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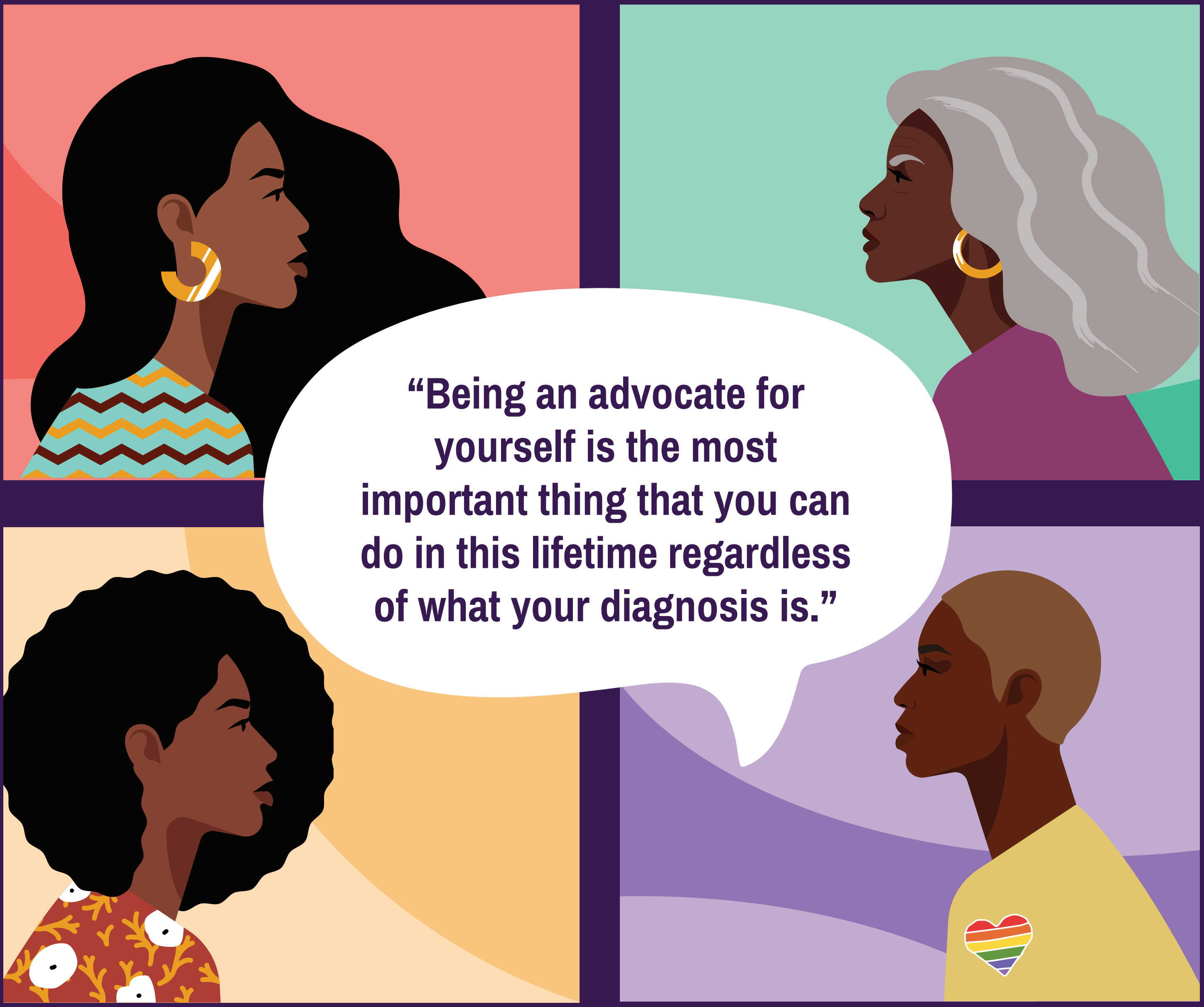
RESEARCH



SHARING OUR OWN EXPERIENCE:
A Qualitative Study with Black Women Diagnosed with Triple-Negative Breast Cancer

Dr. Lucy Ingram, PhD, MPH led an impactful discussion with four TNBC research participants to delve into the exploration of the Black experience in being diagnosed with TNBC. This panel discussion was held at Getting Our Fair SHARE: 2023 Conference to End Health Disparities.

