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Short communication

Characteristics associated with healthcare disruptions during the COVID-19 pandemic for women in the United States at high risk for breast cancer

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ABSTRACT

Delays in healthcare, including breast cancer screening, were documented during the coronavirus disease 2019 (COVID-19) pandemic. However, no studies have examined the impact of COVID-19 on healthcare among women at high (≥20 % lifetime) risk for breast cancer. This study fills that gap. Between August 2020 and January 2021, high-risk women (N = 225) living in the United States (US) completed an online survey assessing COVID-related healthcare disruptions. Descriptive statistics characterized the frequency of breast cancer screening (mammogram and breast magnetic resonance imaging [MRI]) since the beginning of the COVID-19 pandemic. Multivariable linear regression analysis with backward selection examined demographic characteristics associated with COVID-related healthcare disruptions. Since March 2020, 40 % of participants had received a mammogram and 12 % had received a screening breast MRI. On average, participants reported low levels of COVID-related healthcare disruptions (M = 1.97 on a 0–4 scale, higher = more disruptions). Participants who were younger (β = -0.21, p = 0.002) and not working (β = 0.18, p = 0.009) reported more COVID-related healthcare disruptions. Compared to non-Hispanic White participants, those from any other racial or ethnic group reported fewer COVID-related healthcare disruptions (β = −0.15, p = 0.020). Although few high-risk women received breast cancer screening after the declaration of the COVID-19 pandemic, they reported overall low levels of COVID-related healthcare disruptions. Results identify subgroups of high-risk women whose healthcare may have been more affected by the pandemic. Efforts to encourage US women at high risk for breast cancer to return to routine preventive care (including breast cancer screening) may need to be targeted towards women who are younger, not working, and non-Hispanic White.

1. Introduction

The coronavirus disease 2019 (COVID-19) pandemic caused significant delays in preventive healthcare, particularly in cancer screening (Chen et al., 2021). Rates of screening mammography in the United States (US) dropped over 90 % after the March 13, 2020 declaration of a national emergency (Naidich et al., 2020). By March 2021, volume was still 13 % below historical averages. (McBain et al., 2021).

In the US, 6–15 % of women are at high risk for breast cancer (Dyrstad et al., 2015; Lambertini et al., 2016; Kleibl and Kristensen, 2016), defined as ≥20 % lifetime breast cancer risk (National Comprehensive Cancer Network (NCCN), 2022). For these women, national guidelines recommend annual screening breast magnetic resonance imaging (MRI) as a supplement to annual screening mammography, alternating at six month intervals (Monticciolo et al., 2018; National Comprehensive Cancer Network (NCCN), 2020). COVID-related delays in breast cancer screening are predicted to have a small but significant impact on long-term breast cancer mortality (Alagoz et al., 2021). However, no studies have examined the impact of COVID-19 on preventive healthcare among high-risk women. Therefore, we used secondary data from a cross-sectional survey of women at high (≥20 % lifetime) risk for breast cancer to: (1) characterize COVID-related healthcare disruptions, and (2) identify sociodemographic characteristics associated with COVID-related healthcare disruptions.

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2. Methods

2.1. Participants & procedures

We used secondary, cross-sectional data from an observational study designed to examine psychosocial barriers to breast MRI among women at high risk for breast cancer. All study procedures were reviewed by the Advarra Institutional Review Board (IRB) and determined exempt from IRB oversight due to minimal risk (Protocol #00000971). Eligibility criteria included: assigned female at birth; ages 25–85 years; English-speaking; living in the US; up-to-date on screening mammograms; and high risk for breast cancer. Participants were considered high risk if they met at least one of the following criteria: (1) pathogenic genetic mutation in self or a first-degree relative; (2) history of lobular carcinoma in situ (LCIS); (3) received thoracic radiation between ages 10–30; or (4) estimated lifetime breast cancer risk ≥20 % per the Breast Cancer Risk Assessment Tool (BCRAT) (Costantino et al., 1999).

Exclusion criteria were: prior diagnosis of breast cancer; history of bilateral mastectomy; and medical contraindications for breast MRI (e.g., pacemaker, brain aneurism clip). Consistent with best practices for detecting fraudulent responses to online research studies (Teitcher et al., 2015), we also excluded individuals who made multiple attempts at completing the eligibility screener.

