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## The Meaning of Breast Cancer Risk for African American Women

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### Abstract

**Purpose**—To describe African American women’s experience of being at high risk for breast cancer.

**Design**—A hermeneutic phenomenological approach was used to guide in-depth interviews and analysis. Methods to ensure trustworthiness and rigor were included.

**Methods**—Open interviews were conducted with 20 African American women who were at high risk for breast cancer (family history, personal history, genetic mutation). They were recruited from a cancer risk clinic and community based settings. Data were transcribed verbatim and themes were labeled among and between all interviews.

**Findings**—Five themes were identified: (a) life changing experience; (b) relationships: fears, support, and concerns; (c) the health care experience; (d) raising awareness; and (e) strong faith.

**Conclusions**—Young women at high risk for breast cancer have unique emotional and support needs that are shaped by stage in life, relationships with significant others, their faith, and interactions with the health care delivery system.

### Keywords

breast cancer; young women; African American women; phenomenology; high risk

## Breast Cancer Risk and African American Women

Breast cancer is the most commonly diagnosed cancer among women in the world with an estimated 1.4 million new cases in 2008. (American Cancer Society, 2011A). Globally, half of breast cancer cases occur in economically developing countries (ACS, 2011A). According to the World Health Organization, breast cancer is the leading cancer killer among women aged 20–59 years in high-income countries (WHO, 2009). In the United States, breast cancer is the second leading cause of cancer death for women.. Despite the many advances in breast cancer detection, diagnosis, and treatment, African American women (AAW) are more likely to die from the disease. While the overall incidence of breast cancer is higher in white women after age 45, incidence of breast cancer in African American women under age 45 is higher. Regardless of age, African American women are more likely to die from the disease (ACS, 2011B). Young AAW age 45 have an increased risk for a higher incidence of breast cancer, higher probability of recurrence and thereby higher mortality rates when compared to other women of comparable age.

Regardless of age, African American women across all age groups have a higher death rate from the disease. African American women age 45 and younger with breast cancer are more likely to have tumors characterized by poor prognostic factors increasing the risk of recurrence and higher mortality rates (Yankaskas, 2005/2006; ACS, 2011B)). Women under the age of forty are under the recommended age requirements for mammography screening, the gold standard for the early detection of breast cancer. To date no established preventive measures exist for breast cancer; therefore the greatest hope for reducing breast cancer mortality and improving breast cancer survival lies in early detection and prompt follow-up treatment. The American Cancer Society (ACS) provides one of the most frequently cited guidelines for the early detection of breast cancer in average risk asymptomatic women age 40 and older. These include: 1) annual mammography; 2) annual clinical breast examination and; 3) optional monthly breast self examination for women age 40 and older. For average risk, asymptomatic women age 20–39, recommendations include 1) clinical breast examination every three years and; 2) optional monthly breast self examination (ACS, 2011B). For women at an increased risk (family history, genetic mutation, past breast cancer) the ACS recommends that women talk with their physicians about the benefits and limitations of starting mammography screening earlier, having additional examinations such as MRI and ultrasounds or having more frequent examinations (ACS, 2011B). Genetic testing may also be recommended for high risk women.

Currently limited research exists that examines the breast cancer risk perceptions and related behaviors among high risk young African American women. Several studies have examined breast cancer risk perceptions and related behaviors with African American women (Hughes Halbert et al., 2006; Kessler, Domchek, Stopfer, & Hughes Halbert, 2008; Underwood, Richards, Bradley, & Robertson, 2008; West et al., 2003). However, no studies were located with the explicit purpose of exploring the meaning of breast cancer risk for African American women age 40 and under. Few researchers have used qualitative methods to examine the meaning of being high risk. One qualitative study by Spector and colleagues (2009) examined risk perceptions and lifestyle behaviors among high risk black and white women. Results showed that high risk African American women were more likely to have a higher perceived risk for developing breast cancer and were more likely to make lifestyle changes due to their family history when compared to white women in the study.

