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# “Girl, just pray ...”: Factors That Influence Breast and Cervical Cancer Screening Among Black Women in Rochester, MN

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**Abstract:** *Background:* Black women in Minnesota and beyond have a greater burden of death due to some cancers than their White counterparts. Delayed screening and treatment may explain these disparate statistics. The purpose of this study was to work in collaboration with a local Black faith-based organization to gain an updated understanding of Black women’s knowledge, attitudes, and behaviors related to breast and cervical cancer, and determine to what extent known factors persist as barriers to accessing cancer screening among Black women in Rochester, MN. We also sought to identify unique barriers for Black women residing in a particularly health resource rich community.

**Methods:** Using a community-based participatory research approach, two academic institutes worked in collaboration with a local Black faith-based organization to conduct focus groups. Focus groups were utilized to identify factors that may limit Black women’s access to cancer screening and health care.

**Results:** Forty-five eligible participants attended one of eight focus group sessions. All participants self-identified as Black women and most were born in the United States. Content analysis of participant responses suggested that Black women’s health-seeking behaviors related to breast and cervical cancer screening continue to be very much influenced by known factors that serve as barriers to screening services. Four primary themes pertaining to these influential factors emerged from participants’ focus group discussions: 1) knowledge of cancer, risk factors, and screening options; and 2) socioeconomic factors, 3) psycho-social factors, including lack of trust of doctors specifically involved in clinical research, and 4) cultural factors, including reliance on religious practice in place of medical intervention.

**Conclusion:** Black women face real and perceived barriers to cancer screening even where health resources are abundant. Results reiterate an on going need for culturally appropriate interventions to improve Black women’s breast and cervical cancer screening participation by minimizing barriers and engaging entire communities – including Black women, religious leaders, and health care providers.

**Keywords:** Healthcare disparities ■ Focus groups ■ Community-based participatory research ■ African Americans ■ Faith-based organizations

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## INTRODUCTION

Cancer is the second leading cause of death in the United States, accounting for one-fourth of all annual deaths.<sup>1</sup> In Minnesota (MN), nearly half of the population can expect some type of cancer diagnosis during their lifetime and about one quarter of all deaths in MN are related to a cancer diagnosis.<sup>2</sup> Some Minnesotans, however, are more likely to be diagnosed with or die from cancer than others.<sup>2</sup> Specifically, for Black or African American women in MN and the greater United States, the burden of death due to some cancers is greater for them than their White counterparts.<sup>2,3</sup> In MN, while breast cancer incidence for Black women is thirty percent lower than White women, Black women’s breast cancer-related mortality is eight percent higher.<sup>2</sup> Black women also experience a twofold risk of death due to cervical cancer compared to White women, despite just a moderately increased risk of a cervical cancer diagnosis.<sup>2</sup>

Delayed screening and treatment may explain these disparate statistics.<sup>4</sup> A study by Harcourt and colleagues that examined participation rates in breast and cervical cancer screening among Black women living in metropolitan areas of Minnesota showed that 61% of the 112 women within the breast cancer group (all age 40+) reported never receiving a mammogram. Among the cervical cancer subgroup 48%, of 441 women respondents (age 18+) reported never receiving a pap smear.<sup>4</sup>

Timely screening results in early detection of cancer, appropriate treatment, and greater survival rates. Among Black women barriers to cancer screening include lack of knowledge about screening recommendations, competing life demands, difficulty navigating the health care system, low socioeconomic status, limited health care access and cultural beliefs.<sup>5–8</sup> Cancer fatalism or fear is a leading barrier to seeking screening and treatment among women

of color.<sup>9</sup> Frequently, distrust of the medical community is cited as being higher among Black or African American populations compared to Whites.<sup>10</sup> This distrust is a contributing factor to the lower utilization of cancer screening services and disparities in health outcomes for Blacks.<sup>11,12</sup> Many of these barriers may help explain the health challenges facing one city in Minnesota where the population has become increasingly diverse.

Rochester is located in rural southeastern Minnesota approximately 90 miles from the State's capital city of St. Paul. It is Minnesota's third largest city and home to an emergent population of Black residents who make up an estimated 6.9% of the population, compared to 6.2% of the State's total population.<sup>13</sup> As with other Black communities, many of Rochester's local Black residents are often noted as being socially connected through the faith-based organizations they attend.<sup>14</sup> Health-related interventions based in Black faith-based organizations have previously been successful.<sup>15–17</sup> It has also been noted that spirituality and religiosity may influence cancer screening in Blacks.<sup>18–20</sup>

The purpose of this study was to work in collaboration with the local faith-based Black community to gain an understanding of Black women's knowledge, attitudes, and behaviors related to breast and cervical cancer, and determine to what extent known factors persist as barriers to accessing cancer screening among Black women in Rochester, MN. We also sought to identify unique barriers and, in some instances, motivators for Black women residing in a particularly health resource rich community. As part of a larger study, focus groups were conducted to identify these factors that influence Black women's access to cancer screening and health care.

