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Women's considerations and experiences for breast cancer screening and surveillance during the COVID-19 pandemic in the United States: A focus group study

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ABSTRACT

The COVID-19 pandemic resulted in numerous changes in delivery of healthcare services, including breast cancer screening and surveillance. Although facilities have implemented a number of strategies to provide services, women's thoughts and experiences related to breast cancer screening and surveillance during a pandemic are not well known. This focus group study with women across seven states recruited through the Breast Cancer Surveillance Consortium aims to remedy this gap in information. Thirty women ranging in age from 31 to 69 participated in five virtual focus groups, eight of whom had prior breast cancer. The first three focus groups covered a range of topics related to screening and surveillance during the pandemic while the last two groups covered experiences and then a review of sample communications to women about screening and surveillance during the pandemic to obtain reactions and recommendations. More than half of the women had screening or surveillance during the pandemic. Coding and analyses resulted in nine themes in three topic areas: decision factors, screening experiences, and preferred communications. Themes included weighing the risks of COVID-19 versus cancer; feelings that screening and surveillance were mostly safe but barriers may be heightened; feeling safe when undergoing screening but receiving a range of pandemic-specific communications from none to a lot; and wanting communications that are personalized, clear and concise. Based on these findings, providers and facilities should assure women of pandemic safety measures, review methods and content of communications, and assess for barriers to screening that may be amplified during the pandemic, including anxiety and access.

1. Background

In the United States, routine breast cancer screening with mammography is recommended as biennially for women aged 50–74 years old according to the US Preventive Services Task Force (Siu, 2016). Women aged 40–49 years are recommended to talk with their doctor about risks of breast cancer according to family history and other factors prior to initiating screening (Siu, 2016). About 67% of US women 40 years and older have had a mammogram within past 2 years (Centers for Disease Control and Prevention, 2019) and nearly 40 million mammograms are conducted annually (U.S. Food and Drug Administration, 2019). Since there are no centralized breast cancer screening programs within the U.S., use and services are driven by both patient demand and

provider marketing (Williams et al., 2015).

Given the large volume of mammograms performed in the U.S. with no centralized organization, the COVID-19 pandemic (herein pandemic) upended breast cancer screening services across the country. The pandemic created numerous challenges for healthcare systems to provide care for patients, including breast cancer screening and surveillance (Carethers et al., 2020; Patt et al., 2020; Song et al., 2020). Radiology facilities rapidly responded to the pandemic by canceling non-urgent services such as breast cancer screening and surveillance imaging, and some diagnostic imaging and breast biopsies (Smetherman, 2020). In addition, women themselves canceled, postponed, or delayed imaging (Warner et al., 2020) although primary reasons for women's decisions are not clear.

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As the pandemic evolved, a number of recommendations from major organizations and practice leaders have emerged to guide medical practices in re-opening in general (Centers for Disease Control and Prevention, 2020) and more specifically for breast imaging, including the American College of Radiology (ACR) (Davenport et al., 2020) and the Society of Breast Imaging (Society of Breast Imaging, 2020). These recommendations have centered around the following major areas: safety measures, monitoring local spread, creating a tiered plan for triaging women for imaging based on clinical indication and risk factors, addressing any backlogs in appointments, and managing fear among providers, staff, and patients (Smetherman, 2020). In addition, ACR and other organizations (e.g., American Cancer Society) have created sample letters, fliers, or information on their website for how to communicate with women about breast cancer screening and surveillance in the time of the pandemic (American Cancer Society, 2020; American College of Radiology, 2021). However, aside from one survey with a convenience sample (Warner et al., 2020) and anecdotal information about women's reactions, no study has explored women's thoughts and experiences when thinking about or engaging in breast cancer screening during a pandemic.

To address this lack of information on women's perspectives, we conducted a focus group study with women across the United States to understand their experiences and thoughts around breast cancer screening and surveillance during the pandemic. Our study's primary purpose was to understand factors that facilitated or created barriers to engaging in breast cancer screening, to understand women's experiences, and to get input on desired information and communications related to breast cancer screening.

2. Methods

This qualitative study was part of a larger study by the Breast Cancer Surveillance Consortium (BCSC) to create data-driven evidence for prioritizing women for breast imaging and biopsies during the pandemic. The BCSC is a network of breast imaging registries that link breast imaging data from academic and community-based radiology facilities to state, regional, or Surveillance, Epidemiology, and End Results cancer registries and pathology databases (Ballard-Barbash et al., 1997; Breast Cancer Surveillance Consortium, 2021). We conducted the study between October and December 2020 through five BCSC registries. The registries included Carolina Mammography Registry, Kaiser Permanente Washington Registry, Sacramento Area Breast Imaging Registry, San Francisco Mammography Registry, and Vermont Breast Cancer Surveillance System. The institutional review boards of Dartmouth College and participating registries approved this study.

