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Views of Low-Income Women of Color at Increased Risk for Breast Cancer

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Abstract

Individual risk assessment (IRA) for breast cancer may increase adherence to risk-appropriate screening and prevention measures. However, knowledge gaps exist regarding how best to communicate IRA results and support women at increased risk in future health care decisions, in part because patients conceptualize and make meaning of risk differently from the medical community. Better understanding the views of low-income women of color identified as being at increased risk for breast cancer can inform efforts to conduct IRA in an ethical and respectful manner. We conducted in-depth interviews with 13 low-income African American and Latina women who receive care at a federally qualified health center (FQHC) and had recently learned of their increased risk for breast cancer. These interviews explored their experience of the IRA process, their interpretation of what being at increased risk means, and their reactions to provider recommendations. Eight key themes were identified. We conclude with recommendations for the implementation of IRA for breast cancer in underserved primary care settings.

Keywords

African Americans; Breast Cancer; Health Disparities; Individual Risk Assessment; Latinas; Prevention; Primary Care; Qualitative Interviews

Background

Cancer prevention education has been increasing its emphasis on the importance of knowing one's individual risk. This emphasis is particularly strong in breast cancer prevention because the disease is not monolithic and risk may vary greatly among diverse groups of women across the life span (Kurian, Fish, Shema, & Clarke, 2010). Screening and prevention recommendations are also risk dependent (Saslow et al., 2007; Visvanathan et al., 2013). Therefore, individual risk assessment (IRA) for breast cancer is being introduced into primary care settings with the aim of increasing adherence to risk-appropriate screening and

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prevention measures (Hoskins, Zwaagstra, & Ranz, 2006; Kaplan et al., 2014; Moyer et al., 2013, 2014).

Risk is a complex construct; it is central to the understanding of health and health-related decisions (Robertson, 2000). However, the ways in which patients understand and interpret risk vastly differ from its clinical meaning (Sanders, Campbell, Donovan, & Sharp, 2007). The medical community assumes that patients' understanding of risk is a key motivator of their health and health care practices, but this may not always be the case. Risk does not exist in isolation from individual circumstances and social context, and human decisions are not always rational (Vahabi & Gastaldo, 2003). A review of qualitative studies on lay understanding of cancer risk found this to be "affected by people's feelings, their intuitions, and the degree to which they feel in control or wish to be responsible for their risk ... [Understanding of cancer risk] is also changed by people's personal experience of cancer, their life-stage relative to ... [these] experiences, their sense of their own bodies, the way in which they are able to incorporate cancer risk into their identities, and their intimate and communal relationships (Lipworth, Davey, Carter, Hooker, & Wu, 2010). Accurate knowledge of risk may be necessary to guide (appropriate) action, but it is not sufficient.

There are many theoretical perspectives on risk. Key theories can be thought of as existing along a continuum. At one end of the spectrum is a realist or postpositive approach, which completely ignores the influence of social and cultural contexts on understanding of risk. In this perspective, risk is synonymous with probability, and failure to adhere to a risk-related recommendation, such as more frequent mammography, is deemed irrational. At the other end of the continuum, a strong constructionist perspective believes that the way in which humans understand risk is completely different from (mathematical) probability and entirely dependent upon social context. A middle position, the weak constructionist perspective—which we espouse—views risk-related decisions as primarily driven by rationality but also limited by time, cognitive issues, and the fact that some factors influencing a decision or action (e.g., access) are simply beyond an individual's control (Vahabi & Gastaldo, 2003).

Other studies examining patients' knowledge of disease risk have found that understanding is generally poor and that women of color may incorrectly underestimate their risk of breast cancer (Orom, Kiviniemi, Underwood, Ross, & Shavers, 2010). Yet the ability to accurately recall what was said by a doctor is not the same as meaningful understanding, and accurate understanding does not necessarily translate into action (Sivell et al., 2008). Research on the psychological and emotional impact of genetic counseling and testing services suggests that knowing more about one's health status and risk ultimately improves psychological well-being (Hilgart, Coles, & Iredale, 2012). However, research on the psychological impact of learning about individual breast cancer risk in the primary care setting has not included sufficiently diverse samples of women. Many underserved women receive primary care at federally qualified health centers (FQHCs). Patients served by FQHCs are at increased risk for a variety of cancers, and they generally have worse outcomes when they are diagnosed (Ward et al., 2004). Therefore, we were not solely interested in the accuracy of women's understanding of their individual risk for breast cancer. Gaps exist in knowledge regarding how best to communicate IRA results and how to support women at increased risk regarding future health (e.g., weight loss, smoking cessation) and health care decisions (i.e., enhanced