## METHODS

### *Community engagement*

This study was initiated in response to a community-identified need for increased access to cancer-prevention education and health services for Black women living in Rochester, MN. Two of the co-investigators of this project were previously involved with the development of another community-driven, church-affiliated men's health project.<sup>21</sup> Their work sought to describe Black men's perceptions and knowledge of diabetes via focus groups held in a barbershop that was uniquely affiliated with a church. At the conclusion of that project, members of the church suggested to their minister — a co-investigator of this project — that he conduct more research relevant to

addressing cancer-related health needs of local Black women.

Using a community-based participatory research (CBPR) approach we sought to include community stakeholders “in all aspects of the research process”.<sup>22</sup> Relationship building is fundamental to establishing CBPR efforts, and the relationship between the church and two academic institutions was developed over several years.<sup>22</sup> This was facilitated, in part, by the study being designed by three co-investigators — one from each of the involved organizations. The co-investigators also actively worked in partnership with several members of the church congregation to shape the study. The church members voiced concerns that the study results would not be accessible to them and sought assurances from the co-investigators that the study results first be directly shared with the participants and local community. Staying true to the principles of CBPR, the investigators ensured accessible dissemination of the research to the community stakeholders and research participants.

### *Participants*

Eligible study participants self-identified as Black women (i.e., of African American or African descent), were fluent English speakers and 18 years of age or older. Most participants had no formal medical/nursing training, nor were they currently employed as health care providers (i.e., nurses, physicians); all resided in Rochester, MN. Participants were recruited through one of several mechanisms, including flyers distributed at church or community center events by members of the community-academic research team, word-of-mouth, and social media posts. Although participants were largely recruited at events/venues that were associated with the local Black Christian church, several Black women of Muslim faith were also included in the study. These participants were largely recruited through flyers at a local community center and word-of-mouth from their Christian friends. Participant eligibility was determined via a short questionnaire when participants contacted the recruitment liaison to ask questions about the study or reserve a spot for an upcoming focus group session.

### *Study design*

The research team utilized a mixed methods approach using both focus groups and a sociodemographic survey instrument as the modes of data collection. Qualitative methods, such as focus groups, are commonly used to examine complex health issues that are influenced by

culture, race or ethnicity, and other aspects of group identity.<sup>23,24</sup> Qualitative methods can complement data collected via traditional survey methods. A focus group semi-structured facilitators' guide was created by the CBPR team to examine barriers and motivators to breast and cervical cancer screening, and to determine participants' knowledge, attitudes, and behaviors related to breast and cervical cancer and screening.

Each focus group session lasted approximately 90–120 min depending on the number of participants and their level of engagement. The sessions were held at one of several locations in Rochester, including spaces in the community/church, university conference rooms, and a hospital meeting room. During each session participants were welcomed and thanked for their willingness to participate, offered lunch, and asked to confirm that they met the study's eligibility requirements. Next, members of the research team obtained informed consent, assured participants of the confidential nature of the study, and asked permission to audio record the focus group discussions. Participants were remunerated with a \$20 gift card and lunch.

Just prior to the focus group discussions participants were asked to complete a survey developed by the investigators. Survey items inquired about sociodemographic variables including: age, race, country of origin, family income, educational attainment, type of health insurance, and previous cancer diagnosis. All participants completed their surveys in 20–30 minutes and focus group discussions commenced after the surveys were completed. Two members of the research team co-facilitated the focus groups with one serving as the moderator and the other a note taker whose primary role was to summarize participant comments on a series of visible large-scale post-it notes. Notes on participants' visual cues were recorded by a second note taker.

The lead facilitator followed the semi-structured focus group guide that the investigators developed to assess participant knowledge, attitudes, and behaviors related to breast and cervical cancer. Participants were asked to identify specific barriers and motivators to seeking breast and cervical cancer screening. Questions asked of participants included:

- What is breast/cervical cancer?
- What are the causes of breast/cervical cancer?
- What are the screening options for breast/cervical cancer?
- What prevents you from getting breast/cervical cancer screening?
- What motivates you to get screened for breast/cervical cancer?

The study protocol was approved by the Institutional Review Boards at the University of Minnesota and Mayo Clinic.

### Data analysis

After each focus group the audio recording was reviewed by two of the investigators. All recordings were then transcribed verbatim by a transcriptionist and verified for accuracy by comparing the transcripts to the original audio recordings. Two members of the research team independently reviewed the transcripts to identify emergent themes across the participants' responses. They utilized a directed content analysis approach and developed an agreed upon coding scheme to categorize factors that influenced breast and cervical cancer screening.<sup>25</sup> These codes were applied across all transcripts to identify and describe key thematic areas that emerged as barriers or motivators to timely cancer screening. After independently coding, the two investigators discussed differences in their coding and reached consensus on any discrepancies. *NVivo* (version 11.1.1, *QSR International*) software was used to organize and categorize participant responses. All members of the research team were involved in interpreting the results.

Sociodemographic survey data were entered into *Qualtrics* software (version 8/17, *Qualtrics*, Provo, Utah) to generate descriptive statistics for survey items. The continuous variable (age) is reported as a mean and range, and each categorical variable (e.g., country of origin, marital status, educational attainment, etc.) is reported as a frequency and percentage.

