

Advocacy in Action: Spotlight on TOUCH

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Advocacy In Action: Spotlight on TOUCH

Ricki Fairley, BA, MBA CEO of TOUCH, The Black Breast Cancer Alliance, Annapolis, Maryland

Black Breast Cancer



Ricki Fairley, BA, MBA:

I'm Ricki Fairley, and I am a 10year survivor of TNBC. I'm very pleased to have this talk with you today.

Overview

- $\circ~$ The State of Breast Cancer in Black Women
- Key Factors Affecting Mortality
- What's the Perception of Clinical Trials?
- o Black Data Matters Research
- What Will Change the Game?

Let's talk about TNBC and. really, breast cancer overall for black women. It's really a different disease state for black women. So I'm going to cover the state of black breast cancer, some key factors affecting the mortality of black women, our perception of clinical trial research, and some research that I recently did under the title Black Data Matters and how I'm working really hard to change the game on the situation.

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Breast Cancer Is One of the Most FATAL Health Issues for Black Women!

- Black women are 41% more likely to die of breast cancer than white women
- Black women under 35 get breast cancer at two times the rate of white women and die at three times the rate
- Black breast cancer survivors have a 39% higher risk for breast cancer recurrence compared to white women
- Black women with breast cancer have a 52% higher risk for death than white women

east Cancer Prevention Partners; American Cancer Society; Oncology Times 2019;41(1):24.



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Metastatic Breast Cancer

- The odds of advanced (stage III/IV) disease versus stage I disease among black women were almost four times those of white women
- Black women are 61% more likely to develop metastatic breast cancer than white women
- Black women are diagnosed with de novo metastatic breast cancer at a 58% higher rate than white women

ource: NIH, National Institutes of Health.

Breast cancer is one of the most fatal health issues for black women, especially relative to white women. We are dying at a 41% higher rate than white women. Black women under 35 get breast cancer at twice the rate and die at three times the rate, well before they would have their first mammogram at age 40. Black breast cancer survivors like me have a 39% higher risk for breast cancer recurrence, compared to white women. That's really true for TNBC because we don't have a drug to prevent recurrence. TNBC is the only breast cancer subtype that doesn't have a drug to prevent recurrence, which makes us special and different and more deserving of attention from the science. Black women with breast cancer have a 52% higher risk of death than white women. These numbers are devastating and really need to be addressed.

So let's talk about metastatic breast cancer. The odds of getting stage III or IV disease versus Stage I disease among black women is almost four times that of white women. Black women are 61% more likely to develop metastatic breast cancer than a white woman. And black women are diagnosed with de novo metastatic breast cancer at a 58% higher rate than white women. This means their breast cancer diagnosis was metastatic from the beginning. And again, these numbers are astounding.

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Triple-Negative Breast Cancer Is Wreaking Havoc

- The risk of developing TNBC is nearly 3-fold higher in black women vs non-black women, which may predict a worse prognosis
- 20% to 30% of breast cancers diagnosed in black women are triple negative
- Women under age 40 have a 2-fold higher risk of being diagnosed with TNBC than women age 50-64
- Women diagnosed with late-stage breast cancer are 69% more likely to have triple-negative disease than other breast cancer subtypes



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The risk of developing TNBC is nearly threefold higher in black women versus nonblack women, and we know that it has a worse prognosis. 20 to 30% of breast cancers diagnosed in black women are triple negative. And women under the age of 40 have a twofold higher risk of being diagnosed with TNBC than women ages 50 to 64. Women diagnosed with late-stage breast cancer are 69% more likely to have triple-negative disease than other breast cancer subtypes.



Black women are less likely to survive 5 years: 76.9% versus 82.9% for white women.

Black Women Are at Higher Risk for Triple-Negative Breast Cancer Mortality

- A greater proportion of black women have (vs. white women):
 - Stage III tumors (20.3% vs 15.2%)
 - Tumors exceeding 5 cm in size (14.3% vs 9.6%)
 - Positive lymph nodes (39% vs 31.6%)

t al. JAMA Oncol. 2021;7(7):1016-1023

 Poorly-differentiated or undifferentiated histology (81.5% vs 76%) Black Women Have an 18% Higher Risk for Death Due To Non-Metastatic TNBC Than White Women

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We don't really know why the mortality numbers are so devastating. But there are a lot of contributing factors that indicate that our bodies are different. Black bodies are different and warrant different treatment options. So let me go into those a little bit. And it really will dictate kind of the risk of breast cancer for black women.