The purpose of this study was to describe the experience and meaning of being at high risk for breast cancer (family history, personal history, and genetic mutation) for African American women age 40 and under. An understanding of African American women's experience with breast cancer risk and related follow-up screening and lifestyle behaviors is needed in order to promote healthy lifestyles and early detection, prompt follow-up for abnormal findings, and adherence to breast cancer surveillance recommendations. Elucidating psychosocial issues, health seeking behaviors, information and coping needs of this population is important in order to be successful in promoting breast cancer early detection and prompt follow-up care for high risk populations.

## Methods

This study was guided by hermeneutic phenomenological, descriptive and interpretive, research methods (Cohen, Kahn, & Steeves, 2000). These research methods are based on phenomenological philosophy and are used to determine how people interpret their lives and make meaning of what they experience. The approach was selected because the purpose of the study was to understand the meaning of an experience from the perspective of persons who have had that experience (Cohen, Kahn, & Steeves, 2000).

## Sample and Setting

Twenty high risk African American women age 23–40 with a family history, genetic mutation or personal history of breast cancer were recruited from a major academic medical center specializing in managing high risk populations. In addition, women not receiving care at the clinic were recruited from community based settings including through a breast cancer support group for African American women, and through referrals and postings in community based settings. The recruitment of high risk individuals outside of the Cancer Risk Clinic setting was done to increase the diversity of experiences described. The first author recruited, screened, and interviewed all participants upon arrival to the cancer risk clinic. For women outside of the clinic, this investigator screened women for eligibility and interest via the telephone. Women who met the criteria and agreed to participate were interviewed in a setting of their choice including their homes or the researcher's office. Twenty women were interviewed twice until no new themes were apparent.

Twelve of the 20 participants had a personal history of breast cancer and eight of the participants had a family history of breast cancer. Women with a known history of breast cancer regardless of length of diagnosis or history of remission were eligible to participate. The age at diagnosis ranged from 20–37. Thirteen of the women were unmarried and all had at least a high school education with 9 having a college degree. Five of the women were on Medicaid and 14 women had private insurance. One participant reported having a state issued women's health card for women's health services only. Eight participants had a first degree relative with breast cancer, 7 had two first degree relatives with breast cancer and 2 participants had 3 or more first degree relatives with breast cancer.

## Data Collection Schedule and Procedures

Permission to conduct this study was obtained from the institutional review boards of three medical centers, the University of Chicago, University of Illinois, and University of Nebraska Medical Center. After women signed informed consent forms, they were interviewed in phenomenological interviews. Women were asked to share the experience of being at high risk for breast cancer. Interviews were all conducted by one African American interviewer who used open-ended questions to ensure that the person being interviewed, rather than the interviewer, determined the content discussed. Specific examples were asked for to illustrate general statements. The goal was to help participants verbalize — that is, they were encouraged to discuss their experiences fully, and to clarify their own meaning and to ensure that the meaning of their experiences was clearly understood. Interviews were designed to capture participants' perceptions relative to breast cancer risk.

Each initial taped interview lasted from 60–90 minutes and second interviews ranged from 30 to 60 minutes. During the second interview, participants were asked to review and add to their transcribed interviews. They made minor corrections, usually transcription errors, and no additions. All transcripts used pseudonyms to ensure confidentiality. Participants completed a questionnaire assessing personal demographics and personal/family health history of breast cancer. Participants were given \$50.00 for the completion of both interviews. Finally, four participants reviewed a summary of the themes identified in the overall study. Participants reviewed the themes as well as a sample of quotes representing the respective themes. Participants confirmed that their experience was accurately captured.