## RESULTS

### Participant characteristics

Forty-five eligible participants attended one of eight focus group sessions. All participants self-identified as Black women and most were born in the United States. Several of the focus group sessions included participants who were first- or second-generation immigrants from one of several African countries (see [Table 1](#)). Of those reporting their age ( $n = 32$ ), the average age was 36.5 years (range: 18–56). All of the participants completed at least the equivalent of a high school diploma, more than two-thirds obtained some level of education following high school or completed a college degree. Most reported having health insurance that was either employer-provided or public health insurance. Most also knew of at least one family member or friend who had been diagnosed with breast or cervical cancer, but only one participant had a previous cervical cancer diagnosis.

*continued...***Table 1.** Sociodemographic characteristics of Black women study participants (n=45)

Characteristic	Average	Range
Age		
Years	36.5	(18-56 years)
Characteristic	Frequency (n)	Percentage (%)
Country of origin		
United States	29	(63.8)
Sudan	7	(15.4)
Somali	5	(11.0)
Kenya	1	(2.2)
Nigeria	1	(2.2)
No response	2	(4.4)
Marital status		
Single	22	(48.4)
Married	13	(28.6)
Divorced/Separated	5	(11.0)
Committed relationship	3	(6.6)
No response	2	(4.4)
Education		
High School Diploma or GED	13	(28.6)
Associate Degree	3	(6.6)
Some college	11	(24.2)
Bachelors	9	(19.8)
Masters	6	(13.2)
Professional Degree	1	(2.2)
Doctorate	1	(2.2)
No response	1	(2.2)
Employment status		
Full-time (more than 32 hours/week)	18	(39.6)
Part-time (less than 32 hours/week)	9	(19.8)
Not currently working	13	(28.6)
Disabled and unable to work	1	(2.2)
Other	1	(2.2)
No response	3	(6.6)
Annual household income		
\$0-14,999	10	(22.0)
\$15,000-24,999	6	(13.2)
\$25,000-34,999	5	(11.0)

*continued...*

Characteristic	Frequency (n)	Percentage (%)
\$35,000-44,999	6	(13.2)
\$45,000-54,999	4	(8.8)
\$55,000-64,999	2	(4.4)
\$65,000-74,999	2	(4.4)
No response	10	(22.0)
Type of health insurance		
Private insurance (employer provided)	20	(44.0)
Public health insurance	19	(41.8)
No health insurance	5	(11.0)
No response	1	(2.2)
Previous cancer diagnosis		
Yes, cervical cancer diagnosis	1	(2.2)
No, cervical cancer diagnosis	43	(94.6)
No response	1	(2.2)

### *Emergent themes: factors that influence breast and cervical cancer screening among Black women*

Content analysis of participant responses suggested that Black women's health-seeking behaviors related to breast and cervical cancer screening are influenced by several factors. Focus group conversations revolved around factors that served as barriers to accessing cancer screening more so than motivators. Four primary themes pertaining to these influential factors emerged from participants' focus group discussions: 1) knowledge of cancer, risk factors, and screening options; and various 2) socioeconomic, 3) psycho-social, and 4) cultural factors.

**Knowledge of cancer, risk factors, and screening options.** Participants were asked to describe causes of breast and cervical cancer, as well as screening options for each. Participants demonstrated some knowledge of the risk factors for breast cancer by citing poor diet, physical inactivity, obesity and hereditary/genetic factors. Across all focus groups, at least some participants were able to identify or describe known risk factors for breast cancer. Participants also used unique language to describe social or interpersonal relationship concepts to describe what they saw as other risk factors for breast cancer:

**Table 2.** Emergent Themes: Barriers to Cancer Screening with Participant Quotes

Barriers	Participant Quotes
<b>1. Knowledge of cancer, risk factors, and screening options</b>	
<i>Low knowledge of risk factors for breast cancer</i>	"Okay, it caused when you're feeding the babies ... the milk's now going through and sitting [in] that area, it cause cancer. But I'm not sure."
<i>Low knowledge of risk factors for cervical cancer</i>	"Where – where is the cervix? I don't know what that is." "I thought it [cervical cancer] had – it just had to – it was just something that was there." "You don't hear as much about that [cervical cancer] as you do the breast cancer."
<b>2. Socioeconomic Factors</b>	
<i>Lack of health insurance (or under-insured)</i>	"I have insurance but it's real limited. It doesn't cover much, so that makes you very reluctant to want to go to the doctor if you've got to spend a lot of money..."
<i>Lack of transportation</i>	"... access to health care might not be a matter of the insurance or paying for it, but it might be a matter of getting there."
<b>3. Psycho-social Factors</b>	
<i>Family obligations</i>	"We as women, we so busy taking care of other people we don't think about ourselves ... and I notice that in my own family, they take care of everybody else and the next thing you know, they got type 2 diabetes."
<i>Perceived judgment from health care providers</i>	"... since I was young and having a kid, I had all these different diseases, I was like—she was just very judgmental, and she was very mean to me."
<i>Lack of trust in health systems and providers</i>	"Yes, it's not for us, yeah, they're [health systems/providers] out to get you ... and give you a disease." "... they don't trust the doctors where I come from." "...somebody's [doctor is] always trying to get them [patients of color] into a study because of Rochester [predominately white community], we're limited in the people that could participate in studies outside of Caucasian race."
<i>Lack of trust in conventional cancer treatments</i>	"Yeah, honestly if I had cancer, I would go to [African country]. I will be honest. I probably wouldn't want to go to the health care here [in Rochester, MN]."
<i>Fear of cancer or "the unknown"</i>	"That's all I can think of is scared of getting the bad news."
<b>4. Cultural Factors</b>	
<i>Religiosity</i>	"Because if I got cut, I went and got stitched. But if it was something else internal going on in my body, I prayed and asked the Lord to – take it away or remove it." "Trust God. Yeah, Pray about it." "...I wanted to trust God with my body." "Girl, just pray. Trust in God ... God going to take care of everything."
<i>Preferences for certain health care providers (gender, race)</i>	"I used to be afraid to have a male do it [gynecological examination] because I thought that he might be on some other things ..." "I mean I have also had Black women as doctors. And it's not [a] fact that I feel comfortable with them. The way they deal with me as a patient is what drives me to them."