2.1. Recruitment

We used BCSC data to purposefully sample women ages 40–74 without a history of breast cancer and women ages 20–74 with a previous breast cancer diagnosis. The BCSC registries sent referral letters to women whose BCSC registry records indicated potential participants were due for a screening, surveillance, or short-interval follow-up mammogram between March–August 2020 (the initial United States pandemic shutdown). Among eligible women due for mammography, we purposefully selected women by race, ethnicity, and cancer risk (e.g., family history of breast cancer, heterogeneously or extremely dense breasts) to expand diversity within the study population. After low responses to recruitment letters, we expanded the recruitment pool for the last two focus groups by posting ads for the study on the BCSC Twitter and Facebook pages to meet the study's recruitment goals. These posts were then shared in a variety of geographically diverse community groups and by email.

In the BCSC referral letters and the subsequent social media recruitment, women were directed to an online Qualtrics (Qualtrics, 2005) screening eligibility questionnaire to determine if they met

inclusion criteria, to collect additional demographic information, and to provide contact information. To ensure technology access to the focus groups, referral materials also included a telephone number for women to complete the Qualtrics questionnaire over the phone if they lacked online access. Ninety-seven women completed the screening and 74 women met our inclusion criteria. Those who did not meet our criteria included women who were currently being treated for breast cancer or were not due for screening. We attempted to contact all women who qualified for the study to invite them to one of five focus groups. While scheduling, we verified if women knew how to use Zoom (Zoom, 2016) and gave brief tutorials if needed. In addition, we allowed women to join Zoom by telephone if they did not have access to a computer or similar hardware. Lastly, women received detailed information by email about the study, including information about recording and confidentiality, and who to contact with any concerns. Women in all five focus groups received \$50 Amazon.com gift cards as a thank you for their time.

2.2. Data collection

We conducted five 90-minute virtual focus groups via Zoom in two waves and obtained waiver of consent documentation for participation. We composed groups based on history of prior breast cancer or not since these women have different past experiences and risks for future breast cancer. All focus groups were conducted by two of the researchers (KES, DV) and four were observed by at least one patient partner (DJ, GJN, JB) and one additional researcher (KJW).

Wave 1 included three focus groups, one for women with prior breast cancer and two for women with no prior breast cancer. Using an interview guide, we focused on what women had heard in the news about getting breast cancer screening during the pandemic, how they felt about screening, what their experience had been scheduling and attending or canceling an appointment, and if they had any safety concerns. Focus groups closed by discussing what and how women wanted to hear from their screening sites and providers about screening during the pandemic.

Wave 2 included two focus groups, one each for women with prior breast cancer and with no prior breast cancer. Using a focus group interview guide, we asked women to share their thoughts on the pandemic's influence on their decision to attend or cancel a mammogram. The rest of the time we focused on presenting and discussing a curated sample of potential communication materials about screening and surveillance during the pandemic (see Table 1). Materials included template letters, flyers, and a short video. Women were asked to provide feedback on the materials and discuss potential messaging strategies for informing women about screening and surveillance during the pandemic.

2.3. Analysis

Focus groups were recorded, transcribed, imported into Dedoose (SocioCultural Research Consultants, 2018) and analyzed using a mixed inductive and deductive approach (Fereday and Muir-Cochrane, 2006; Hsieh and Shannon, 2005). Two researchers (KES, DV), who facilitated all the focus groups, jointly developed an initial codebook after reviewing transcripts. One researcher (DV) then applied codes to the focus groups which was then reviewed by KES. Questions or disagreements in coding were discussed and resulted in modifications to the codebook. DV then used this revised codebook to review and recode excerpts as needed. Code applications were then reviewed by both researchers to identify key themes with a particular focus on thoughts and experiences women had related to screening and communications. These themes were reviewed and approved by a third researcher (KJW). A final review of findings was completed by our patient partners (DJ, JB, GJN) who each attended one to two focus groups.

Table 1
Communication materials shown during Wave 2 focus groups.