surveillance, chemoprevention, or genetic counseling/testing) (Anderson & Hoskins, 2012). Understanding the views of low-income women of color identified as being at increased risk for breast cancer can inform efforts to conduct IRA in an ethical and respectful manner. Therefore, we aimed toward a better understanding of what additional supports might be needed to encourage women to act on risk-specific recommendations. To this end, we conducted interviews with 13 low-income women of color receiving care at an FQHC clinic who had recently learned about their increased risk status from a discussion with their primary care provider (PCP).

Methods

Recruitment and sampling

Results presented here were gathered within an exploratory study on the feasibility and acceptability of conducting IRA for breast cancer in low-income primary care clinics (Anderson et al., 2015). Research took place between September 2012 and April 2013 at two sites of an FQHC in Chicago. The protocol was approved by the University of Illinois at Chicago IRB. Female patients ages 25–69 presenting for a scheduled annual well-visit appointment with their PCP were invited to participate in a study on women's views of breast cancer. In order to be eligible, participants had to have no previous history of breast cancer and at least one intact breast. During our 8-month study period, a total of 448 women were identified as eligible for participation. Of these, 261 were approached, 246 agreed to participate, and 243 enrolled.

Immediately prior to each participant's visit with her PCP, research staff administered a baseline survey and collected risk factor data, which were entered into the Breast Cancer Risk Screening (BRS) Tool created specifically for this study. A more detailed description of the BRS Tool is reported in our prior publication (Anderson et al., 2015). Briefly, the BRS Tool incorporates the modified version of the Gail model (Gail et al., 1989) available as the National Cancer Institute Breast Cancer Risk Assessment Tool; the latter also includes both the CARE (Contraceptive and Reproductive Experiences) model developed for African American women (Gail et al., 2007) and the Claus model (Claus, Risch, & Thompson, 1994). Because the Gail and Claus models do not account for some factors that indicate increased risk for hereditary breast cancer and may fail to identify women at risk for hereditary breast or ovarian cancer and non-BRCA hereditary syndromes, the BRS Tool also includes the Pedigree Assessment Tool (PAT) (Saslow et al., 2007; Hoskins, Zwaagstra, & Ranz, 2006; Teller et al., 2010), which evaluates family history to identify women at increased risk for BRCA-related and non-BRCA hereditary breast cancers who require referral to genetic counseling. The PAT was developed by one of the authors of this article (KFH) for screening women in the primary care setting; it is one of the four instruments recommended by the U.S. Preventive Services Task Force (USPSTF) to identify women who should be referred for genetic counseling (Moyer et al., 2014). The BRS Tool classified women at increased risk if they had a 5-year risk $\geq 1.7\%$, a lifetime risk $\geq 13\%$, or a PAT score ≥ 8 . Otherwise they were classified as population-average risk.

If a woman agreed to learn her IRA status by discussing the result with her provider, risk was calculated immediately and shared with the provider prior to the appointment. A total of

213 women (87.6% of 243 participants) agreed to learn their IRA results. Recommendations for screening, prevention, and genetic counseling generated by the BRS Tool are guideline-based and risk-specific.

Recommendations regarding frequency of screening as well as early initiation of mammography are based on National Comprehensive Cancer Network (NCCN) guidelines (NCCN, 2013a); recommendations for breast MRI as an adjunct to mammography are based on American Cancer Society (ACS) guidelines (Saslow et al., 2007). Risk-reducing lifestyle modifications for women in all risk categories are based on ACS recommendations. The recommendations for chemoprevention for women at increased risk are based on Food and Drug Administration (FDA) indications for specific drugs (Waters, McNeel, Stevens, & Freedman, 2012). Recommendations for referral for genetic counseling are based on NCCN guidelines (NCCN, 2013a, 2013b).