Well, when you harbor unforgiveness in your body, you don't forgive somebody and you're still holding onto something that happened ten years ago, that cause your stress level to be up. Your body is never at peace because you're holding onto something you need to let go. It's [that] the forgiveness is not for the other person; it's for you to let go so you can be at rest. Your body has to be at rest as far as your stress—your hormones and your—I don't know some of the words—

This participant described “unforgiveness” or chronic stress due to unresolved interpersonal conflict as a causal factor for breast cancer, which resonated with other women in her group (see [Table 2](#)).

While most of the participants were aware of the recommendations for self-administered breast exams, routine physical exams, and mammography for detecting breast cancer; however, knowledge of cervical cancer risk factors and its screening were much lower among the participants. Many participants were not aware that the routine “pap” smear test is used to detect pre-cancerous cells or cervical cancer. When asked about cervical cancer, many participants indicated that they didn't know how to describe cervical cancer. A few participants lacked knowledge of the female anatomy or where the cervix is located in a woman's body:

Interviewer: So, what is cervical cancer?

Participant 1: I really don't know.

Participant 4: I don't know.

Participant 3: I don't know either.

Participant 2: Where — where is the cervix? I don't know what that is.

After another participant described the anatomical location of the cervix to the group, a participant followed up by stating: “No, sorry, I don't know how the cancer get there.”

Participants also described poor hygiene practices, female hygiene products, and incisions or tears from childbirth as possible risk factors for cervical cancer. In spite of the generally low knowledge of risk factors for cervical cancer, a few participants were able to identify Human Papilloma Virus (HPV) as the cause of most cervical cancers. Many more participants, however, were surprised to learn that a sexually transmitted infection was associated with development of this type of cancer. After a short discussion among participants about HPV as a cause of cervical cancer, one participant leaned back in her chair and said: “... what I did not know was if it was a specific

cause or reason why you could get it [cervical cancer] ... I thought it had ... it was just something that was there.”

Several participants acknowledged their own lack of knowledge of risk factors for women's cancer — cervical, in particular — and suggested that even if their awareness were improved, being aware of risk factors for the disease would not help them to reduce their individual risk of a cancer diagnosis:

... I feel like there are no preventive measures for cancer. There are things that you can do to keep your body healthy, but there are no preventative measures that you can take because if it is meant for you to take that path in your life and cancer is one of the paths you come across, then that is what your path is.

That is, they voiced a sense of hopelessness or lack of control in the face of a cancer diagnosis. Participants further indicated that their cervical cancer awareness may have been low because of what they saw as a lack of educational campaigns and public service announcements about cervical cancer compared to breast cancer. Participants also expressed frustration that the cancer prevention education messages they do receive often leave them with a lack of clarity regarding how to apply the health information or recommendations to help maintain their own health and wellness.

Many participants noted that they utilized what they did know about women's cancer risks to encourage their family members to seek cancer screening and other health care. They described ways in which they had used their own knowledge of cancer screening options to encourage hesitant female family members, in particular, to seek out cancer screening. One participant indicated that her intergenerational sharing of knowledge, limited or not, was critical because it was not cancer that had taken the lives of her older female relatives but rather that they had “died from the lack of knowledge of getting the disease or how to go in for treatment.” Participants repeatedly described ways in which they used their knowledge to motivate female family members to seek out mammograms or other cancer screenings.

**Socioeconomic factors.** Many participants also noted the ways in which various socioeconomic factors influenced their choices regarding accessing cancer screening. They explicitly described two socioeconomic factors that limited their access: lack of health insurance and transportation. Lack of health insurance or insufficient health insurance coverage was described as the major socioeconomic barrier to timely cancer screening. Among participants with private or employer-provided health insurance, many noted they felt that despite having health insurance

they were “under-insured” and thus, “reluctant to want to go to the doctor if you’ve got to spend a lot of money.” Among those without insurance or the under-insured, many were aware of the availability of free cancer screening programs for low-income women in the community but noted that these clinics still did not seem accessible given the possibility that they may incur additional “hidden” health care costs associated with the “free” breast or cervical screening or a subsequent cancer diagnosis.

**Psycho-social factors.** Several psycho-social factors were framed as barriers and, in some cases, motivators to accessing cancer screening. The psycho-social factors that influenced cancer screening include those related to one’s family obligations, perception that one might be judged by health providers, lack of trust in health systems or providers, lack of trust in conventional cancer treatments, and fear of cancer or “the unknown.”