## Data Analysis

As is usual with hermeneutic phenomenological designs (Cohen, Kahn, & Steeves, 2000), data analysis began during data collection. Interviews were audio-taped and transcribed verbatim, and the transcription's accuracy was verified by the interviewer. Phenomenological analysis was performed by the interviewer and another investigator with

extensive experience using this type of analysis. Both researchers began the analysis by reading each transcript several times to get a sense of each interview as a whole. Themes were identified in each transcript by examining it line by line and underlining and labelling passages with tentative theme labels. Passages from interview text and labels, or theme labels, for each interview were compared with passages and themes among and between all other interviews (Cohen, Kahn, & Steeves, 2000). In the hermeneutic circle, the researcher starts uncovering a tentative notion of the meaning of an experience using reflective awareness. This awareness leads to dialectical examination of parts of the data to better understand the whole. When the whole is understood, different data or the same parts of the data are examined at a deeper level. Then the analysis is repeated. The process helps the researcher to understand the statements in relation to the larger context of the individual's experience.

Procedures to ensure scientific rigor included validation of the themes with several women who were interviewed and between members of the research team. Both authors of the paper reviewed the theme labels and passages, and discussed them until consensus was reached. Interviews were conducted until data saturation was reached (that is, until no new themes emerged), meeting the standard criterion used in qualitative research (Cohen, Kahn, & Steeves, 2000).

## Findings

Five themes were identified: (a) life changing experience; (b) relationships: fears, support, and concerns; (c) the health care experience; (d) raising awareness; and (e) strong faith

**Life Changing Experience**—Dealing with breast cancer was described as a life changing experience both by those who had a personal history and those with a family history of breast cancer. For those who were living with an actual diagnosis of breast cancer, life took on new meaning. One patient explained:

Striving for the best. I'm not going to shortcut any places. I've been given a new lease on life and each day is an adventure and I take it very serious. ... What am I going to do today? What kind of fun are we going to have? And I just make it happen. (37 year old women newly diagnosed with breast cancer)

A long term survivor described the life changing experience of breast cancer by sharing:

Life itself has taken on a different meaning, you know. I always tell people to give me a sweat-shirt that says, 'whatever.' I don't sweat small stuff anymore, and I was one that, I was like always stressed. I wanted to be in control of everything. I wanted to get this done; caring about everyone else, and now it's about, it's okay, and me. (40 year old, diagnosed at age 34).

Having breast cancer in one's family was also life changing, prompting a call to action. One woman noted:

I guess because I'm getting older now the majority of women in my family developed breast cancer around middle age or whatever, like early 50's and 40's like that- my grandmother and my great grandmother. It's just, I feel that I should be more concerned about it now, especially since I'm going to get my exams and everything. (24 years with family history of breast cancer)

**Relationships: Fears, support, and concerns**—This second theme includes women's relationships with families, significant others and children. For some, relationships got stronger, for others they were less supportive or disappointing. One woman spoke of the strain between herself and her mother who was struggling to cope with the threat of her

daughter being diagnosed with breast cancer. This participant experienced a strained relationship with her mother as she coped with repeated biopsies and expressed concern that her mother did not take her fear of breast cancer seriously. . This participant was very frightened and preoccupied with the threat of developing the disease. She noted:

My mom can't accept if I was sick. She can't accept that, so it's like, "all girl, you go ahead on," this that or the other. "What do you need? You need a car? You need this, you need that". She can't accept, she can't talk to me about my breast. (39 year old with multiple biopsies, fibrocystic condition on preventive Tamoxifen)

One participant with a personal history of breast cancer commented on the strained relationship with her father. She attributed some of the tension to his unresolved grief related to her mother's death at age 35 from breast cancer. Her father had unresolved issues and perhaps fears for his daughter now diagnosed with the same disease.

I think he just feels bad because he lost my mom to breast cancer and I think maybe his having to watch me suffer through it—it made him angry with me.. He's done and said things that have been very hurtful. He says things like I use cancer to get what I want or I think that because I have cancer, like nobody can tell me "no" about anything. That's not the type of person that I am. (28 year old, survivor of multiple reoccurrences, first diagnosed at age 20)

Participants commented on their relationships with their significant other. Whether single or married, women expressed concerns regarding their relationships with the men in their lives. One participant commented on the challenges of dating while coping with the threat of breast cancer. She noted the difficulties with communicating with the men in her life about the emotional issues associated with being at risk developing for breast cancer.

