifically in how the global community can improve the resilience of health systems to reduce the second and third order impacts of emergencies, which have historically disproportionately impacted underserved individuals. This includes identifying barriers that may inhibit care-seeking during emergencies both from the patient and healthcare system perspectives and identifying ways that we can better leverage the nursing profession to improve readiness for public health emergencies. Relatedly, I am also interested in ways to better improve the readiness of the nursing workforce for future pandemics and disasters and to increase representation of nurse experts in global health security,

Keywords
global health security, health systems strengthening, health systems resilience, nursing