Of the 213 women who agreed to learn their IRA results, all who were identified as being at increased risk ($n = 16$) were invited to participate in a follow-up interview, which was completed within 2 to 6 weeks following enrollment. Thirteen agreed to participate, including 11 African American women and 2 Latinas (both of these interviews were conducted in Spanish, the participants' preferred language). We do believe that we reached saturation of themes (Sankar & Jones, 2008), but would have continued conducting interviews with Latina women identified as being at increased risk for breast cancer had our study identified more of them. This would have allowed us to identify differences and enable comparisons with African American women.

Interviews were conducted by three individuals (an author [ST]) or one of two research assistants) using a structured interview guide developed based on a literature review. Interviewers shared the same race/ethnicity as the participant in all but one case. At the start of the interview, participants were reminded of their choice to opt in or out of learning the results of their IRA. Women were asked to talk about what they learned as well as their reasons for deciding to learn the results of the assessment. Follow-up questions focused on exploring their psychological and emotional reactions to learning that they were at increased risk for breast cancer, actions or plans regarding prevention or screening (e.g., mammography, genetic counseling), and general beliefs about breast cancer. Interviews lasted an average of 23 minutes.

Data analysis

All interviews were audio-recorded and professionally transcribed. Spanish transcripts were translated into English. Data were managed using Atlas.ti (Version 7.0). Interview transcripts were coded using conventional content analysis (Forman & Damschroder, 2008; Hsieh & Shannon, 2005). Although interviewers followed a structured interview guide, we decided against attempting to categorize responses according to a preconceived set of codes; instead, we used an inductive approach to content analysis, allowing themes to emerge from participants' own words. Coding was completed by two investigators (EA and ST). Each manuscript was read independently by both coders to generate open codes and create a preliminary codebook. For the interviews conducted in Spanish, one coder (ST) coded the original Spanish transcripts. After the initial codebook was developed, the coders re-read the

manuscripts, then met to discuss discrepancies and create a final set of codes. After coding of all manuscripts, a final list of eight themes with subthemes and representative quotes was generated. These themes are summarized in Table 1 and discussed in more depth after a brief description of participant characteristics.

Results

Description of sample

Of the 13 participants we interviewed, 11 were African American and 2 were Latina. Three were between the ages of 18 and 39, four between ages 40 and 49, and six between ages 50 and 69. The majority (69%) had greater than a high school education; all except one reported annual household income below \$30,000, and about half (54%) were employed full- or part-time. Most (92%) reported being uninsured. Nine (90%) of the 10 women who were over 40 self-reported ever having had a mammogram, and 7 (54%) reported having previously discussed breast cancer risk with a health care provider. Only one participant stated at the beginning of the interview that she did not remember being told by her doctor that she was at increased risk for breast cancer. Pseudonyms are used in reporting quotes.

General views on breast cancer risk

In discussing their general views of breast cancer risk, participants' comments highlighted several predominant beliefs, particularly that breast cancer is common. The views that all women are at risk for breast cancer, and that the disease strikes women at random without reason or pattern, were also often expressed. Comments such as "anyone is vulnerable to getting it" (Angela, age 54) and "breast cancer is so prevalent in the world today" (Betty, age 53) exemplify these attitudes. Perhaps most illustrative of the belief that breast cancer may not be avoidable is this comment from Marisa, a 32-year-old Latina whose aunt and cousin on her father's side had both had breast cancer:

Nowadays I have the mentality that you don't get breast cancer because of something; you're going to get it because you're going to get it. You can get it, I can get it, anyone can get it ... I say that when you get cancer it's because it was your turn. It's a disease that you get and you don't know if it's because of how you cared for yourself or if it's just that it was your turn.

Several participants' comments suggest that probabilities related to chances of developing breast cancer are not strictly—or accurately—interpreted. Many of the women interpreted any and all "chances" as being equal: that is, they believe that risk is random. Family history and behavior are important, but ultimately you still might get breast cancer no matter what you do.