So black women are at higher risk for TNBC mortality. We have more stage III tumors, more positive lymph nodes, bigger tumors, and black women have an 18% higher risk of death due to nonmetastatic TNBC.

Physiologic Factors Increase Incidence of Obesity in Black Women

- CDC age-adjusted prevalence of obesity among US adults (2017-2018): 42.4%
 - 41% for black men
 - 57% for black women
- Prevalence among non-Hispanic black women was higher than all other groups

s et al. https://www.cdc.gov/nchs/products/databriefs/db360.htm. Gower et al. Eur J Clin Nutr. 2021;75(4):628-635.

- Researcher Barbara Gower, PhD investigating reasons for these differences
- Preliminary conclusions suggest that black women are more prone to obesity because:
 - They secrete more insulin and clear less of it
 High amounts of insulin in bloodstream after meals signals body to store more fat
 - Factor in diets high in sugar that cause insulin levels to spike, and these women already prone to higher levels of circulating insulin will store more fat, compared to women with lower insulin secretion and higher insulin clearance

Some other factors increase our incidence of getting breast cancer. Obesity is really a problem in black women, and this is a risk factor for breast cancer. According to the CDC, the age-adjusted prevalence of obesity among US adults was 42.4% in 2017 to 2018. The rate is 41% for black men and 57% for black women.

In a recent study this year, a researcher named Barbara Gower currently is investigating the reasons for these differences. And she's got some preliminary conclusions that suggest that black women are more prone to obesity because they secrete more insulin and clear less of it. We have high amounts of insulin in the bloodstream after meals, and that signals the body to store more fat. And there's a factor in diets high in sugar that cause insulin levels to spike. So when we're eating bad food, our insulin levels spike, and we have more obesity. So that could be a factor here.

Obesity Is a Breast Cancer Risk Factor for Black Women

- Black women have a significantly higher mean BMI (23%) compared with white women (32 kg/m² vs 26 kg/m²)
- Having a BMI >30 kg/m² is associated with an increased risk (HR 2.77) for TNBC and an increased risk for ER+/PR+/HER2- breast cancer in postmenopausal women
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 Black women have a significantly higher BMI compared with white women. Having a BMI of greater than 30 is associated with an increased risk for TNBC and an increased risk for other breast cancers, as well, in postmenopausal women.

Most Black Mothers Are Single Parents



- 67.9% of all black working women are single moms, making them the primary, if not sole, economic providers for their families
- Add breast cancer to those dynamics!
- What choice will a single mom make between missing work to receive treatment versus going to work to feed her kids?

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Another factor that could impact this is that most black mothers are single parents. Almost 70% of all black working women are single moms, making them the primary, if not sole, economic providers for their households. So what does that mean? That means without disease. we are working hard to take care of our kids. They're the priority. Add breast cancer to those dynamics and what choice will a single mom make between missing work and not feeding her kids and maybe not going to treatment or not getting a mammogram? So her focus is on her kids.

Black Women May Miss a Risk-Reducing Opportunity **Because Breastfeeding May Not Be an Option**

- o 85% of white mothers say they breastfed versus 76% of black mothers
- Black moms are less likely to breastfeed because:
 - Hospital maternity wards that serve larger black populations are less likely to help black women initiate breastfeeding after giving birth or offer lactation support following delivery, according to the CDC study. Often, staff in these facilities instead offer black babies formula
 - Black women are more likely than others to need to return to work earlier than 12 weeks, and tend to be confronted with "inflexible work hours" that make consistent nursing and expression of milk difficult
- Parous women who breastfed for at least 1 year had a 31% lower risk for TNBC than women who had never breastfed
- Parous black women aged 20-44 years who breastfed for 6 months or longer had an 82% lower risk for TNBC than their counterparts who had never breastfed

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By the Numbers 92% of black 25% of women 17% have taken steps to better women agree breast health is understand breast health their risk important AXIS

Black women may miss a risk-reducing opportunity because breastfeeding may not be an option for them. So breastfeeding is shown as a way to potentially prevent TNBC; 85% of white mothers say they've breastfed their babies versus 76% of black mothers. Black moms are less likely to breastfeed because maybe sometimes hospital maternity wards that serve larger black populations are less likely to help black women initiate breastfeeding after giving birth.

Black women are more likely than others to need to return to work earlier than 12 weeks and may not be able to have the flexibility to nurse their babies for a long enough time. Parous women who breastfeed for at least 1 year had a 31% lower risk for TNBC than women who had never breastfed. So parous black women aged 20 to 44, who breastfed for 6 months or longer, had an 82% lower risk for TNBC. But they didn't always have that opportunity.