Title	Message type	Date last accessed	Link
Is it safe to schedule my mammogram?	Flyer	1/26/2021	https://www.acr.org/-/media/ACR/Files/Breast-Imaging-Resources/Care-Toolkit/Infographic-on-Safety-Precautions.pdf
Should I get a mammogram now?	Flyer	1/26/2021	https://www.acr.org/-/media/ACR/Files/Breast-Imaging-Resources/Care-Toolkit/Should-I-Get-a-Mammogram-Now.pdf
Cancer screening during the COVID-19 pandemic	Webpage	1/26/2021	https://www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines/cancer-screening-during-covid-19-pandemic.html
Return to screening letter	Letter	1/26/2021	https://www.acr.org/-/media/ACR/Files/Breast-Imaging-Resources/Care-Toolkit/Return-to-Screening-Template.docx
Reassurance letter	Letter	1/26/2021	https://www.acr.org/-/media/ACR/Files/Breast-Imaging-Resources/Care-Toolkit/Reassurance-Letter-Template.docx
Extra measures and extended hours for safely getting your annual mammogram	Video	1/26/2021	https://www.youtube.com/watch?v=8rtx7EXXG4U

3. Results

Thirty women participated across the five focus groups (22 no prior breast cancer; 8 prior breast cancer). For the eight women who had prior breast cancer, it had been an average of three years (range 1–9 years) since their initial breast cancer diagnosis. Of the 30 women who participated, 29 were due for a mammogram between March and August 2020. More than half ($n = 17$, 59%) had scheduled and attended their breast cancer screening appointment during the pandemic, six (35%) of whom previously had breast cancer. The other 12 (41%) women who were due for a mammogram did not attend a screening appointment. Most women who did not attend a screening appointment never scheduled their appointment ($n = 8$) compared to having an appointment canceled or canceling the appointment ($n = 4$). Table 2 summarizes participant demographics, cancer risk factors, and feelings about the pandemic collected on the screening survey.

The final code book consisted of 138 codes, which we applied to 207 excerpts and resulted in four main themes related to decision factors for completing breast cancer screening or not during the pandemic, two themes related to screening experiences, and three themes related to reactions to and preferred communications about screening during the pandemic. Fig. 1 provides an overall summary of the themes in each area in order of relative weight which we describe in detail below.

3.1. Decision factors: reasons to have screening or not

When considering having breast cancer screening during the pandemic, four main themes emerged for what women considered. The primary theme was weighing the risk of getting cancer versus the risk of getting COVID-19. Women who chose to have breast cancer screening were more concerned about missing breast cancer than getting COVID although some did delay mammography a few months to ensure safety protocols had time to get in place in radiology facilities. In general, women who chose not to get breast cancer screening felt at higher risk of getting COVID-19 (e.g., age, issues with lungs). Some of the women who

Table 2
Focus group participant demographics ($n = 30$).

Average age and range		57	31–69
		n	%
State	California	8	26
	Vermont	6	20
	Washington	5	17
	New Hampshire	4	13
	Minnesota	3	10
	Florida	2	7
	North Carolina	2	7
Race and Ethnicity	White	19	64
	Black	5	17
	Asian	3	10
	Latina	2	7
	American Indian	1	3
Education	Graduate degree	16	54
	College degree	9	30
	Associates/Some college	4	13
	High school graduate	1	3
Prior breast cancer	Yes	8	27
	No	22	73
Family history of breast cancer	Yes	9	30
	No	21	70
Have dense breast tissue	Yes	23	77
	No	6	20
	Unsure	1	3
How serious is Covid-19?	Extremely serious	16	53
	Very serious	11	37
	Moderately serious	2	7
	Slightly or not at all serious	1	3

chose not to get screening also felt that their risk for getting cancer was low based on past screening (e.g., normal screening mammograms) or no breast cancer risk factors.

“I think different people have a different risk analysis. Because of my age, I’m more likely to get very sick if I get COVID and my husband, who’s a few years older than me, has COPD, heart problems, third stage kidney disease. He’s terrified of getting it. And since I have no history of breast cancer in my family, and I do realize that a lot of people get breast cancer without having any contributing factors, but I still think right now people have to make a decision which they think is riskier for them. Now, for me, I think COVID’s riskier.” (no prior cancer).

A second primary theme related to having breast cancer screening during the pandemic was the feeling that screening is safe. Women described several reasons they perceived this, including trusting medical sites to follow safety protocols, being able to wear a mask during the entire appointment, and living in a region with low COVID rates.

“I was also comfortable knowing that, with the mammogram, you could still keep your mask on the whole time, so I felt in control.” (prior cancer).

The last two themes revealed reasons for not having breast cancer screening that were not strictly related to the pandemic but heightened by it. This included general logistics and barriers to getting breast cancer screening, such as not receiving scheduling reminders and issues with transportation. Some women also reported that anxiety or fear of testing, such as not liking mammograms or feeling more anxiety in general, made it harder to do things such as schedule medical appointments.