Participants were recruited from August 2020-January 2021. Participants were recruited online through: (1) targeted Facebook advertisements through the Georgetown-Howard Universities Center for Clinical and Translational Science (n = 134, 60 %); (2) study invitation emails through ResearchMatch.org (n = 60, 27 %); and (3) email and social media promotions from community organizations serving women at high risk for breast cancer (n = 14, 6 %). The remaining participants either heard about the study through word of mouth (n = 8, 3 %) or did not specify (n = 9, 4 %).

Interested individuals were redirected to a secure website with eligibility screening questions. Eligible individuals continued to the web-based survey.

2.2. Measures

2.2.1. Sociodemographic characteristics

Included age, race, ethnicity, education, employment status, household income, health insurance type, and where they usually receive healthcare.

2.2.2. Receipt of breast cancer screening

Prior receipt of a screening mammogram (yes/no) or screening breast MRI (yes/no). Participants also reported the month and year of their most recent procedure which were used to categorize procedures as pre-COVID (i.e., before March 2020) or during COVID (i.e., after March 2020).

2.2.3. COVID-related healthcare disruptions

The healthcare disruptions subscale of the COVID experiences questionnaire (Penedo et al., 2020) includes two items rated on a 5-point Likert-type scale from (0 = "strongly disagree" to 4 = "strongly agree"). Item scores are averaged to create total scores ranging from 0 to 4 (higher = more disruptions). In the present study, α = 0.77.

2.3. Statistical analyses

All analyses were conducted using IBM SPSS 28. All tests were two-tailed, and significance was specified as $\alpha < 0.05$. First, independent samples t-tests or chi-square analyses (as appropriate) were used to compare participants who did and did not complete the COVID experiences questionnaire. Second, descriptive statistics characterized (a) the frequency of breast cancer screening (mammogram and breast MRI) during the COVID-19 pandemic and (b) summarized COVID-related healthcare disruptions. Finally, a backward stepwise linear regression examined associations between sociodemographic factors and COVID-related healthcare disruptions. Due to sparse data, we combined response categories for race and ethnicity (non-Hispanic White = 0, person of color = 1), health insurance type (private = 1, other = 0), and typical healthcare setting (private doctor's office = 1, other = 0). All other variables were entered into the model as shown in Table 1. The criterion for staying in the model was set at $p < 0.1$.

3. Results

Of 1,566 individuals who completed the eligibility screener, 404 (26 %) were eligible (Supplemental Figure 1). Of these, 45 (11 %) were lost to follow-up and 359 (89 %) completed the online survey. To detect fraudulent responses, two study team members independently reviewed all responses for consistency, multiple attempts at completion, and impossibly short response times (i.e., <5 min). Final validity checks excluded 60 respondents (17 %). An additional 74 respondents (21 %) did not complete the COVID experiences questionnaire and were excluded from these analyses. Thus, our final sample was N = 225.

In comparing participants who did and did not complete the COVID experiences questionnaire, questionnaire completers were significantly more likely to be non-Hispanic White (86 % versus 59 % of non-completers, $p = 0.031$) (Supplemental Table 1). There were no other significant differences in sociodemographic characteristics between

Table 1
Sample Characteristics (N = 225).

Variable	N (%)/*M* [SD]
Age (years)	44.4 [12.8]
Race[†]	
American Indian/Alaska Native	4 (1.7)
Asian	4 (1.7)
Black/African American	14 (6.2)
Native Hawaiian/Pacific Islander	1 (0.4)
White	203 (90.2)
Other	1 (0.4)
Ethnicity	
Hispanic/Latina	10 (4.4)
Non-Hispanic	223 (95.6)
Education	
Less than a college degree	53 (23.6)
College degree	115 (51.1)
Post-graduate degree	57 (25.3)
Employment Status	
Working	161 (71.6)
Not working	64 (28.4)
Annual Household Income (USD)	
<$24,999	16 (7.1)
$25,000-$99,999	123 (54.7)
≥$100,000	65 (28.9)
I don't know/I prefer not to answer	21 (9.3)
Health Insurance Type	
Private	153 (68.0)
Public (e.g., Medicare, Medicaid)	54 (24.0)
Other	6 (2.7)
None	11 (4.9)
Missing	1 (0.4)
Typical Healthcare Setting	
Private doctor's office	175 (77.8)
Community health center/clinic	36 (16.0)
Other (e.g., urgent care, emergency room, etc.)	14 (6.2)
Reason for elevated breast cancer risk[‡]	
Pathogenic genetic mutation carrier	91 (40.4)
First-degree relative with pathogenic genetic mutation	65 (28.9)
History of lobular carcinoma in situ (LCIS)	9 (4.0)
History of thoracic radiation	13 (5.8)
BRCAT score ≥ 20 %	47 (20.9)

BCRAT = Breast Cancer Risk Assessment Tool (Costantino et al., 1999).
[†] as participants could select more than one, does not total 100 %.
[‡] due to branching logic of the eligibility screener, these categories are mutually exclusive.

completers and non-completers.