*Family obligations.* Participants agreed that having significant obligations to take care of family members — being “so busy taking care of other people” — prevented them from being able to prioritize their own health and wellness. Participants described the heavy burden of their obligations to take care of elderly parents, children and grandchildren, suggesting that it is an excess burden common for Black women. Participants concurred with the notion that their own health comes secondary to the health of their children but also cited family as a motivator to seek out cancer screening as they recognized that maintaining their own health was important for the well-being of their family unit. Participants noted a desire to unburden their own children from care-taking expectations such that younger women in their families — their daughters — would have more time to prioritize their own health and wellness.

*Perceived judgment from providers.* The perception of negative judgment from health care providers was frequently mentioned by participants as a reason for not being screened. Several participants noted they felt judged by their health care providers during provider-patient encounters for various reasons including having started a family at a young age or seeking out treatment for sexually transmitted infections. Others noted that they had encounters with providers that left them feeling judged for reasons such as being overweight. One participant described how she felt that her former health care provider focused too much on the fact that she was overweight while recommending gastric bypass surgery and drugs that were “good for Blacks,” rather than listening to her health concerns.

Several of the participants of African descent, many of whom were second-generation immigrants, also feared that they may be judged by health care providers because they

were “different” in terms of their cultural or religious beliefs, language spoken, or atypical anatomy due to female genital mutilation or cutting (FGM/C). For example, one participant noted:

Especially for women who are circumcised. I think it's a lot more because the stigma of being circumcised [FGM/C] and being different and knowing that you know how it should look like and having to go show it to a doctor. ... Even if you were suggested and you know you don't look normal, it just—it puts out another pressure of not even wanting to—if you were offered the opportunity to get an exam.

Overall participants described their fears of being judged and shamed by providers for their life choices or other reasons beyond their control, and this frequently kept them from seeking out cancer screening.

*Lack of trust in health systems or providers.* Several participants also described a lack of confidence in their health care systems or providers. One participant noted that her lack of trust in health care providers had been instilled in her since childhood when she described how in the Southern state where she grew up “... they don't trust the doctors where I come from.” Others agreed that there was a shared cultural norm of not trusting health systems or providers because they were essentially “out to get you” or “give you a disease.”

In addition to this learned lack of trust, participants also described a lack of trust in some of the providers who were locally available because these providers were affiliated with a prominent research institution. To participants, this meant that providers were more interested in clinical research than patient care. Several participants discussed their perceptions of their providers as sometimes being overly interested in recruiting them as biomedical research study participants. Because the local community was predominantly White, one participant suggested that patients of color were sought after and targeted or recruited by physicians for enrollment in research studies. In her mind this came at the expense of patient care. At least one participant stated that after she felt she had been treated in this way by her doctor, she chose not to seek care from that provider.

*Lack of trust in conventional cancer treatments.* Some participants also specifically identified a lack of trust in or understanding of conventional cancer treatments, such as chemotherapy. A lack of trust in the type of treatment which they might receive as a result of a cancer diagnosis seemed to deter participants from seeking out cancer screening. Several participants noted that should they receive a cancer diagnosis after a screening, their



preference would be an herbal or what they described as a “100% pure” and “natural” cancer remedy rather than conventional chemotherapy. In addition, there was folklore about other “natural” or home remedies for cancer that emerged among both African American and African-born participants. These included “self-remedies ... castor oil,” “camel milk” with “no added preservatives,” and a combination of “goat meat and herb oil” as possible or preferred remedies for cancer.

*Fear of cancer or “the unknown.”* Participants noted fear as one of the most significant barriers to accessing cancer screening. Across all focus group sessions, fear of a cancer diagnosis and subsequently dying as a result of the diagnosis was the first barrier identified and agreed upon by members of each group. One participant said, “Fear of getting the bad news,” to which nearly all other group members nodded in agreement. At least one woman explicitly noted that while she recognized the need for mammograms, “fear” kept her from following through on her screening appointments. Others noted they recognized that early detection of cancer was important for an improved prognosis, but that fear still influenced their health decision-making around scheduling cancer screening appointments: “Right, procrastinating and dragging your feet because you technically want to know, but you really don’t.”

Conversely, some women noted that their strong desire “to know” had helped motivate them to overcome their fears and seek out cancer screening. Several other participants echoed that they “just want[ed] to know” of a cancer diagnosis as soon as possible for an improved prognosis. Many women noted that fear of cancer perpetuated a learned culture of secrecy around women’s cancers which persists in Black communities and families. Participants suggested that their profound fear of cancer was reinforced by this type of secrecy, which served to deter many of the participants from actively seeking out health care and screening in a timely manner.

**Cultural factors.** Several cultural factors emerged in participant discussions and were framed by participants as being significant barriers to cancer screening. These factors included religiosity and a preference to receive care from female providers. In certain instances, participants also described aspects related to their religiosity or religious practice as motivators to get screened for cancer.