It's been a really emotional rollercoaster. I have not—dated and stuff....because I know that I can't give the emotional support I guess that most people want. To me with guys that I've dated before, they act like they understand and then after while it's like, 'okay, you ain't got it, get over it and let's move on.' (39 years with multiple biopsies for fibrocystic condition, on preventive Tamoxifen)

One married survivor shared her need to have her husband better understand what she was experiencing as a breast cancer survivor.

As much as men understand, he doesn't really think about it. I have to remind him of certain things like, 'this is my bad arm, don't touch me on that arm, I don't like to be touched back there,' just stuff like and, and reminding, you know, that he 'you need to know certain things like, I had my ovaries out. So in case I can't speak for myself, medically, you need to know what's going on. I never forget when I had my oophorectomy he's like 'are you having this because I didn't get the vasectomy?' I'm like, 'are you listening to me? That has nothing to do with you!' (40 years diagnosed at age 34)

Many women with and without a history of breast cancer had very supportive spouses or significant others. Some commented on the fact that their loved ones accompanied them to doctor visits and supported them as they waited for reports.

To have my husband go with me to all the appointments; and there is something to be said about when you're the patient, you are so distracted and scattered brain—as a medical student, you hear all this, that they don't hear half of what you say—and you leave and you're like, 'they didn't tell me that?' 'Yes, we did,' you just didn't, couldn't hear. So to have someone else who was there with me to ask questions that I would have ask if I were in my right mind, and you know, so whatever, so I felt

like we had a good experience in general. (39 year old physician, diagnosed at age 35)

One woman commented on waiting to hear results of her genetic testing. She noted:

I told my fiancé about it. He asks me if I was sure I wanted to know. I told him yeah. But other than that--I told my sister. My sister thought I was too young and that I should've waited... I ask him was he going to come with me, and he told me yes. And he asks me why did I want to know at such an early age. I told him because that was very important and something that I need to know—that was it. He was just like, okay, that he was going to come with me. (25 year old with strong family history of breast cancer)

A newly diagnosed unmarried woman described marriage and child bearing as being central to her quality of life. She envisioned one day getting married:

I am very excited about marriage. I cannot wait to finally meet the man that wants to marry me; very, very excited—can't wait to have children. My mom is like beyond excited for that. I don't know, 'when you're going to meet the man, because you're always running somebody off, and I'm not ever going to have any grandchildren.' So she's even more excited. But I'm very excited. I cannot wait to meet the man that I will marry. I want to get married first, and then a couple of years later, we'll have children. (23 year old, diagnosed 9 months earlier)

All of the women who were mothers spoke of their children and the need to be around to see them grow up. Others commented on alerting their children to their family history of breast cancer. One participant talked about her daughter in light of having five affected female family members with breast cancer:

Knowing that my sister has the gene. This is something that I need to be more serious about, that's another reason why I came on in [to be tested]. I have a three-year old daughter that I want to see grow up and graduate from college and high school. I want to be able to see her kids and my grandkids, you know. My mother wasn't here to see my daughter. (33 year old with strong family history of breast cancer)

One mother noted that her children got her through treatment and daily activities. A mother of nine year old twin boys fondly recalled her son saying:

'Mommy don't worry, we got two more days and you will be okay.' I would say, 'yes I am,' and that's what really got me through; them—those two—they really got me through it—because it were days like, 'I just can't do this; I can't do this,' and they would come in, 'Hi Mommy, it's going to be a great day.' (37 year old, recently diagnosed)

**The Health Care Experience**—Participants spoke about barriers to care, some were financial and others were related to health care providers and the health care delivery system. Women spoke of the high cost of being treated for breast cancer with little or no health care coverage. Women also spoke about the high cost of surveillance care needed because of their high risk status:

I've had two MRI's, which one was \$5,000 and one was \$2,000. My insurance doesn't pay it at all. ...They don't pay it unless you have been diagnosed with cancer. ...So, that's why I haven't had another one. I haven't had one since 2006. (39 year old with multiple biopsies, fibrocystic condition on preventive Tamoxifen)

Still another spoke about the cost of being treated for breast cancer with limited income and inadequate health coverage.