Interestingly, beliefs that breast cancer is both ubiquitous and random were expressed alongside the understanding that family history is a key risk factor and that behaviors (particularly diet and smoking) also play an important role in cancer risk. Many women accurately expressed that although family history increases your risk, you do not have to have someone in your family with breast cancer to be at risk. The comments of the other

Latina participant, 34-year-old Susana, demonstrate how for many women these beliefs all co-exist side by side:

Many women also get [breast cancer] because of what they've had, because you don't necessarily need ... other people in your family having had cancer for you to get it. That depends on, like, what type of life you've lived, ... the food that somebody eats because, ... like, red meat is the worst thing for a woman, right, many things. So then, that's why I think that many women will probably get breast cancer. Not just because it's hereditary, rather, because they [are] like, "we all have it," but they're not taking care of themselves.

A few women expressed incorrect beliefs about breast cancer, including the belief that women with large breasts are at greater risk and that breast cancer risk decreases with age. However, overall most women expressed a basic understanding that breast cancer is caused by a combination of genetics, environment, and behavior. Women talked about family members who lived healthy lives and still got cancer, as well as family members who did not take care of themselves or go to the doctor and were diagnosed too late. Understanding of the important influence of both behavior and genetics was held in tension with a sense of fatalism that breast cancer may be unavoidable despite healthy behavior or clear family history.

Reasons to learn about individual risk

Participants cited many reasons for wanting to learn the results of their IRA; the most frequent reason given was general curiosity. Echoing health education campaigns, most women stated the importance of awareness and viewed participating in IRA as another way to learn more about breast cancer. Some equated knowing their risk with being empowered for prevention. A few articulated more concrete benefits, such as getting information to help them prevent breast cancer or, more frequently, to detect it earlier and increase their chances of survival. Said Rose, age 37:

It is better to be safe than sorry. So if you know, you can go and take steps to prevent it, maybe defer it, put it in remission, whatever the case needs to be. I would rather know than not know, and then go down the line and they say, "Hey, you have Stage IV breast cancer and there's nothing I can do about it."

Lena, age 45, thought that she might find out "something that could save my life." Some participants mentioned that information about individual breast cancer risk might guide future health and health care decisions, but nothing specific was mentioned in this regard.

Many participants mentioned that knowledge of their family history influenced their decision to learn their IRA results, which is not surprising. Almost all of the women related that prior to their IRA they were suspicious that they might be at increased risk due to family history. However, a few had never talked to a health care provider about this before participating in this study. For example, 53-year-old Gloria said: "That was the first time I heard it, here. You know, didn't know my ... I never ... it wasn't put like that to me... This [that I am at increased risk for breast cancer] is new information."

The fate of future as well as past generations motivated participants to learn their IRA results. Several women mentioned that they thought doing so would provide information to help their children or other younger female relatives. For example, Marilyn, age 62, stated:

I have two daughters and granddaughters and I want to feel that, you know, whatever happen [*sic*] to me, they'll know ... and then they can do research or something or go to the doctor and find out, you know, be more careful... . Get regular checkups and stuff... .

Curiosity, hope for potential benefits, knowledge of family history, and a desire to help future generations motivated these women to learn more about their individual risk for breast cancer.

Reactions to learning about individual risk

Participants expressed a few different reactions in response to learning that they were at increased risk for breast cancer. These included a wide range of emotions, but not too much worry. For most of these women, their increased risk was not new information—or, at least, it was not surprising—given their knowledge of their family history and the role that this plays in breast cancer. However, a few participants did state that they were surprised to learn that they were at increased risk for breast cancer: for example, Judy, age 47, because she had had a mammogram the previous year; and Gloria, despite knowing that her mother had had breast cancer, because she had never been told directly that she was also at increased risk for the disease.

Other responses to learning that they were at increased risk for breast cancer included fear and worry, concern and discouragement, and uncertainty and denial. However, no one expressed extreme negative emotions. A few participants specifically stated that they were *not* worried, either because they did not believe that they would develop breast cancer or because other health issues more prevalent in their family, such as diabetes and hypertension, were perceived as more immediate threats. Several stated that worrying would cause unnecessary stress and that they just needed to be diligent about self-exams and getting mammo-grams in order to detect cancer early. For example, Rose said:

I can't spend my life worrying about if I'm going to get breast cancer or not ... That's unnecessary stress, and I go to the doctor often enough that if I do get breast cancer or if I do have a test where it shows up, I think that I'll be in a situation to catch it early enough that some steps can be taken.