Written by:
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SHARE Cancer Support started as a lone support group for women with breast cancer. In 1976, Dr. Eugene Thiessen brought nine of his patients together, realizing they had no one but him to talk to about their diagnosis. This was our first support group.

From this compassionate origin, SHARE has grown into a comprehensive support system for those diagnosed with breast, ovarian, uterine, cervical, and metastatic breast cancer. We have paid particular attention to diverse and under-resourced communities with our programs in Spanish for monolinguistic patients, with outreach to the African American/Black communities, and with peer support in many languages.

Triple-negative Breast Cancer (TNBC) is a subtype of breast cancer that is disproportionately prevalent among Black women. In the US, Black women face a three-fold higher risk of being diagnosed with TNBC and are less likely to receive guideline-concordant treatment for TNBC. As a result, Black women are more likely to die from the disease than White women.

To better understand the experience of being diagnosed with TNBC as a Black woman, SHARE teamed up with Dr. Tisha Felder, PhD, MSW, who served as the Principal Investigator, and her colleague Dr. Lucy Ingram, PhD, MPH, to conduct a qualitative research study. Twenty Black women diagnosed with early or metastatic breast cancer were interviewed and text analysis software was utilized with an inductive coding approach to develop a codebook. Through a Black Feminist lens, codes were analyzed and themes were interpreted across the interviews.

Eight major themes and 15 recommendations emerged from the deeply personal stories shared by these brave women diagnosed with TNBC.

Working on this study has had an immense impact on the participants, researchers and the SHARE team who participated in every step of the process. We could not have imagined how profound this experience would be. We are forever grateful to Gilead and especially Shannon Weber, Associate Director, Public Affairs - Global Oncology Corporate Giving, for her visionary leadership and faith in our organization to conduct this research.

At SHARE, we believe in the power of people helping people, whether one-on-one, through educational events or support groups - or through important research like this.

We invite you to study our findings and connect with SHARE Cancer Support for more information about the work we do and those we serve.

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EXECUTIVE SUMMARY

"[I]n light of the fact that the statistics are even more dire against us, I think it's okay to want a space, to like lament about that and discuss and figure out what can be done, and to just acknowledge that it's a different experience--Black breast cancer."
– Chavi, 35-44 years old, Stage 4

What is the problem?
Triple-negative breast cancer (TNBC) is a subtype of breast cancer that accounts for 15-20% of all breast cancers in the U.S. and is disproportionately prevalent among Black women.[1] Compared to U.S. White women, Black women face a three-fold higher risk of being diagnosed with TNBC,[2] are less likely to receive guideline-concordant treatment for TNBC, and subsequently are more likely to die from the disease.[3] Given TNBC's impact on Black women, research suggests that Black women may face unique barriers to care and have unmet psychosocial needs.[4,5] However, few studies have captured the lived experiences of Black women with TNBC to discover potential solutions to the persistent racial disparities in TNBC.

What did we do?
Dr. Tisha Felder, PhD, MSW and Dr. Lucy Ingram, PhD, MPH of the University of South Carolina (USC) collaborated with SHARE Cancer Support to conduct a qualitative research study to better understand the healthcare experiences, support, and information needs of Black women diagnosed with or living with TNBC. Specifically, the study endeavored to examine the following:

- *Diagnosis Experience*
- *Involvement in shared decision making*
- *Perceived experience of racism or discrimination in the healthcare setting and its impact on communication and relationship with the cancer care team*
- *Types and sources of support received*