3.2. Breast cancer screening experiences

When considering the experiences of women who completed breast cancer screening during the pandemic, two main themes emerged: feeling safe during appointments and a wide range of communications

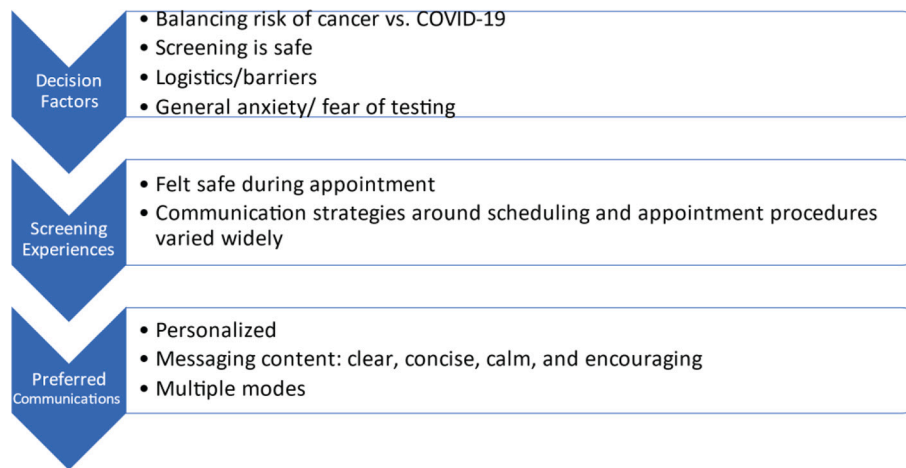


Fig. 1. Summary of focus group themes.

related to screening and appointments. For the most part, women described feeling very safe during their imaging appointment and described a number of safety measures enacted by the radiology facility including very low volume of patients in waiting areas, staff and patients wearing masks, temperature screening of patients when entering, and virtual check-in. A few women described needing to use elevators to get to their screening, which made them feel nervous but had no concerns about the rest of the appointment.

“They took my temperature when I went in there and they asked me questions about, do you feel sick, or do you know anyone who’s got it, and that’s about it, and I felt perfectly safe in there. Every single person in there was wearing a mask, some of them had the shields on too, but I didn’t have a problem at all. I figured that was probably the safest place for me to be if I was going to be outside.” (prior cancer).

Regarding communication from radiology facilities about screening and surveillance, women described a broad mix of messaging ranging from unsatisfying and confusing communication to reassuring and detailed communication. In order of least information received to most: some women received no information about COVID-19 procedures at their facilities and were unclear if their existing appointments would occur because they did not receive any communications. Other women received ‘normal’ reminders with no information about COVID-19. Other women received extensive information about safety procedures from the larger healthcare system tied to their radiology facility sites but not directly from their site. Finally, some women received scheduling reminders which included detailed COVID-19 procedures from their site.

During discussion about communicating with their provider or radiology facilities, some women expressed concerns that they could not reach someone to speak about options. These women fell into two groups: those that had reached out and had a hard time getting answers, and those who had not reached out but assumed they would have a hard time getting answers if they did call. Discussion about being able to reach someone did not apply just to screening facilities; women also felt frustrated about not being able to speak with their providers to discuss options relative to their personal risks. For instance, one woman described trying to schedule an appointment with her surgeon, which was supposed to happen every six months:

“I don’t know if it’s because I’ve bumped down on the importance level, which is probably a good thing, or if it’s just because people had to cancel appointments at the beginning or move them back. And now it’s just harder to get in to see someone, even if you want to. You

can’t even have that conversation about risk, and whether you should be going or not.” (prior cancer).

3.3. Reactions to and preferred communications with women about screening during the pandemic

Although all women were asked about experiences with and preferred communications regarding screening during the pandemic, the example materials (see Table 1) were only viewed by the 18 women who participated in Wave 2 focus groups. For women who viewed the materials, most had positive reactions to the content. However, women’s preferences varied more when considering different modes (e. g., video versus letter versus email). In the end, three themes emerged related to communications about screening during the pandemic, which we describe further below: communications should be personalized; communications should have content that is clear, concise, calm, and encouraging; and communications should use multiple modes to reach more women.

Overall, women valued communications that felt more personal. Examples included letters signed by their provider or having the option to have a nurse or provider discuss options for screening based on personal risks over the phone. Although women understood the need for general information about safety protocols or appointments during the pandemic, they felt that these should be supplemented with communication that was more personal and direct. For women who viewed materials, the support and enthusiasm for the sample letters signed by a provider was universal.