*Religiosity.* Religiosity is a construct that can be used to characterize one’s level of belief in and practice of organized religion, as well as their participation in religious activities such as church attendance.<sup>26</sup> Many participants described ways in which their religiosity or strong “faith in God,” at times, had led them to rely on the “power of

prayer” rather than seeking out health care to detect cancer or treat medical conditions: “... I don’t really like it [gynecological exam], especially when they’re taking a pap smear. I don’t like it. I’d rather not have it [pap smear]. I say, ‘I trust my God.’” Several noted that this strong reliance on faith in the face of illness was passed down through generations: “You was told by your grandma and your great-grandma, ‘Girl, just pray. Trust in God ... God going to take care of everything.’”

Another participant described how, during a point in her life just after she was “born again” or re-committed to Christianity she had been particularly resistant to seek out health care: “When I was younger, I’d say about the age of eighteen, I [had] been reborn again. And I just didn’t go to doctors. Not because I didn’t believe that they were experts in what they did; it’s just because I wanted to trust God with my body.” This participant (2) went on to discuss with other group members how she made the distinction between which types of ailments or injuries required health care and those that she chose to simply “trust God” to resolve:

Participant 2: ... Because if I got cut, I went and got stitched. But if it was something else internal going on in my body, I prayed and asked the Lord to—

Participant 3: Remove it.

Participant 2: —take it away or remove it.

Participant 1: Mm-hm.

Many participants agreed that they regularly delayed seeking care or screening when “something internal [was] going on with my body” such as noticing symptoms that might typically be associated with a possible cancer diagnosis and require invasive medical intervention. Yet they more promptly sought out health care in instances of acute injury or illness.

Both Christian and Muslim participants described being deeply connected to their places of worship and noted the prominent role of the church or mosque in their respective Black communities. Some participants further described ways in which their religious faith helped them to minimize their fears of cancer or a cancer-related death. Others agreed that their strong religious faith was an asset in that their faith leaders were highly trusted individuals who had helped to take “the fear out of it [cancer]” through their religious teachings and social support. Participants suggested that faith leaders could do more by educating congregants and explicitly encouraging them to seek out cancer screening: “You need the pastor to stand up on the pulpit and say, ‘They have a free so-and-so, so-and-so check [up] for our community. I think you should get your kids out there and make sure everybody’s in tip-top shape.’”

Participants further described that their influential religious leader's messages should extend beyond religious teachings and into health messaging "because if you could tell me that I'm going to hell, then you could tell me where I can go, [some laughing] where I can go and get a check-up, so my body can stay good." Christian participants echoed that the "best way for them to hear about breast cancer or cancer in general is at church." Many Muslim participants, however, noted that their mosque was not an appropriate venue to reach them with health education messages. They indicated that their house of worship was often inaccessible to them due to religious and cultural norms. For example, they were not in attendance at the mosque during their monthly menstrual cycle or because they were the primary care taker for their small children in the home.

*Preferences for certain health care providers.* Several participants noted their strong preference to receive medical care from female health providers because "showing your body" to a female doctor was, for them, both culturally acceptable and more comfortable than being seen by a male provider. This often stemmed from the participants' religious beliefs, but sometimes it was simply a personal preference that led them to feel uncomfortable with a male doctor conducting breast or other gynecological examinations. The women stated that despite the wealth of providers in Rochester, it sometimes remained a challenge to ensure timely appointments with female doctors or that they previously made an appointment with a female doctor only to have the clinic change the physician to a male provider prior to their visit. This was particularly problematic for observant Muslim participants who indicated that their religious or cultural beliefs would prompt them to decline to receive health services from a male provider regardless of their immediate health need.

Participants of both religious faiths indicated that seeing a doctor who was of their same race was far less important than patient-provider gender concordance. For example, several participants described instances in which they were treated by a same-race or Black health care provider, but that the race concordance with their provider had not ensured that they felt "comfortable" during the interaction.

## DISCUSSION

Rochester, MN is home to an abundance of world-renowned doctors, clinics, and hospitals — most of which are potentially available to members of both the local and broader community. For many reasons, however, these health resources, including cancer screening, may be under-utilized by the local communities of color. Previous studies, have consistently identified lack of knowledge, low socioeconomic status, limited health care access,

cancer fatalism, fear of the unknown, and other cultural beliefs as factors that influence Black women's cancer-related health care decisions.<sup>6–9</sup> We sought to identify the current factors that continue to influence specifically breast and cervical cancer screening among Black women in this Midwestern community.

Qualitative findings from focus groups revealed varying levels of knowledge of breast and cervical cancer and their screening options. Study results also indicate that Black women may know more about breast than cervical cancer. Participants identified known breast cancer risk factors such as obesity and genetic factors. They were also aware of recommendations to undergo mammograms and perform self-examinations. There was notably less knowledge of cervical cancer, risk factors, and screening among participants. Focus group conversations among some women suggest minimal understanding of the anatomical location of the cervix. Participants concluded that their lack of knowledge may be due to cervical cancer messages not being as prominent in the media. Their lack of awareness of the risk factors and routine screening option for cervical cancer suggests that our participants were not likely to seek out screening even if they were high-risk.