To explore these questions, our team aimed to center Black women's voices using social justice principles.[6,7] From November 2022 to February 2023, 20 Black women diagnosed with TNBC primarily within the previous five years were interviewed. There was a mix of women who had early-stage or metastatic breast cancer diagnoses. About half of the women were between 35-44 years old (45 percent, range: 18-24 to 55-64). Their annual income ranged from less than $25,000 (20 percent) to more than $175,000 (15 percent), and most had private insurance at diagnosis (75 percent). Interviews were conducted via Zoom, and all participants were compensated for their time. The research team used the text analysis software NVivo® 12 for data management and analysis and applied an inductive coding approach to develop and finalize the codebook. A Black Feminist lens[6,8] was used to analyze codes and interpret emerging themes across the interviews. The USC Institutional Review Board approved the study (Pro00123881).

What did we learn?
Eight major themes emerged from the personal stories of Black women diagnosed with TNBC. Each theme is presented below with a deidentified participant's quote to illustrate each theme's meaning.

1. **Advocacy gives you an advantage:**
"I think it's the advocacy. If you don't start off with that, then that kind of puts you at a disadvantage."
– 4sistahs, 55-64 years old, Stage 1

2. **Black women want to be "seen" and treated as Black women:**
"…I think sometimes as a Black woman I feel like White people, they skip pages in the book when they're dealing with us… And so they are treating the diagnosis, but my Black face and my needs, my side effects and things like that, I think that they just kind of nicely nod their head and move on from it."
– Dee, 45-54 years old, Stage 2

3. **Patient-centered communication with Black patients is critical to the diagnosis and treatment experience:**
"…they said we are sorry to tell you that the diagnosis report is here, and you have a very rare breast cancer, and this is very aggressive, so we don't know if we can save you right now."
– Cas, 18-24 years old, Stage 2

4. **Learning from others with shared experiences is invaluable:**
"For other Black women newly diagnosed, I think it would be most helpful if an oncologist or somebody could set them up with somebody who has been through breast cancer, another Black woman."
– Portia, 35-44 years old, Stage 2

5. **Keep the future in mind:**
   "I think I've finally gotten to the point where I can think about more years of future. You are afraid to plan too far ahead."
   – TNBC1043, 55-64 years old, Stage 4

6. **Mental health support is not optional:**
   "…you can have the biggest medical team in the world; if there is not a mental health professional on your medical team, you are lacking."
   – Sonya Blade, 45-54 years old, Stage 0

7. **Support looks different for everyone:**
   "But I'm kind of – it's like I share information, and then I'm also kind of private. Like I really didn't give a lot of people information about my diagnosis, so I didn't really have a big support system per se… they were willing to help, but I just really wasn't open to that."
   – Fari, 35-44 years old, Stage 2

8. **Support needs to be improved in all its forms:**
   "So I just know that there's a lot of things for women of color and triple-negative that needs to be done."
   – Power, 45-54 years old, Stage 1

Across these themes, the women's identity as Black women significantly shaped their perceptions of their TNBC diagnosis and treatment experiences and their preferences for more tailored support. To expand the potential impact of these findings, the research team adapted the themes into recommendations for key interest groups and individuals essential to reducing TNBC disparities and improving the quality of life for Black women diagnosed with TNBC.

What can YOU do?

Recommendations	Black Women Diagnosed with TNBC	Care Teams	Support Organizations
1. Increase awareness about TNBC, especially in Black spaces.		✓	✓
2. Diversify the oncology care team.		✓	
3. Avoid color blindness.		✓	✓
4. Strive for equity, rather than equality, in treatment and care.		✓	
5. Black women should be treated with tenderness.		✓	
6. It is okay not to be okay.	✓		
7. Clinicians need to be better educated about TNBC in Black women.		✓	✓
8. Black women want tailored support groups.		✓	
9. Coversations about the future are necessary.	✓	✓	✓
10. Acknowlegde the mental exhausion of structural racism and its potential additional impact on Black women.	✓	✓	✓
11. Don’t forget the caregivers.	✓	✓	✓
12. Surround yourself with positive others.	✓		
13. Formally integrate pathways for support.		✓	✓
14. Increase awareness about instrumental support resources.		✓	✓
15. Advocate for more research with Black women about TNBC.	✓		✓