A study was done by the Ad Council a couple of years ago, and clearly, blacks don't talk about health at the kitchen table. This study identified that 92% of black women agree that breast health is important. Only 25% of black women have recently discussed it with their friends and family, but a mere 17% have taken steps to better understand their risk. So we're not talking about it. It's not top of mind.

Screening Protocols Are Not Clear to Black Women

- 54% of all women ages 21 to 39 and 26% of women ages 40 to 60 say they don't know how often they should be screened for breast cancer
- 47% of black women of all ages say they don't know how often they should be screened for breast cancer
- 28% of all women have not scheduled any breast cancer screening during the COVID-19 pandemic
- That percentage drastically increases when looking specifically at black women



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A recent study also showed that screening protocols are not clear to black women. 54% of all women ages 21 to 39 and 26% of women ages 40 to 60 say they don't know how often they should be screened for breast cancer. But guess what? 47% of black women of all ages say they don't even know how often they should be screened for breast cancer.

28% of all women have not scheduled any breast cancer screening during the COVID-19 pandemic that's really wreaking havoc on our community. That percentage drastically increases when you look specifically at black women. So the pandemic has had a very negative impact on screening.

So let's talk about some of these ethnic disparities.



Black Women Experience Treatment Delays

- Black women are much more likely to delay following up with a doctor after an abnormal mammogram
- 20% wait more than 60 days to follow up compared with 12% of white women
- Only 69% of black women start treatment within 30 days of diagnosis compared with 83% of white women
- Young black women have the longest and most significant delays in care

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The Hard Truth About Clinical Research

- The unique physiology of black women has not been factored into clinical trial research
- To address the skewed mortality statistics among black women, they must be included in current and future breast cancer research

"[Inadequate minority representation in drug trials means that] we aren't doing good science... If we aren't doing good science and releasing these drugs out into the public, then we are at best being inefficient, at worst being irresponsible."

> – Dr. Johnathan Jackson Founder of Community Access Recruitment and Engagement Center Massachusetts General Hospital



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Black women also experience treatment delays. We are much more likely to delay following up with a doctor after an abnormal mammogram, and sometimes that's based on insurance, but 20% of black women wait more than 60 days to follow up with their doctor compared to 12% of white women. And only 69% of black women start treatment within 30 days of diagnosis, compared with 83% of white women. Young black women have the longest and most significant delays in care. And why is that? They could be single moms, they may have religious reasons, they may not trust their doctors. A lot of reasons for this. But these delays can cost them their life.

Now let's talk about clinical research. The unique physiology of black women, which we've identified as different, now, has not been factored into clinical trial research. And there's a quote that I'd like to read you from Dr. Jonathan Jackson, Founder of Community Access from Massachusetts General Hospital: "Inadequate minority representation in drug trials means that we are not doing good science. And if we're not doing good science and releasing these drugs out into the public, then we're at best being inefficient and at worst being irresponsible." So we must figure out how to get more black women included in research.

Blacks Are Significantly Underrepresented in Clinical Research

- Blacks represent 13.4% of the US population, but only 7% of clinical trial participants
- Since 2016, the FDA has approved four novel drugs for breast cancer. However, none of those clinical trials had more than 3% black participants

7% of	Race and Ethnicity of U.S. Population and Participants in Clinical Trials					
	U.S. P	opulation	vs.	U.S. Clinical	Trial Participar	nts
as	77%		White		80%	
ugs for		18%	Hispanic	4%	~	
r, none	22	13%	Black	4%		
ad more		6%	Asian	12%	2	
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Blacks represent 13.4% of the US population but only 7% of clinical trial participants overall. And since 2016, the FDA has approved four novel drugs for breast cancer; however, none of those clinical trials had more than 3% black participants.

Disparity of Race Reporting and Representation in Clinical Trials Leading to Cancer Drug Approvals from 2008 to 2018



The disparities are really significant in representation in clinical trials, and it's been that way for a while, and it's getting worse over time.

Black Breast Cancer and Barriers to Clinical Research



So what are the barriers to clinical research?

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Black Data Matters

 The mission of Black Data Matters is to empower black patients to directly change a research and medical system that often fails them



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Last year and earlier this year, I went out on a mission to establish a program called Black Data Matters. And I really wanted to dig into how we are different and what's driving the emotional barriers to keeping black women from participating in research. We know there's a lot of historical bias, a lot of earned medical mistrust in our system, but I wanted to dig into what are the deep emotional factors that are keeping us from participating?

So the mission of *Black Data Matters* is to empower black patients to directly change a research and medical system that often fails them.