Being at increased risk for breast cancer does not mean that you will get it

Most participants did not interpret being at increased risk to mean that they would definitely get breast cancer. In fact, only one participant, Susana, stated that she believed being at increased risk means “that I will probably get cancer ... Since my mom ... had ovarian cancer the doctor told me ... that I would probably be getting breast cancer... .” And later on, she minimized the role that family history plays in breast cancer risk:

[I]t isn't something that is more probable, like I'm going to get it because it's hereditary from my mom, right. So there are many women who don't ... have that

disease in their family. There's a chance that they may get it, there's a chance that they won't.

Others simply believed or "felt" that they were not going to get breast cancer, despite being told that they were at increased risk due to family history. For example, 52-year-old Linda said:

I really don't feel that I'm going to get breast cancer. I think that at the age that I am I believe that I would have had it by now. I just believe that. I mean, I've had my mammograms. I've had biopsies back in the past, and thankfully they all came out negative. So for me it's not a big, big concern of mine because I said I think if I'm going to die one day, which I know I will die, I don't think it's going to be because of cancer. I think it's going to be because of something else. Because we're all going to die from something, right? ... I know we're all going to die from something; but again, I just don't believe cancer is going to be my downfall.

Like Linda, a few other women's comments suggest that although they were told they were at increased risk (and understood that family history played a significant role in this calculation), having a recent negative mammogram or biopsy meant that they did not need to worry *now*.

Making sense of family history of breast cancer

Participants' comments describe how complicated family history can be. For example, Darlene, age 47, said:

You know, with my sister having breast cancer ... , I want to tell myself, I want to rationalize and say because me and my sister we have the same mother, not the same father ... , "Well, maybe because my sister got breast cancer, but no one else on my mother's side have [*sic*] breast cancer that I know of, and with us not having the same father, I can't think of anyone on my [side,]" ... so I want to rationalize it. But I'm still, ... you know, I understand that it's a likelihood ...

Darlene's statement also demonstrates a common process of rationalization. For example, Rose said:

I think my sister got breast cancer because she didn't really go get herself checked out or take any precautions ... I don't think cancer runs in our family ... I've got a hundreds [*sic*] family members ... I'm the only one that got a different father ... if it came from their father's side of the family, that ain't got nothing to do with me.

Some respondents acknowledged the link between family history and increased risk but identified other reasons why specific family members developed breast cancer. Marcia (age 47), for example, believed that her daughters were more at risk for breast cancer than she was because, like her sister who had had breast cancer, her daughters have large breasts:

I definitely talk to both of my daughters because they have, they're big breasted women ... and they have more high risk than I do ... because they have, my sister died of breast cancer. She was very big breasted so I always tell them, you know,

the importance of taking a mammogram and ... self breast checking for themselves ... when they see their doctor once a year to get their mammogram done.

Finally, making sense of family history was complicated by the fact that any information these women may have had about a family members' diagnosis, disease progression, or death was almost always incomplete.

Information gaps about genetics

One of the potential benefits of conducting IRA for breast cancer in underserved primary care settings is that high-risk women can be identified and referred to appropriate preventive services. In our study, women identified as being at increased risk for breast cancer were referred for genetic counseling if appropriate. (Genetic counseling was offered to women in this study for free and no data related to genetic counseling were collected for study purposes.) A few mentioned that they had talked to a genetic counselor but for the time being had decided against proceeding with genetic testing. However, some women appeared to be confused as to why they were referred to genetic counseling or believed that they did not need counseling because "everything seems fine now" (Angela, age 54). Some, such as Darlene, mentioned the burden of genetic counseling—including the need to gather all the information about family members' health histories—as "discouraging." Susana talked to her husband and sister, who convinced her not to continue:

Because [my husband and sister] said it's better to try to follow the advice the doctor gave me; try to diet and do everything ... my husband asked me, "But if you wind up knowing, is there something they can give you to avoid it?," and I told him, "No, because if I'm going to get cancer, I'm going to get it." He said, "Okay, then don't get it. It's better to try to follow the advice that they are giving you because ... [the doctor] told you herself that there's nothing that they can give you to avoid it, nothing" ... and my sister also told me the same thing ... they said, "But if either way you're going to get cancer, the cancer is going to appear." They said, "There's no reason to know it already when you're going to get it. You don't know how it's going to affect you. Maybe it's going to mess with your thoughts, your emotions," ... right now I'm a very happy person so they said, "You don't know how it's going to affect you."