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FULL REPORT

Introduction

“[I]n light of the fact that the statistics are even more dire against us, I think it’s okay to want a space to like lament about that and discuss and figure out what can be done, and to just acknowledge that it’s a different experience--Black breast cancer.”
– Chavi, 35-44 years old, Stage 4

Triple-negative breast cancer lacks estrogen (ER), progesterone (PR), or human epidermal growth factor type 2 receptors (HER2). Across racial and ethnic groups, U.S. Black women face unique challenges and poorer TNBC outcomes. Below we highlight key factors that contribute specifically to racial disparities in TNBC and its impact on U.S. Black women:

- **Higher burden:** Black women experience a higher burden of TNBC compared to women of other racial and ethnic backgrounds. Studies have shown that TNBC is more commonly diagnosed in Black women, accounting for a larger proportion of their overall breast cancer cases *(Scott et al., 2019)*.

- **Younger age at diagnosis:** Black women with TNBC tend to be diagnosed at a younger age than other women *(Scott et al. 2019)*. This early onset of TNBC presents unique challenges regarding available treatment options and long-term survivorship.

- **Aggressive nature:** TNBC is regularly described as “aggressive” because it often grows quickly and has a higher likelihood of the breast cancer cells spreading from the breast to other parts of the body. Black women with TNBC often face a more advanced stage of the disease at diagnosis *(Amirikia et al., 2011)*, which can impact treatment outcomes and overall prognosis.

- **Limited targeted treatment options:** Unlike other breast cancer subtypes, TNBC lacks targeted therapies such as hormone receptor-targeted drugs (e.g., tamoxifen) or HER2-targeted therapies (e.g., trastuzumab) *(Yin et al., 2020)*. This absence of specific targeted treatments poses challenges in managing TNBC, particularly in Black women who may have limited access to alternative treatments *(Prakash et al., 2020)*.

- **Genetic factors:** Studies have identified a higher prevalence of genetic mutations, such as BRCA1, in black women with TNBC *(Pal et al., 2015)*. BRCA1 mutations are associated with a higher risk of breast cancer and are more commonly found in Black women with TNBC compared to other women.

- **Racism:** Structural racism refers to the ways in which policies, laws, institutions, practices and processes produce, maintain and reinforce inequities among racial and ethnic groups *(Williams, 2023; Dean & Thorpe, 2022; Lett et al., 2022)*. Black women with TNBC experience notable health disparities linked to structural racism including higher risk of TNBC due to living in lower-income or racially segregated neighborhoods *(Siegel et al., 2023)*, having limited access to high-quality screening *(Alshiek et al., 2021)*, and lower rates of receipt of optimal treatment *(Cho et al., 2021)*.

Given TNBC's disproportionate impact on Black women, it is crucial to address these disparities and improve access to early detection, comprehensive treatment, and supportive care services. In society, Black women face the "double jeopardy" of experiencing both racism and sexism, and potentially other forms of discrimination throughout their lives. Thus, by virtue of their lived experience, researchers have found that Black women diagnosed with TNBC face unique barriers to care and have unmet psychosocial needs *(Bollinger, 2018; Turkman et al., 2016)*. While there are numerous studies and reviews about disparities in TNBC in relation to biological and clinical factors, few studies have explored how being diagnosed with TNBC impacts the lives of Black women. To address this research gap, SHARE Cancer Support, in collaboration with Drs. Tisha Felder and Lucy Ingram at the University of South Carolina, conducted an in-depth, qualitative research study to explore the perspectives, needs and experiences of Black women diagnosed with TNBC. The specific aims of the study were to:

Aim 1: Understand the diagnosis and treatment experiences of Black women with TNBC, including their involvement with decision-making;
Aim 2: Explore the impact of racism and discrimination on the patient-cancer care team communication and relationship; and
Aim 3: Identify types and sources of support received and/or needed through the cancer care continuum.