I'm still broke! Unfortunately, breast cancer affects you in a lot of ways and I had to file Chapter Seven. I had a lot of medical bills, and I still do, because it's like, I'm not going to not go and see my doctors just because I don't have any money. I'm not going to die because I can't pay my bills. I have an aunt that goes to [hospital] on a regular basis with chronic asthma and she tells them, 'as long as I owe you, you'll never go broke.' So I'm not saying that I'm not going to pay my bills, but I pay them as best that I can; but at the same time, I'm not going to deny myself from seeing my doctor. (37 year old, diagnosed at age 34)

Participants spoke about the quality of their relationships with health care providers. Some relationships were very positive; others left much to be desired. Participants expressed concern that providers thought they were too young to have breast cancer. Even for those seeking care for abnormal breast findings, their concerns were not always met with appropriate attention. One participant commented on the watchful waiting recommended for young women with breast symptoms. She noted:

She [physician] told me, 'you're a healthy thirty-four year old, see you in five years' ... I got on the elevator, went upstairs—at the time I was working in surgery—so I talked to one of our head nurses and I'm like, 'you know, that don't sound right because I think—I know my primary doctor is not going to do a needle aspiration—so I would feel better if I went to at least one of the breast surgeons. Do you have someone that you recommend?' And so, that's how that happened. So I called down to breast, and got setup to see Dr. and met with him ... I would prefer even if it is a cyst, to have it removed and tested. And that's how it happened. So we had that surgery. Removed it and went back to get the results and that's when he said it was tested positive for cancer. It was infiltrating ductal carcinoma stage—I want to say Stage 2. (40 year old diagnosed at age 34 strong family history)

Another survivor commented on going from an insensitive provider to one who approached her and her diagnosis with more sensitivity, something she wanted all women to experience. She noted:

He was not a good doctor to me.... He pulled out the freaking algorithm and showed a flow chart like, 'Oh, since you have this, then we will do this.' And I'm like, 'you're going to boil my life down to a flowchart?' So it didn't make me feel like he was really interested in my recovery; so I didn't go to him. So I went and got my second opinion from another lady. I met with this lady and she came in with energy and she was like, 'we're going to knock this cancer out. We are going to get you better.' So just saying that, even if she had the same algorithm, at least she didn't show it to me. So I went with her. (36 year old diagnosed at age 26)

**Raising Awareness**—Regardless of diagnosis, participants were committed to raising awareness about the incidence of breast cancer in younger women.

I would like to get information specific to the younger age bracket, like the age bracket of people that aren't eligible for mammograms and like, I don't know if this is an option, but lifestyle adjustments or things that could be done to help reduce the risk of getting cancer. (22 year old with family history)

One participant with five affected family members was adamant about spreading the word about breast cancer in younger women.

I think more women—definitely younger, black women—need to pay attention to their bodies. They need to know their bodies; know what’s changing and not be afraid to say, ‘hey, something doesn’t feel right.’ Because like I say, especially working in the cancer unit, we are getting younger women. They will come in at 18 and 19, 20 and once they come in, it’s too late. We are going to make them comfortable. We’re going to try what we can, but the cancer is rampant and that’s because you choose—your body told you something was wrong and you choose to ignore it. And I would just like women, especially the younger women not ignore. God gave you intuition and the gut feeling for a reason. And if you have a gut feeling that something is not right, you should check it out. (33 year old, strong family history)

Another survivor with a strong family history commented on her efforts to have all of her family members educated about breast cancer issues.