Because Susana's husband and sister did not understand (or believe) that prevention is possible (and Susana did not know enough to correct them), they saw no additional value to genetic testing and therefore discouraged her from exploring this option further. Furthermore, they feared that knowing more about her genetic-based risk would only make her upset.

Other women, including Marcia, had already decided that they would not take chemopreventive medication even if they had a positive genetic test, and so chose to forgo testing. A few participants expressed mistaken beliefs about the genetic test (e.g., that it would be able to tell you precisely when you would get cancer) or about genetics (e.g., that cancer would skip a generation).

Uncertainty regarding breast cancer prevention

Participants had mixed views regarding what, if anything, could be done to prevent breast cancer. While several acknowledged the role of behaviors such as diet, exercise, and smoking, many did not know about the potential of chemotherapeutic medications (e.g., tamoxifen, raloxifene) to prevent or at least delay the onset of the disease, despite the recommendations automatically generated by the BRS Tool. (Unfortunately, we do not know what the doctors actually discussed, only what the BRS Tool recommended.) Several participants expressed fatalistic attitudes, such as “you’re going to get it because you’re going to get it” (Marisa) or “things happen sometimes and you have no control over it, so you just have to learn to deal with it” (Lena). Some participants (including Marisa) discussed family members who lived extremely healthy lifestyles but still got breast cancer. Others seemed uncertain about breast cancer prevention but at the same time acknowledged the general health benefits of certain behaviors. As Susana expressed it, “In other words, there are things that won’t help you avoid it, but they can help.”

Participants discussed other challenges to prevention and early detection, including barriers to accessing health care, their (and other women’s) propensity to put others’ needs before their own health, the urgency of other health concerns (particularly diabetes and hypertension), and the fact that people do not really talk openly about health in general and about breast cancer specifically.

Women were much more certain, however, about the importance of getting regular mammograms in order to facilitate early detection of breast cancer. However, few participants mentioned risk-specific mammography recommendations such as starting at age 40, getting more frequent (annual) mammograms, or breast MRI. A few participants expressed that they did not particularly enjoy getting mammograms but got them anyway because they were necessary. Most women seemed aware that if cancer was detected early this would greatly decrease the chances of it being fatal. However, based on family members’ experiences, several women talked about going the doctor as soon as they “feel” or “notice” something, indicating that this population may rely too heavily on breast self-exam as a means of early detection.

Skepticism about chemoprevention

Five of the 13 women interviewed in this study were identified as candidates for chemopreventive medication (e.g., tamoxifen or raloxifene); the others were not eligible based on FDA criteria (Waters et al., 2012). Information about chemoprevention was included as part of the feedback automatically generated from the BRS Tool. However, if a PCP was not comfortable talking about or prescribing tamoxifen or raloxifene, he or she could refer the patient to a high risk clinic at our academic medical center at no cost to the patient. Unfortunately, we could not know for sure if PCPs discussed chemo-preventive medications, or the content of such discussions. Several women specifically stated during the interview that there was no medication that could help prevent breast cancer, suggesting that this recommendation was either not communicated or got lost in translation. However, among those who did mention discussing chemoprevention with a PCP or specialist, there seemed to be some ambivalence and in some cases, such as Marcia’s, outright concern:

I think about all of the side effects that is included [*sic*] in taking those pills for the next five years; what can happen, and by me having high blood pressure in my family and diabetic. It's a lot of diabetics in my family. I just don't want to take that risk because I could be—I'm at the level where I could be a diabetic and I don't want anything interfering with mixed medications ...

Discussion

IRA in primary care may be an effective method for addressing disparities in breast cancer mortality, but there are ethical challenges to implementation in low-resource settings. Our exploratory study found that IRA is feasible and acceptable in underserved primary care clinics. Interest in IRA appears high among our sample of underserved women seeking primary care at an FQHC. Women in our study wanted to know more about their breast cancer risk and were willing to engage in a conversation started by their clinician (Anderson et al., 2015). But our findings have implications for implementation.