So I embarked upon this study, and I partnered with some partners—I knew that I couldn't do this alone.

Black Data Matters Goals

- Increase participation of black women in clinical trials to advance science and save lives
- Disrupt how the breast cancer ecosystem engages black women in clinical trial research
- Strive towards health equity for black women diagnosed with or at risk for breast cancer
- Help black women get the best breast cancer care



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And together we did a study with the following goals: We wanted to really focus on increasing the participation of black women in clinical trials. What would it take so we can advance the science and save lives?

We also want to disrupt how the breast cancer ecosystem engages black women in clinical trial research. With 3% participation, something is wrong. And this will all strive for better health equity for black women that have diagnosed with or at risk for breast cancer and help us get the best breast care possible.

Our Research Aims To

- Confirm & validate tactical barriers to clinical trial participation
- Measure the impact of placebo myth
- Unpack the ramifications of medical mistrust
- Uncover & understand emotional barriers to clinical trial participation
- Understand the disconnect between current recruiting tactics/messaging and trial participation
- Prioritize the development of relevant and effective messaging to overcome barriers to participation



So our research really aimed to confirm and validate all those tactical barriers, that we kind of knew about, to clinical trial participation, like transportation, access to healthcare, and not having insurance, measure the impact of the placebo myth. Unpack some of the ramifications of that medical mistrust, but really uncover and understand the emotional barriers to clinical trial participation. And doing that we'd understand the disconnect between the current recruiting tactics and messaging and trial participation.

I'm a marketing person by trade, not a doctor or a scientist, and so everything that we do is about messaging...how we talk to people, how we talk to patients, and the words we use and who says those words, to engage in anything, really. So our research really wanted to figure out how to prioritize the development of a relevant and effective message that would overcome some of these barriers to participation and breakthrough and penetrate the black women to get them to change their minds.

What Was Different About Our Qualitative Approach?

- Designed to explore the deeply rooted emotional barriers and cultural drivers affecting black women's resistance to clinical trials
- Intimate conservations were moderated by a black breast cancer survivor who is a patient advocate and respected member of the black breast cancer community



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What was different about our qualitative approach? I moderated some of the focus groups that we did. And we did 48 interviews with black women at all different stages of breast cancer—some family members and some women at risk for breast cancer. I spent a good amount of time trying to figure out what are the cultural barriers, what are the things that are really driving the resistance? We had these very intimate conversations. And me as a patient and as an advocate, I was able to dig deeper into their psyches because of my experience with the disease.

Qualitative Methodology

- All digital
- o 6 hour-long individual interviews
- 14 two-hour focus groups
- Participants (N = 48) included:
 - Black women with breast cancer who had never participated in a clinical trial, (n = 29)
 - Family members of black women with breast cancer (n = 10)
 - Black women at risk for breast cancer (n = 9)
- Participants ranged in age from 27-63 (mean age 42)
- Patient population included 19 patients with stage II and III breast cancer, and 10 patients with stage IV breast cancer

 We did 6 hour-long individual interviews, and 14 twohour focus groups for 48 participants. The age range was 27 to 63, mean age of 42. And the patient population included 19 patients with stage II and III breast cancer and 10 patients with stage IV breast cancer. So we really tried to get the gamut of people with early-stage and late-stage breast cancer.

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- Metastatic Patient (Stage IV)

"Don't do a clinical trial! You will get the sugar pill and die."



"I feel like a lot of the research is not with Black women. So if I had someone who went through it already, I trust their pain and their feedback."

"Whenever I would hear clinical trial, I would always think experiment because it was never really broken down to me, I never considered it, and I've never been approached personally to participate. But I know with my former oncologist, I wouldn't say that I trusted him too much... he didn't really answer a lot of my questions..."

- Patient Stage II/III

- Patient Stage II

And one of the most confounding messages was coming from a 'Breastie,' "Don't do a clinical trial, you'll get the sugar pill and die." And that was from a metastatic breast cancer patient, a black woman. So when I say as a Breastie, when a Breastie says something, it's a credible thing to another Breastie. So we what we found in the research was that our Breasties were giving incorrect information to other Breasties because of their own personal fears and biases.

Another quote: "Whenever I would hear clinical trial, I would always think experiment because it was never really broken down to me. I never considered it, and I've never been approached personally to participate. But I know with my former oncologist, I wouldn't say that I trusted him too much...he didn't really answer a lot of my questions."

So our data showed that about one-fourth of black women, really that 30% were not even asked to participate in a trial. And when they brought it up, they really weren't educated adequately to feel good about it.