Qualitative Study Results

About half of the 20 interview participants were between the ages of 35 and 44 (45 percent), were married (45 percent), worked full-time (60 percent), and had a bachelor's degree or higher (55 percent). The women reported a broad household income range from less than $25,000 (20 percent) to more than $175,000 annually (15 percent). Most women reported having private health insurance (75 percent) and living with other adults and/or children (85 percent) at diagnosis. Regarding their TNBC, half reported being diagnosed as Stage 2 (50 percent); most received chemotherapy (85 percent), surgery (75 percent), and/or radiation (45 percent). The women received information about TNBC from various resources, with cancer organizations (e.g., SHARE, American Cancer Society (85 percent), their oncologist (75 percent), and general internet searchers (60 percent) being the three most frequently reported information sources **(Figure 2)**.

Qualitative Themes

The team identified eight major themes from the personal stories of Black women diagnosed with TNBC. Each theme is presented with a deidentified participant's quotation to illustrate each theme's meaning, followed by a description of the minor themes and exemplar participant quotes.

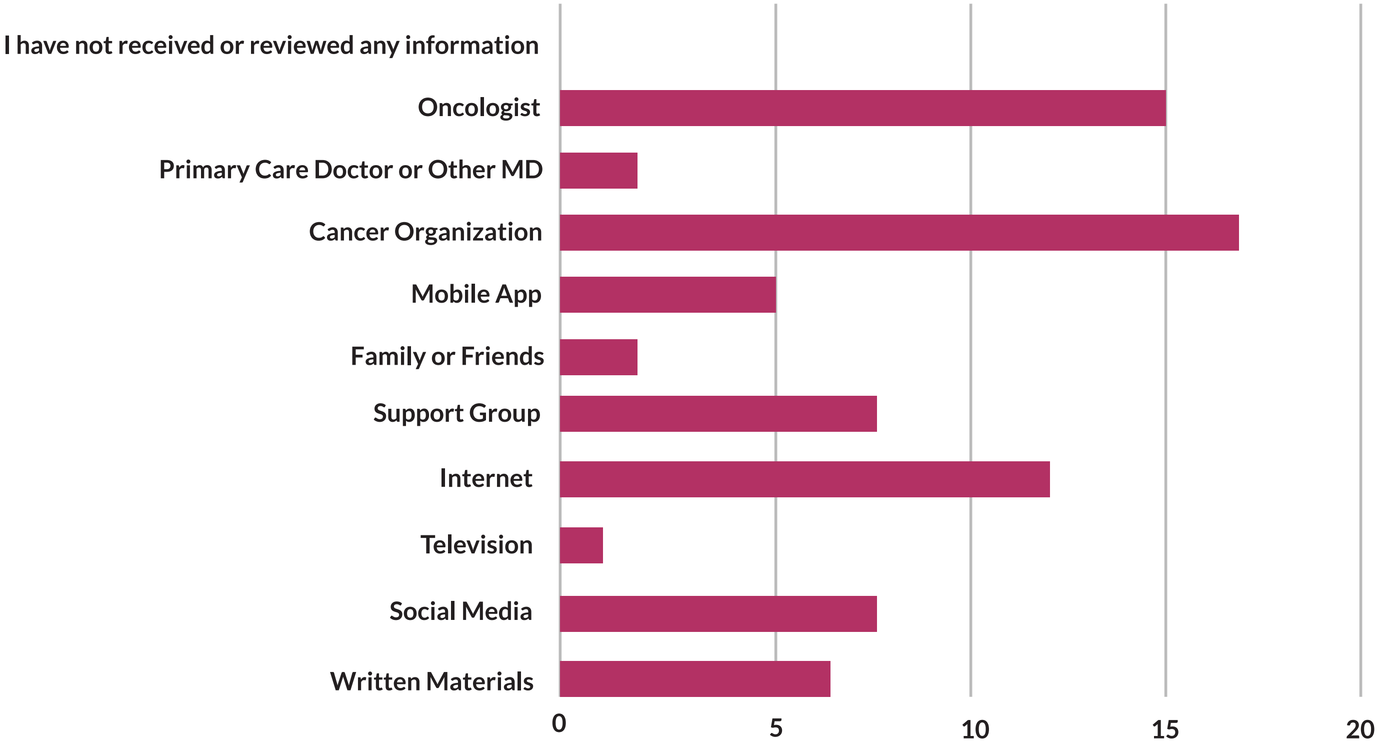

Figure 2. Information Received About TNBC

1. Advocacy gives you an advantage:

"I think it's the advocacy. If you don't start off with that then that kind of puts you at a disadvantage."
– 4sistahs, 55-64 years old, Stage 1

From diagnosis to survivorship, Black women discussed the importance of advocacy, including self-advocacy, others advocating on their behalf, and being motivated to become a patient advocate to help others. Advocacy was vital to their involvement in treatment decision-making.

"I really feel that being an advocate for yourself is the most important thing that you can do in this lifetime regardless of what the situation is, regardless of what a diagnosis is. Because if you walk in and you are uninformed some people don't see you as having a voice. It doesn't matter if you have insurance or if you have a great insurance or not you have to advocate for yourself, because I really feel if I didn't get online and start researching doctors and just out doing my own research with people that have had the disease and got past it and just taking my life and meditating and just being positive, I don't think that I would be here." – Fari, 35-44 years old, Stage 2

Figure 3. Word Cloud of Our Research Data Describing Experiences as a Black Woman