Ethical concerns have been raised regarding the potential psychological harms of risk assessment (Anderson & Hoskins, 2012). Consistent with our findings from quantitative assessments of negative emotions such as worry (unpublished data), women who learned of their increased breast cancer risk did not express particularly strong negative reactions in their interviews. However, findings from these interviews suggest that more education and support are needed to help women better understand the implications of being at increased risk for this disease. There appear to be significant educational gaps and a need for *tailored* educational efforts for low-income, underserved women identified to be at increased risk for breast cancer. The widely held belief that breast cancer is common and that everyone is susceptible is consistent with current media messages, indicating that beliefs are likely to be influenced by many sources besides PCPs. This creates an interesting and complicated backdrop for learning about “individualized” risk. Women viewed participating in IRA as a way to learn more about breast cancer, but they did not necessarily personalize the information as intended. Some of those whom we interviewed expressed an implicit belief that even though the IRA identified them as being at increased risk, they were fine because they had had a recent negative mammogram. This incorrect belief, combined with the fact that only a few women noted increasing age as a risk factor for breast cancer, means that the individualized and long-term implications of the IRA may not have been adequately communicated or understood.

The women we interviewed appeared to understand that family history plays an important role in breast cancer risk, but the connection between family history and lifestyle and screening behavior is complex. Consistent with the literature on family health history and chronic disease, many factors affect individuals' perceptions and feelings about their risk, and family history influences these perceptions, feelings, and, importantly, behaviors in a variety of ways. As in other studies, we found that factors such as the experience of a relative's illness and perceived differences or similarities between themselves and the affected relative can conflict with epidemiological risk models (Claassen et al., 2010).

However, as other studies have found, gaps persist in the understanding of genetic risk (Sivell et al., 2008). The women in our study did not necessarily express belief in genetic determinism, but there were several statements indicating a lack of understanding about how disease is passed from generation to generation. Additionally, IRA for breast cancer in primary care will require linkages to services for women identified as being at increased risk (e.g., genetic counseling and testing, enhanced mammography).

As an adjunct to IRA, more education is needed regarding the importance of mammography for early detection, specifically the importance of enhanced screening for women at increased risk. Women must understand that it is not enough simply to go to the doctor when you feel that something may be wrong. This message is especially important for those who are at increased risk due to a family history of breast cancer, as they should be getting earlier and more frequent mammograms and perhaps even MRI screenings, which may not be available at community-based health centers and may require referrals and additional costs.

Education is also needed about prevention and not just early detection. Many women in our study implicitly or even explicitly expressed a belief that there is no way to prevent breast cancer, whether through health behaviors or preventive medication, which is contrary to scientific evidence. Very few mentioned any plans to change their behaviors in accordance with specific breast cancer prevention recommendations (e.g., increasing physical activity). Our interviews also suggest that education is needed for high-risk women regarding *lifetime* risk for breast cancer. It is particularly worrisome that several of the women we interviewed indicated a belief that having had a recent, negative mammo-gram seemed to contravene their IRA's identifying them as being at increased risk.

Our study has several limitations. First, our sample was small and limited in geographic scope. Our sample also included only relatively healthy women seeing their PCP for a well visit, not for any acute condition or current problem with a chronic condition, and who also had high rates of mammography. We did interview almost all of the women identified at the clinic during an 8-month recruitment period as being at increased risk, and we reached saturation of themes among African American women. However, because we did not identify very many Latina women at increased risk for breast cancer we could not determine whether their beliefs or concerns differed at all from those of African American women.

Second, we do not know exactly what each provider talked about with each woman; we only know which recommendations were automatically generated by the BRS Tool. There may have been cases in which conversations did not happen, were brief or unclear, or were misunderstood. Nevertheless, we do know that in most cases the primary care provider discussed something about breast cancer risk (only one woman did not remember being told she was at increased risk). Knowing more about the patient-provider interaction would be helpful in terms of making recommendations for future educational efforts, but we are still able to make some recommendations for future research and implementation of IRA for breast cancer in underserved primary care settings based on our conversations with patients.