I wanted to do like a group with the women [in my family] so we could talk about our health history and talk about what we need to do, especially now that we know that two, probably three of us, have the gene; more of us may have it. We all came from the same grandmother. (40 year old, diagnosed at age 34)

**Strong Faith**—Many participants acknowledged faith in a higher power as a major source of strength as they coped with their diagnosis or the threat of developing breast cancer. Strong faith comforted them when they were diagnosed, during treatments, when fearful about being diagnosed or experiencing a recurrence. One woman commented:

I tried to live on a philosophy that God only puts on you what you can handle. And I see people every day come in and are literally fighting for their lives and never complain. It wouldn’t be fair of me to complain or have an attitude like, ‘Woe is me.’ If ever a time that I do get diagnosed--have a positive diagnosis--I’m not a quitter. So I will make sure, pray that is caught early, and I will fight. (33 year old with multiple affected female members)

Another woman noted that she hears about others dying from breast cancer and commented that she relies on her faith to ease her fears about dying from breast cancer.

However I would say God. I would just say the Holy Spirit.... it just came to me that, ‘you know what, that is not your journey.’ (36 year old, diagnosed at age 26)

Another woman said:

My spiritual life has taken on a new meaning, you know. I definitely know that it was through my faith that I was brought through this. So everything that I can do to give glory to just give glory to God for that, I do. I remember being first diagnosed, I was like, “okay, God, I don’t know what you’re trying to get me to see. What is the message in this? But I always say, if you are going to use me in any kind of way, then I’m willing to do that. Breast-cancer education and awareness has become my passion. I do that at my church. I do every October; I do a breast-cancer awareness table at my church.” (40 year old, diagnosed at age 34).

## Discussion

To our knowledge this is the first phenomenological study to examine the meaning of breast cancer risk for African American women age 40 and under. The findings from this study add to the limited body of knowledge about breast cancer issues and young African American women. As is consistent with phenomenological methods, the goal of this study was to

describe the meaning of the experience of being at risk for developing breast cancer or experiencing a diagnosis or recurrence of breast cancer.

These women described being at high risk for breast cancer as a life changing experience. Relationships were often changed from this experience- some ended and others became closer. While women noted a number of barriers related to breast health care, other women noted a positive health care experience characterized by good patient provider communication and timely follow-up care. Women stressed the importance of raising awareness in the community and in families, especially by informing daughters. Strong faith was central to living with a potential threat or actual diagnosis of breast cancer.

The transformative effects of illness has been described by others, for example, among persons after being in an intensive care unit (Cox, et al, 2009), and after a myocardial infarction (Groleau, Whitley, Lesperance, & Kirmayer, 2010). These positive effects are underscored by Mols, Vingerhoets, Coebergh, & van de Poll-Franse (2009), who found women who were survivors of breast cancer reported higher life satisfaction compared with an age- and gender-matched normative population in the Netherlands.

Although breast cancer is more likely to occur in older women, ample data show that African American women age 45 and under have a higher incidence of the disease. Women in the current study expressed concern that when they approached their provider with breast symptoms; they were not taken seriously because of their “young” age. Some providers were reluctant to perform testing or provide timely referrals because of the notion that women were too young to be diagnosed with breast cancer. Some participants reported providers were insensitive when delivering the news of their diagnosis. In contrast, others expressed satisfaction that their providers took time to discuss long term personal issues such as childbearing and prophylactic mastectomy or oophorectomy. These observations suggest a need for more provider knowledge and sensitivity when working with young women coping with a threat or actual diagnosis of breast cancer. Others have noted the importance of providers giving information and support, especially when expressing needs with family member is difficult (Bluman, Borstelmann, Rimer, Iglehart, & Winer, 2001; Dzul-Church, Cimino, Adler, Wong, & Anderson, 2010; Kristiansen, Tjornhoj-Thomsen, & Krasnik, 2010). Family and social support have been found to predict wellbeing (Boyes, Girgis, Zucca, & Lecathelinais, 2009), adaptive coping (Zucca, Boyes, Lecathelinais, & Girgis, 2010), and to be important among Latina breast cancer survivors (Buki, et al, 2008).