"...advocate for yourself. Don't ever, ever stop speaking up for yourself, what you want, what you need. If you need a new doctor or if you need to go to a new hospital do what you've got to do. Forget the doctor's feelings. They will be all right. At the end of the day what matters is you want to be taken care of. That's first and foremost. If you don't like what they're saying go for a second opinion. Do what you need to do. Don't be afraid to speak up for yourself." – Nicole T, 35-44 years old, Stage 3

On the other hand, they also shared how self-advocacy can reinforce the "angry Black woman" stereotype and take a tremendous toll on their lives because they often felt forced to advocate for themselves for fear that they would not be offered the best care.

"But it was the advocacy, that's it. It's exhausting. It's not fair." – Sage Thriver, 45-54 years old, Stage 3

"They took too long to do something and I literally had to call the oncologist and tell her do y'all take this seriously? I can't remember exactly the situation that happened because I have a fogged memory, but I definitely one time had to get "Black" and tell them like it is. You know Black women die at a higher rate than anybody with this disease. Do you care about my life because I did." – Mel, 35-44 years old, Stage 3

2. Black women want to be "seen" and treated as Black women:

"...I think sometimes as a Black woman I feel like White people, they skip pages in the book when they're dealing with us... And so they are treating the diagnosis but my Black face and my needs, my side effects and things like that, I think that they just kind of nicely nod their head and move on from it."
– Dee, 45-54 years old, Stage 2

Black women consistently described their cancer care teams and care settings as being predominantly White. While most women felt they received good treatment for their cancer, they felt that cancer care team members failed to recognize their identity as a "Black woman," which was critical to them feeling they were being treated as a whole person.

"You know what, sometimes, I'm sorry to say this but sometimes it's so hard to go to a hospital and you find a White person and you are Black and you are speaking out like sharing your problem, maybe to them they think like after all you are a Black. So what. You should accept it like you are there. It's okay for you to be sick, but you are getting a Black person. She understands. She was like, "You know what, I will be there for you and I will help you." I think she understood me very well." – Evvah, 18-24 years old, Stage 2

A few women even shared instances of where they felt they were not heard and were even mistreated by care team members, including some who were also Black:

"My doctor who examined me was an older Black woman, so it made me very angry with her because

I'm like you already know the healthcare disparities we experience as people of color and then for you to continue to perpetuate that, so yeah, I was not happy with her at all." – Baddie, 35-44 years old, Stage 2