Future Research Directions

Our qualitative findings provide some suggestions for future research on how IRA may increase adherence to risk-specific breast cancer prevention and screening guidelines. Prevention guidelines recommend chemoprevention for many women identified as being at increased risk for breast cancer (Moyer et al., 2013). Similar to other studies (Ropka, Keim, & Philbrick, 2010; Karavites, Allu, Khan, and Kaiser, 2015), we found that women's interest in chemopreventive medication was low. Future research should explore in greater depth views and decisions about chemoprevention, especially among low-income women of color at increased risk for breast cancer and including those who have been diagnosed with or are at risk for other acute or chronic conditions. Studies have also found that PCPs are reluctant to prescribe chemopreventive agents (Ravdin, 2010), and future research should investigate underlying reasons for such attitudes and the potential effects on patients' knowledge, interest, and uptake.

Our interviews focused on the conversations that women had with their PCPs, and it was not an aim of our study to follow up with women specifically regarding genetic counseling and testing (although this may have happened after the interview). Future research should explore the perceived benefits and experience of genetic counseling and testing among low-income women of color. More research on individual breast cancer risk assessment with Latinas is needed, as we only identified and interviewed two Latinas who were at increased risk.

Future research should also examine longer-term outcomes of implementing IRA in primary care settings, such as the prevention or delay of onset of breast cancer, the stage at which breast cancer is identified, and mortality rates. Studies measuring long-term outcomes should be sufficiently powered to assess racial and ethnic disparities.

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Table 1**Themes Identified in Interviews with Women of Color at Increased Risk for Breast Cancer**

Theme	Description of Subthemes
General views on breast cancer risk	<p>Breast cancer is common.</p> <p>All women are at risk for breast cancer, even those without family history.</p> <p>Breast cancer strikes at random.</p> <p>A woman might still get breast cancer no matter what she does.</p> <p>Family history, environment, and behavior play a role in breast cancer.</p> <p>Some women expressed incorrect beliefs.</p>
Reasons to learn about individual risk	<p>Women were generally curious about breast cancer.</p> <p>Women know breast cancer awareness is important, and believe that “knowledge is power.”</p> <p>Women wanted information.</p> <p>Women knew that they had a family history of breast cancer and that this meant something for their health.</p> <p>Women wanted information to help future generations—daughters, granddaughters, and nieces.</p>
Reactions to learning about individual risk	<p>Emotional reactions varied.</p> <p>Not many women expressed worry, and no one expressed extreme negative emotions.</p> <p>Some women were surprised.</p> <p>Only one woman did not remember being told she was at increased risk for breast cancer.</p> <p>A few women were uncertain about what it means to be at increased risk for breast cancer, or in denial about their own increased risk.</p> <p>Other health issues were perceived as more immediate threats.</p>
Being at increased risk for breast cancer does not mean that you will get it	<p>Women knew that being at increased risk was not a “death sentence.”</p> <p>Some women simply “felt” they would not get breast cancer, despite being told that they were at increased risk.</p> <p>Some women assumed that having a recent negative mammography or biopsy meant that they were no longer at increased risk.</p>
Making sense of family history of breast cancer	<p>Family history can be complicated.</p> <p>Women do not always have complete information about their family history.</p> <p>Some women rationalized their family history, identifying reasons other than genetics to explain why specific family members developed breast cancer.</p> <p>Some women with a family history of breast cancer believe that they are not at risk because the family member with breast cancer looked or behaved differently from them.</p>
Information gaps about genetics	<p>Some women were confused about why they were referred to genetic counseling.</p> <p>Some women did not want to have genetic counseling because it was too burdensome.</p> <p>Family members also need education to help women make decisions about genetic counseling.</p> <p>Some women believed that breast cancer cannot be prevented and therefore saw no point in genetic counseling.</p> <p>Women have incorrect understanding about what information a genetic test can provide.</p>
Uncertainty regarding breast cancer prevention	<p>Many women did not know about chemopreventive medications.</p> <p>Some women expressed a sense of fatalism and lack of control when it came to breast cancer.</p> <p>Women cited several barriers to accessing preventive care, including the health needs of other family members and more urgent personal health problems.</p> <p>Uncertain as to whether breast cancer could actually be prevented, women focused on mammograms and the importance of early detection.</p> <p>Women over-emphasized the importance of breast self-exam and believed that going to the doctor when they “feel” or “notice” something was equivalent to early detection.</p>
Skepticism about chemoprevention	<p>Women who were aware of chemopreventive medications expressed ambivalence or concerns about side effects.</p>