Existing literature suggests that lack of knowledge or awareness is associated with failure to participate in measures to reduce cancer risk or receive early diagnosis.<sup>27</sup> A literature review by Jones et al. (2014) explored barriers to early presentation and diagnosis with breast cancer among Black women and similarly found delays in screening were due to poor knowledge of symptoms and risk factors.<sup>6</sup> The consequences of such delay can include late-stage cancer diagnosis and symptom exacerbation.<sup>28</sup> There is some evidence that Black women appear less likely than White women to have a thorough understanding of certain cancers and their risks.<sup>29</sup> Thus, disparities in cancer outcomes by race may, in part, be attributed to differences in knowledge or awareness of cancer risk factors and screening options. In alignment with previous studies, our results reiterate an on-going need for culturally appropriate health education messages about cervical and other cancers that target and resonate with Black women.

Participants openly acknowledged feeling that they lacked sufficient knowledge of women's cancers. They also expressed a strong desire to learn more about the risk factors and screening options for women's cancers — in particular, cervical cancer. Despite a lack of comprehensive cancer knowledge across all participants, many still described their efforts to use what knowledge of cancer they did have to educate older female relatives on risk factors and the importance of screening, and to motivate their relatives to seek out health care. Our results suggest

that Black women can and do play an important role in helping to educate their family members about cancer screening and risk factors. This intergenerational knowledge sharing may be critical to increasing uptake of cancer screening among older Black women, as it is well-documented that having limited cancer-related knowledge at an advanced age is also a barrier to screening.<sup>30</sup>

Development of a strong knowledge base is an essential first step toward promoting health-seeking behaviors intended to detect and prevent cancer. Studies suggest, however, that many women fail to seek out cancer-related care despite having appropriate information.<sup>31</sup> A study that explored women's health-seeking behavior for a self-discovered breast symptom determined that even when they were knowledgeable about cancer, other factors impeded women from taking action to protect their health.<sup>32</sup> Similarly, women in our study suggested they felt that even if they were aware of risk factors for cancer that they still would not be able to prevent themselves from developing cancer. Thus, in addition to providing targeted health education messages on breast and cervical cancer, health promotion efforts must also address other barriers such as those which emerged in our study.

Consistent with the literature our study found two prominent socioeconomic factors that contribute to delays in cancer-related health care seeking behavior: lack of adequate health insurance and transportation. In MN, Blacks are more than twice as likely to be uninsured when compared to Whites.<sup>33</sup> This difference in health care coverage may help explain the cancer disparities across racial groups in MN. Congruent with other studies conducted among Black women<sup>34</sup> our participants also noted that inadequate health insurance greatly limited their access to health care. In some instances, participants mentioned free breast or cervical cancer screening programs available through community resources but indicated these free screenings had hidden costs or would lead to additional burdensome costs. Participants perceived free screenings as largely inaccessible because of their fears that a possible cancer diagnosis could result in additional medical expenses not covered by their limited health insurance.

As has been previously documented, Black women in our study also cited a lack of reliable transportation as a barrier to accessing health care.<sup>35</sup> Rochester's public transportation system is not as extensive as larger metropolitan areas. Regular bus routes, however, operate on weekdays from various points across the city. In a reasonable amount of time these buses bring passengers to the downtown area, where many of the city's clinics and hospitals are located. Participants seemed to suggest that lack of transportation was a barrier, but that it could more

readily be overcome than the more significant barrier of not having access to sufficient health insurance.

Several psycho-social factors were also identified by the women as deterrents to seeking cancer screening, including: family obligations, perception that one might be judged by health providers, lack of trust in health systems or providers, lack of trust in conventional cancer treatments, and fear of cancer or "the unknown." Other studies have previously reported these as influential factors that shape women's decisions regarding seeking cancer screening and other types of health care. For example, feeling embarrassed to share information about one's body parts and believing that the responsibilities of the home take priority are commonly cited psycho-social factors.<sup>36</sup> Moreover, being fearful of the outcome of cancer screenings causes some women to avoid care or deny their cancer symptoms.<sup>37</sup> Our findings confirm that these psycho-social factors persist and continue to influence cancer-related health-seeking behavior among Black women — even those who reside in a health resource rich community.

Our results also suggest that lack of trust in health systems and providers, another psycho-social factor, is a barrier to accessing cancer screening among Black women. This type of lack of trust may be contributing to disparities in cancer morbidity and mortality, and may have other negative health implications for communities of color. Participants voiced concern about feeling targeted for participation in research by their health care providers and suggested they did not trust that providers would have their best interests in mind when connecting them to opportunities to enroll in clinical trials. This is cause for concern given that Blacks historically have been underrepresented in biomedical research.

Studies suggest many Blacks may have a strong interest in participating in research.<sup>38–40</sup> Increasing the participation of Blacks in biomedical research is critical to ensure that study results are generalizable to broad populations like the increasingly racially diverse population of Rochester, MN. Black women's negative attitude toward research has been noted as a barrier to recruiting them for clinical research studies.<sup>41,42</sup> Our research suggests that many Black women may continue to lack trust in health care providers and health systems, which often serve as gateways to cancer screening services as well as inclusion in biomedical research. It is important for providers to remain aware of these perceptions as they continue to work to build trust with Black women in an effort to increase their access to cancer screening and other health resources which may be available via clinical trials.