Women expressed concern that other young African American women needed to know about risk factors, especially their family histories. Consistent with this finding, Underwood and colleagues (2008), in a pilot study examining the breast cancer experiences of high risk African American woman, recommended that all women have the opportunity to discuss breast cancer risk status and related management guidelines.

Women were eager to share their stories and resources with others as a means of empowerment and advocacy. Some talked about sharing their breast cancer experience so that other younger women would know breast cancer is not restricted to older women. In reaching out to others they empowered themselves as well.

Finally participants’ experiences suggest the need for health policies that address mammography screening guidelines for women under age 50. Thus younger women need comprehensive breast health services. This concern compliments current efforts to find better breast cancer diagnostic tools for younger women.

The finding that strong faith was a critical coping mechanism for study participants is consistent with previous breast cancer studies targeting African American women (Phillips,

Cohen & Tarzian, 2001; Gregg 2010). Religion's role in coping has also been found to be important to Latinas (Buki, et al, 2008), and in persons with various chronic illnesses (van Leeuwen, Tiesinga, Jochemsen, & Post, 2007).

### Limitations

Although this study was cross sectional, women were interviewed at varying points along the continuum of breast cancer risk and experience. However, a longitudinal approach with detailed interviews would more clearly show how the experience, including breast cancer risk perception and related behaviors change over time. This study included only African American women, so the experience of persons from different cultures is not known.

### Clinical Implications

Findings from this study highlight the importance of provider education and sensitivity about the incidence of breast cancer among younger women and the unique needs of young women coping with breast cancer issues. Traditional breast health education and clinical care must be broadened to address the unique needs of this population.

Additional research is needed to explicate the unique needs of young women coping with a diagnosis or the threat of developing breast cancer. Given the paucity of published research examining risk perceptions and related behaviors among young high risk African American women, further studies are needed that build on the current research. Of particular need is the design of a longitudinal study that follows high risk African American women over time to fully capture the long term experience of living with a known breast cancer risk. Research examining the emotional and resource needs of younger women, their families and significant others is yet another important area.

Detailed descriptions of the impact of genetic testing in young women also warrant investigation. Findings from such research would be instrumental in designing tailored interventions aimed at addressing risk perception, reducing psychological distress and promoting adherence with surveillance recommendations among high risk populations.

Findings from the current study are particularly timely given the introduction of the Education and Awareness Requires Learning Young Act by Congresswomen Debbie Wasserman Schultz during spring 2009. This legislation directs the Centers for Disease Control and Prevention (CDC) to develop and implement national consumer and health professions education on breast cancer and young women. The CDC will provide grants to organizations that support young women living with breast cancer and address the psychosocial issues these women face once diagnosed. Provisions outlined in the legislation have been included in the Affordable Care Act signed by President Obama March 2010.

### Conclusions

Findings from the current study underscore the ongoing need for breast health programs that address the unique support and resource needs of young women coping with breast cancer issues. Traditional programs should consider assessing the meaning of breast cancer risk when designing breast health programs for high risk populations. While the meaning of breast cancer risk and related needs may change over time, for some African American women concerns about risk will remain ever present. As one participant noted:

There is like a dagger hanging by a thread or something, it's hanging over someone's head ...it's like this tiny little trend, like any minute it's going to hit you in the head. That's sort of the idea about risk perception. I know that really it's

fairly small, but I sometimes have this nagging feeling like, um, like I never had before. (39 year old, 5 year survivor)

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### Clinical Resources

Organizations devoted to providing breast cancer education and related support

Young Survival Coalition (targets young women): [www.youngsurvival.org](http://www.youngsurvival.org)

Sister's Network (Support group targets African American women):  
[www.sisternetworkinc.org](http://www.sisternetworkinc.org)

Bright Pink (targets young women at risk for breast and ovarian cancer)  
[www.bebrightpink.org](http://www.bebrightpink.org)

**Clinical Relevance**

Breast cancer does occur in young women. This highlights the need for timely and sensitive approaches to care when young women present with breast health concerns or abnormal breast findings.