"Oh, Black women need to go to Black doctors." Dr. [Last name] is a Black lady. She's a Black doctor and Dr. [Last name]l is a Black doctor. The only one I listened to is Dr. [Last name] and he's a White man. [Laughs] So for me it's not about your color it's about who is going to actually listen to me and help me, you know." – Nicole T, 35-44 years old, Stage 3

"He is not friendly with Black people. He's not. He's really not. You can see he's seeing another White person and you are a Black person so different. He is so charming, happy. Like you know, the face that a doctor can give you, it's not the same face that he will give you. He's so different. I can say he's not friendly with Black people." – Sur, 25-34 years old, Stage 1

3. Patient-centered communication with Black patients is critical to the diagnosis and treatment experience:

"...they said we are sorry to tell you that the diagnosis report is here, and you have a very rare breast cancer, and this is very aggressive, so we don't know if we can save you right now."
– Cas, 18-24 years old, Stage 2

Nearly all participants found a lump in their breast, leading them to seek follow-up care. Women shared stories of some care team members dismissing the possibility of them having cancer—even when the women were aware of their family history.

"The person who did the mammogram she was really nice. She saw the mass and she said, "Oh, it's probably a result of your breast reduction," because in 2019 I had a breast reduction. So she saw it and she said something she thought might be nice to make me feel better about it. "Oh it's probably just scar tissue." No, but okay." – Dee, 45-54 years old, Stage 2

"So I went in, she examined me, she didn't feel anything. I actually had to place her fingers on the spot and she said, "Well, I don't think that's anything.

I think it might just be a cyst." And I told her, "Well, you can't say that because I have a family history, BRCA1 positive of breast cancer. My grandmother had breast cancer twice. Three of my four aunts have had breast cancer," like you can't tell me that. And so she was like, "Well, in my medical opinion I don't think it's anything…" – Baddie, 35-44 years old, Stage 2

Women also felt some team members dismissed their reporting of uncommon side effects. When care team members expressed empathy and emotional support to the women, the women reported a more favorable treatment experience.

"He was like, if you were my wife or sister, I'm not going in there and doing a mastectomy because it's too risky going in there that long with you because of the blood clots." – Portia, 35-44 years old, Stage 2

"When the doctor called me to tell me my scans were clear, he actually called me on a Sunday and I was scared. I was like oh no, this man is the hardest man to get a hold of and you're calling me on Sunday? He was like, "No, I'm calling you with good news because I don't want you to worry until Tuesday." Like I said I really trust my oncologist." – Jay, 35-44 years old, Stage 4

"I love to make people laugh. Even with tears in my eyes I still made people laugh. That's just me. That's my personality, so they had no choice but to listen to me. But our relationship as medical team and patient, as doctor and patient, nurse and patient, it was excellent. It was excellent. Like I said, they kept me informed every step of the way. They valued my opinion. They wanted to hear feedback from me. They kept me included in every decision every step of the way, so my experience with both teams in [U.S. state] and [U.S. state] has been awesome, has been awesome. I don't have anything bad to say about either one of them, anything negative. They treated me like family. They treat their patients like family and that's the most important thing."
– Robinette, 35-44 years old, Stage 2

4. Learning from others with shared experiences is invaluable:

"For other Black women newly diagnosed, I think it would be most helpful if an oncologist or somebody could set them up with somebody who has been through breast cancer, another Black woman."
– Portia, 35-44 years old, Stage 2

Participants overwhelmingly expressed a desire or the vital importance of having "someone who looks like me" to inform them about treatment options and existing resources and provide emotional support through their shared lived experience with TNBC. Some also desired that their spouses, children, or caregivers be able to connect with others who have experienced a loved one diagnosed with TNBC.