Lastly, several cultural factors emerged from our participant discussions and were described as barriers to

seeking cancer screening. These factors included, participants' preference for specific provider characteristics, such as gender. As the literature suggests, female patients commonly prefer to receive their medical care from health providers of the same gender as them.<sup>43</sup> Our study affirmed this and suggests that the participants might delay cancer screening and other health care if they were unable to receive that care from a female gender-concordant provider. Indeed gender-concordance was considered more important than race-concordance among our focus group participants.

Religiosity, another cultural factor, played an important role for participants. Understanding the influence of one's religiosity on health decision making is particularly important for this population given that, based on measures such as "attending religious services at least once a week," African Americans are deemed "more religious" than their White counterparts and other ethnic groups.<sup>44</sup> Results of studies examining the relationship between religiosity and general health suggest that higher levels of religiosity are associated with better mental and physical health, and more health promoting behaviors.<sup>45-47</sup> Results of other studies that specifically examine religiosity and cancer screening are more mixed. Some suggest that those with higher levels of religiosity are more likely to be screened for cancer,<sup>18,48,49</sup> while others suggest that religious beliefs or belief in God either has no association with or may deter patients from seeking out cancer screening.<sup>50,51</sup>

Results from our study suggest that Black women may at times rely on faith or "trust God with my body" particularly when it comes to "internal" symptoms that could be consistent with a possible cancer diagnosis. As such, high levels of religiosity might be framed as a barrier to cancer screening. Women also described several ways in which their religious leaders, in particular, had served or could serve to motivate them to seek out cancer screening. Some participants noted that support from their faith leaders could allay their fears of cancer or cancer-related death. High levels of religiosity among participants also meant that they, especially those of Christian faith, were receptive to receiving more health education and cancer prevention messages directly from their most trusted faith leaders.

### *Strengths and limitations*

A strength of this study is that we utilized a CBPR approach to address a specific community-identified need to identify barriers such that access to cancer screening and health care might be improved for Black women. Several members of a local Black faith-based organization were involved in development of the research plan and their faith leader served as a member of the research team. All

of the co-investigators were responsive and accountable to the community stakeholders and ensured that the results were made accessible to them prior to dissemination to the scientific community. Results were shared at a community health event in which participants and their invited guests were informed of the results. Also, as per the participants' request, the event included an interactive breast and cervical cancer "question and answer" education session that was facilitated by a female doctor of color. In addition, participants were connected to representatives from free local cancer screening programs and other cancer-related health information through a small health resource fair. Future research should continue to focus on the development of culturally appropriate interventions that take into consideration providing screening, health education, and referrals to resources based on participants' needs and screening results.

Our qualitative study included a culturally and ethnically diverse group of Black women all of whom noted strong ties to their Christian or Muslim religious faiths. We saw this religious diversity as a strength; however, future research questions might further explore specific barriers for women of faith versus those who do not have strong ties to religious faith. Our study also included women from various countries of origin, including several of whom were recent immigrants to the United States. Further investigations could shed light on specific barriers or motivators to cancer screening that may differ between domestic and foreign-born Black women. Future research in this community might also include Black women living beyond the city limits of Rochester, as they may experience unique challenges if they utilize health services within the city limits but reside further from the centrally-located clinics and hospitals. Lastly, because our study focused on Black women our findings may not be generalizable to other groups of women.

As with other qualitative studies, our data collection process depended on participant self-report and focus groups, which can result in reporting of socially desirable responses. While we were able to successfully recruit participants to the study we ran into some recruitment challenges which participants suggested were due, in part, to the time of year. Some reported not wanting to participate in focus groups during the study period which coincided with the short warm weather season in MN. Initially the research team chose to partner with one church and thus intended to recruit only Christian women to the study, however, with the help of the community partner and research participants we were able to adjust our recruitment plan to include women from the Muslim community.

## CONCLUSION

Even in a city with an abundance of health resources and low doctor to patient ratio, Black women continue to face a collection of known barriers to accessing cancer screening and other health care. These barriers include those related to knowledge, socioeconomic, psychosocial, and cultural factors. Cultural barriers related to one's religiosity seem particularly powerful as some Black women of faith may at times "trust God" or rely on faith as they delay medical interventions or screening that could detect cancer. The unique cultural and medical environment of "Med City" (Rochester, MN's nickname) may also present some additional challenges for accessing care or cancer screening. For example, participants noted a lack of trust in providers or health systems due, in part, to negative perceptions that their doctors intended to enroll them in biomedical research studies simply because they are people of color in a predominantly White community.

Findings further suggest that Black women often engage in intergenerational knowledge sharing within their families as they educate and encourage family members to seek out cancer screening. Black women voiced the desire to learn more about breast and cervical cancer and may be particularly receptive to cancer prevention interventions that are led by faith leaders in their churches. A community engaged research approach increases the development of sustainable community-academic partnership, builds trust, and empowers community members to shape the nature of research projects.<sup>22</sup>

This project laid groundwork for further opportunities in Rochester with other Black faith-based leaders to effectively engage in delivering cancer prevention information. Ultimately our findings reiterate that there remains significant work to be done toward increasing access to cancer screening for Black women such that we might minimize racial disparities in cancer outcomes in MN and beyond.

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