“I’m just really waiting for a nudge from the screening center for them to say, ‘Hey, we understand why you might’ve wanted to skip the appointment earlier in the year, but we do think it’s safe and we’re able to do it. And would you like to schedule it?’ It’d have to be kind of personal. It’d have to be they would have to call or send me an email or a message or something. I think that’s what it would take for me.” (no prior cancer).

The second most common theme related to communications was providing clear, concise information to women regarding breast cancer screening that was both calming and encouraging. Examples of the content of information women wanted included pandemic safety measures, specific information about their own appointments (e.g., rescheduling), and phone numbers or other resources to answer women’s questions. Most women who viewed materials preferred having content that was concise and calm, rather than alarming, but still encouraged breast cancer screening. Additional comments related to content included using eye-catching visuals or highlights, such as icons

or pictures, bold letters to emphasize certain information, and consistent messaging. For instance, one infographic showed a woman getting a mammogram but neither the technician nor the woman wore masks which was inconsistent with the accompanying list of safety measures.

“We live in a very visual society. Most people don’t like to read and don’t read much. So, give them as many pictures and as few words as possible, and get right to the point.” (prior cancer).

Although women appeared to have varied reactions to communication modes (e.g., email, online patient portals), they nevertheless acknowledged that multiple modes of communication were important and most effective. This was particularly evident in the focus groups where women viewed the sample materials. In these two groups, most women agreed that a short personal letter accompanied by an information sheet (e.g., a one-page infographic) might be most effective in communicating with women.

“I think the different media will go to different people. The one that was short and brief with all the colors on it, that is going to hit the people that don’t like to read a lot. That’s just going to be the quick visual boom in your face. Some of the people...need that audio visual cue, where it shows actually inside the office, seeing how they’re actually disinfecting. They need to see people in masks and what have you... and see the actual sanitation process taking place. That’s going to work for them. People that need that actual personal response with a letter actually addressed to them, reminding them to call need that personal touch, they’re going to need that. People that need an address from an actual organization, like the American Cancer Society, that’s going to hit them specific way, it’s going to need a brochure. So each different medium that’s being used and each different media outlet. That’s what’s going to matter, it’s going to hit each different person differently.” (no prior cancer).

4. Discussion

Our qualitative study reveals a number of insights into how women have thought about and experienced breast cancer screening and surveillance during the COVID-19 pandemic. In terms of decisions around screening, women used their own personal risk information for both breast cancer and COVID in making their decisions. Most of the women who participated in our focus groups continued to have screening, and felt safe and comfortable during their appointments. For women who chose not to have screening, reasons were both directly and indirectly related to the pandemic. Regardless of choice, women want multiple forms of communication—personal communication plus additional safety information to aid in their own decision making and potential scheduling process.

While our study had several strengths, it was not without limitations. For instance, we recruited women from several states and had some racial/ethnic and cancer history diversity, but we were limited to English-speaking women. In addition, although we used purposeful sampling and screening to try to reach women from a variety of educational backgrounds, most of our participants (84%) had a college degree or higher. This means that we may have missed some different thoughts and experiences of women related to screening during the pandemic. For instance, one of our participants shared that she could not go to screening because she is unable to wear a mask. We were not able to ascertain the exact reason she was unable to wear a mask, such as access or for medical reasons. However, it is possible she is one of the millions of Americans who are able but unwilling to wear a mask (Palosky, 2020). Another important factor is unemployment and loss of insurance for millions of Americans due to the pandemic that disproportionately affected women and people of color further limiting women’s ability to access breast cancer screening (Carethers et al.,

2020). Although these did not emerge as prominent themes in this study, we recognize that these are important barriers to consider and address. Lastly, as with all qualitative studies, we had a small sample size which limits our ability to know how generalizable the results of our study are to the larger U.S. population or beyond. However, our data analysis included triangulation and review by three researchers to assess dependability of our findings and member checking by our patient partners to assess transferability of our findings. These strategies to enhance rigor improves the trustworthiness of our findings (Korstjens and Moser, 2018) which can be assessed further for generalizability through additional quantitative studies (e.g., random survey).

Based on these findings, we recommend that providers and screening facilities continue to assure women of pandemic safety measures, practice safety measures, and review current methods and content of communications with women. In addition, barriers to screening that existed prior to the pandemic (e.g., access, anxiety about mammograms) are amplified and require additional consideration and resources to address. By paying attention to what women want and addressing their needs, we might mitigate some of the impacts of the pandemic on women’s health and well-being.

Disclosures

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Declaration of Competing Interest

The 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.

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