3.1. Descriptive and preliminary analyses

As shown in Table 1, the sample (N = 225) was mostly White (90 %), non-Hispanic (96 %), and in middle adulthood (M = 44 years). About three-quarters had a college degree or higher level of education (76 %). Most had an annual household income between $25,000 and $100,000 (55 %), were working (72 %), had private health insurance (68 %), and typically received medical care at a private doctor's office (78 %).

Participants' elevated breast cancer risk was due to carrying a pathogenic variant in a gene associated with elevated breast cancer risk (40 %), having a first-degree relative with a pathogenic variant in a gene associated with elevated breast cancer risk (29 %), a personal history of LCIS (4 %), or a history of thoracic radiation between ages 10 and 30 (6 %). The remaining participants (n = 47, 21 %) had a BCRAT (Costantino et al., 1999) score indicating ≥ 20 % lifetime risk for breast cancer.

3.2. Aim 1: Impact of COVID-19 on healthcare among high-risk women

Since March 2020, 105 participants (47 %) had received at least one type of breast cancer screening. Specifically, 90 (40 %) had received a mammogram and 27 (12 %) had received a screening breast MRI. On average, participants reported low levels of COVID-related healthcare disruptions (M = 1.97), akin to "neither agree nor disagree" on the Likert-type response scale.

3.3. Aim 2: Characteristics associated with impact of COVID-19 on healthcare

Backward selection resulted in a final multivariable linear regression model with three independent variables: age, race, and employment status (Table 2). Participants who were younger ($\beta = -0.21$, $p = 0.002$) and not working ($\beta = 0.18$, $p = 0.009$) reported significantly more COVID-related healthcare disruptions. Compared to non-Hispanic White participants, participants from any other racial or ethnic group reported fewer COVID-related healthcare disruptions ($\beta = -0.15$, $p = 0.020$). The model accounted for approximately 7 % of the variability in the outcome of interest ($R^2 = 0.069$).

4. Discussion

The COVID-19 pandemic has had a dramatic impact on preventive care, including breast cancer screening (Chen et al., 2021). Our study demonstrated low overall levels of COVID-related healthcare disruptions, but highlight some groups whose healthcare may have been more affected by the pandemic.

In the 5–10 months since the beginning of the COVID-19 pandemic, 40 % of participants had received a mammogram and 12 % had received a screening breast MRI. Given that US guidelines recommend screening with mammogram and breast MRI annually (Monticciolo et al., 2018; National Comprehensive Cancer Network (NCCN), 2020), we would not expect 100 % of participants to have completed screening in the study time frame. However, prior research on uptake of breast cancer screening among high-risk women provides estimates ranging from 72–82 % for mammography and 29–81 % for breast MRI (Wernli et al., 2014; Schwartz et al., 2012; Stout et al., 2014; Metcalfe et al., 2019). Thus, the rate of breast cancer screening was lower among participants in our study than previously observed. Interestingly, this contrasts with participants' perceived disruptions in healthcare due to COVID-19. The average score on the healthcare disruptions scale was 1.97 out of a possible 4. For context, the average subscale score in the validation sample (N = 11,325 cancer survivors) was 1.77 (Penedo et al., 2020). Taken together, these data suggest that participants did not perceive that the COVID-19 pandemic had a significant impact on their ability to get preventive healthcare, including breast cancer screening. The low overall rates of screening observed here may therefore be due to other factors.

We also identified sociodemographic characteristics associated with COVID-related disruptions in healthcare. Specifically, women who were younger, not working, and non-Hispanic White reported more COVID-related healthcare disruptions. These data add to the extant research on involuntary healthcare disruptions related to COVID-19, which has primarily focused on the general population and demonstrated mixed findings. For example, one large US survey conducted in May 2020 (N = 1,502,680) found older, more highly educated, and non-Hispanic White respondents were more likely to experience involuntary healthcare disruptions (Callison and Ward, 2021). In contrast, a *meta*-analysis of 11 UK-based longitudinal studies (N = 68,912) demonstrated that participants who were female, older, and non-White were more likely to report healthcare disruptions (Parsons et al., 2021).