Another patient, stage II: "I feel like a lot of the research is not with black women. So if I had someone who went through it already, I would trust their pain and their feedback." So again, that trust in another Breastie is so important to these conversations.





Key logistical barriers to trial participation include financial expenses, living far away from healthcare facilities, and interference with work commitments



- Although they see benefits, many view trial participation as risky because of the clinical trials' experimental nature, and they believe they could cause serious and long-term side effects. So, in our quant study what we learned was side effects was a really important issue about why they feared clinical trials. Are the side effects going to be worse than what I'm already taking from regular chemo? How's it going to impact my life? And some of the qualitative discussions were about, okay, I get warned about a trial, my hair is going to fall out, I'm going to be nauseous, but it didn't really talk about or address the impact it will have on my life. Will I be able to go to work? Will I be able to feed my kid?
- There are also logistical barriers to trial participation, including: Am I going to have to pay for it? Is it far away from my home? Is it going to interfere with my work?



Also, uncertainty shapes our emotional barriers of trial participation: side effects, again, the trial doesn't guarantee the best health outcome for me, it could make my condition worse, receiving an experimental treatment instead of an approved treatment is scary.
I may get the placebo drug – and the placebo drug came up again, even in the quantitative study.



Almost two-thirds of the patients in our study have actually discussed a clinical trial with their doctor, but it's the patient who was more likely to initiate the conversation. In fact, our data shows that 53% said they brought the idea of a clinical trial up to the doctor versus 33% of the time the doctor bringing it up to them.





Almost a third of the patients we talked to who discussed clinical trials with their doctor felt somewhat or not informed after the conversations. So they didn't feel like the conversations were really long and deep enough for them to feel good about really understanding what they were up against with a clinical trial. And oftentimes, even though they walked out of the office feeling kind of favorable to a trial, they would go home to their families, and their families would question them and say, oh, my god, don't do that, you're going to get the sugar pill and die. And it would undermine everything that the doctor said, because they didn't feel adequately educated to even be able to explain it to their family members.

The top reasons why eligible patients didn't participate include not having a wellestablished relationship with their HCP, feeling rushed in the conversation, and a preference for their current treatment just because they were somewhat comfortable with it. So those are some of the fears.

Top reasons why eligible patients didn't participate include not having a well-established relationship with their HCP, feeling rushed, and a preference for their current treatment



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But There's Hope!

Culturally relevant, educational messaging delivered by a trusted member of the community is effective in driving a perception shift, with many respondents willing to reconsider their hesitation or skepticism But the good news, though, is that there's hope.

Messages That Changed Perceptions



- A clear, simple explanation of standard of care and how cancer trials work
- Think about community & family: Do it for your daughter!
- Every drug they take (ibuprofen, diphenhydramine) was once in a trial
- You get high quality of care & surveillance in a trial
- Even standard treatments are actually a trial for their body and their cancer



And what I learned in talking to these Breasties, that if we have culturally relevant and educational messaging from a trusted member of the community, a 'Breastie,' it's effective in driving a perception shift, with many of the respondents willing to reconsider their hesitation or skepticism. once they talk to a Breastie with very simple messaging. And really, I learned in the groups that I can move someone from a 1. I'll never do a trial to a 5. sign me up tomorrow, really with a few very simple messages that would change their perceptions.

The first one being a clear and simple explanation of standard of care and how a trial works. That you're not going to get the sugar pill. In cancer research, there's no such thing. But explaining how the science works. Every drug you take has been in a trial. That ibuprofen that you took last week, that acetaminophen that you gave your baby a couple of weeks ago was once in a trial, and they were astounded by that.

You get a high quality of care and better surveillance in a trial. You get more closely watched by doctors. And even standard treatments are actually a trial for their body. But the most compelling messaging that really worked with this audience was do it for your daughter. do it for your granddaughter, think about your community, think about your family. Do it for your daughter because you'll be here for your daughter, or you can potentially help your daughter prevent getting breast cancer. But those simple messages in 5 minutes could convince these women to change the game and change their mind on how they felt about trials. and really, because I'm a voice of credibility as a Breastie.



We did this rigorous research, and now we're working on changing the game.

Movement Evolution

- \circ A surround-sound, collaborative, community-based education movement
- o Led by 'Breastie Choir'
- The right information from the right voice delivered where black women live, work, pray and play

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We're putting together a surround-sound, collaborative, community-based education movement that's going to be led by what I call our Breastie Choir. We've engaged about 40 breast cancer survivors to help us get this message going, to be in the community with a grassroots outreach to be where black women live, work, play, and pray.

Thank you.

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