In the context of breast cancer screening for high-risk women, our findings likely reflect the fact that high-risk women who are younger and non-Hispanic White are more likely to receive recommended screening (Wernli et al., 2014; Haas et al., 2016), and thus are also more likely to have had that care disrupted during the pandemic. Regarding employment status, our "not working" participants were a heterogeneous group including full-time homemakers, retirees, students, individuals unable to work, and those between jobs/unemployed. Many of these groups may be at higher risk for complications due to COVID-19; for example, full-time homemakers may be caring for young children, retirees may be older, and individuals who are unable to work may have chronic medical conditions. Thus, it is possible that perceived risk of COVID-19 may have contributed to disruptions in medical care for this group. Additional research with larger sample sizes is needed to further explore possible differences in COVID-related healthcare disruptions based on employment status.

Table 2
Results of multivariable linear regression model with backward selection examining factors associated with COVID-related healthcare disruptions (N = 225).

Explanatory variable	B	Std. Error	β	*p* value	95 % C.I.
Age (years)	−0.02	0.01	−0.21	0.002	[−0.03, −0.01]
Race/Ethnicity					
Non-Hispanic White	(ref)				
Person of Color	−0.50	0.21	−0.15	0.020	[−0.92, −0.08]
Employment Status					
Working	(ref)				
Not working	0.44	0.17	0.18	0.009	[0.11, 0.77]

B = unstandardized coefficients.
β = standardized coefficients.

4.1. Strengths and limitations

Study strengths include the nationwide recruitment, enhancing generalizability of findings to the broader high-risk community, rather than only those who choose to seek care at large, academic medical centers. In addition, this sample includes women who are at high risk for varied reasons, who may face different barriers to care; prior research has focused almost exclusively on carriers of pathogenic genetic variants (e.g., *BRCA1/2*).

Nonetheless, results should be interpreted in light of limitations. First, the cross-sectional nature of the data precludes causal conclusions. Second, self-reported data may be subject to recall bias and/or demand characteristics; future research might thus incorporate electronic medical record data. Third, our sample was predominantly non-Hispanic White, high socioeconomic status, and insured. The sample sizes for certain sociodemographic categories were small (Table 1), which may

have limited our ability to detect effects. For the multivariable linear model, we used the approach of backward selection with significance set at $p < 0.1$. Some independent variables (e.g., education) were close to the cut-off for inclusion (e.g., $p = 0.109$). The exclusion of these variables from the model may be an artifact of our relatively small sample size. Thus, studies with larger, more heterogeneous samples are needed to confirm the patterns observed here. This would also increase the generalizability of the results. Fourth, data was collected between August 2020 and December 2021 but did not include the full 12-month interval post-COVID in which participants might have been due for breast cancer screening. Additional research with an extended follow-up time period is needed to examine the long-term impact of COVID-19 on preventive healthcare for high-risk women. Finally, our final multivariable regression model only accounted for 7 % of the variability in COVID-related healthcare disruptions, suggesting that there are important factors not assessed in this study associated with healthcare disruptions. As this was a secondary data analysis, studies specifically designed to assess COVID-related healthcare disruptions among high-risk populations may provide greater insight into this important issue.

5. Conclusion

It is critical to identify and correct COVID-related delays in breast cancer screening, particularly for high-risk women. This study suggests that, on average, high-risk women in the US had few COVID-related healthcare disruptions; however, we also identified subgroups experiencing more disruptions. Future efforts to encourage high-risk women to return to routine preventive care (including breast cancer screening) may need to be targeted towards women who are younger, not working, and non-Hispanic White.

CRediT authorship contribution statement

Claire C. Conley: Conceptualization, Funding acquisition, Formal analysis, Visualization, Writing – original draft. **Jennifer D. Rodriguez:** Investigation, Data curation, Project administration, Writing – review & editing. **Naomi C. Brownstein:** Data curation, Formal analysis, Methodology, Writing – review & editing. **Suzanne C. O'Neill:** Conceptualization, Supervision, Writing – review & editing. **Susan T. Vadaparampil:** Conceptualization, Funding acquisition, Resources, Supervision, Writing – review & editing.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Drs. Conley and O'Neill have received research funding from Pfizer.

The remaining authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Anonymized data that support the findings of this study are available in the Open Science Framework at https://osf.io/xpz35/.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pmedr.2022.101975.

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