"…they need to have a strong advocate, and an advocate person that looks like them and can kind of relate when the emotions are in high gear so it won't be misconstrued as an angry Black woman type thing [Laughs]." – 4Sistahs, 55-64 years old, Stage 1

"I hear that there's lots of husbands that are taking care of their wives and they really don't have anybody to share. I mean they're on their own in terms of finding sources of support. I wish my husband could

talk to somebody about sex. I wish he had somebody he could talk to about maybe resources, financial resources, managing his stress, what sex with a cancer patient is like, you know. I don't know, whatever men need. So I wish that he had that." – Dee, 45-54 years old, Stage 2

Intersectional shared experiences were perceived as even more impactful, such as young Black women connecting with one another or learning from other Black women who were also parenting:

"So I think that age piece felt more like up to the forefront than I think my experience, I think it was 25 and Black. I think 26 just felt more present in my mind also of like I hate that I'm going through this so young. I shouldn't be having to do this." – Kay, 25-34 years old, Stage 2

"I found many in there who survived and just not Black women. Black women who are middle class or lower class and they dealt with this, how they maneuvered through it every day because there's a lot to do as a mom and you have to pay your bills. So I think I learned a lot not just about treatment and about cancer, I think about getting through cancer and your everyday life how to take care of your kids and everything because the doctor will not tell you that." – Cas, 18-24 years old, Stage 2

TNBC Research Participants: Latoya Cauley and Ife Lenard, MSW at Getting Our Fair SHARE: 2023 Conference to End Health Disparities.

While some participants identified individuals with shared experiences through existing support groups, others expressed continued challenges with finding such individuals.

"I wish they would give you a peer or something, somebody you could talk to that you could relate to, not just doctors and nurses but somebody that's going through what you've been through or going through, what you're going through right now because they understand." – Portia 35-44 years old, Stage 2

5. Keep the future in mind:

"I think I've finally gotten to the point where I can think about more years of future. You are afraid to plan too far ahead."

– TNBC1043, 55-64 years old, Stage 4

The women discussed perspectives on the future often in relation to their stage at diagnosis, age at diagnosis, or another intersecting identity, such as their current role or future desire to be a parent.

"…after healing up from the flap my oncologist was like, "All right, time to get this uterus out," and I was like, "Ugh!" The whole time I'm thinking like, well, I was dating someone, I wasn't married, maybe I can have a baby, because I really, really, really wanted to be a mother. I really wanted to be pregnant and have that whole experience, give birth, have a child or two and the relationship part did not work. And then I also struggled with the feelings of because I have such a strong genetic history, do I want to pass this on to my kid? I remember how my mother's voice sounded when I told her I had cancer. I remember watching her cry and all I could think about was I don't want to live through that. I don't want my kid to deal with that, so, very reluctantly I moved forward with having the hysterectomy." – Baddie, 35-44 years old, Stage 2

"They did the exam and I told the oncologist that I was not going to do chemo, and he told me that if I didn't do chemo that I was going to die, that there was no way that at the rate that the tumor was growing that I could live successfully with that. I was really frustrated because I was 32 years old at that point. I had started losing weight to hope that I could have another child." – Jay, 35-44 years old, Stage 4

Some shared feelings of angst once their active treatment ended and not knowing "how to go on" into their future, given the possibility of a recurrence. Many women emphasized accepting that they would never return to their old life, so they needed to reframe their future.

"I think it's always the concern until I get to five years or so of it coming back. I think the first fears were like the hardest for me to like…in survivorship of accepting that I was okay, like moving on with my life, like being more confident and planning for the future." – Kay, 25-34 years old, Stage 2

"But they don't tell you about the aftereffects, after life, living life after cancer I tell people you never go back to your old life. Like my cousin described you're a butterfly because you're becoming a new person. The old Portia, the old person is gone. You'll never get the old Portia back. It's the new Portia. Nothing is ever the same." – Portia, 35-44 years old, Stage 2

6. Mental health support is not optional:

"…you can have the biggest medical team in the world; if there is not a mental health professional on your medical team, you are lacking"

– Sonya Blade, 45-54 years old, Stage 0

Most women discussed how their TNBC diagnosis and treatments impacted them physically and mentally. They talked about their mental health challenges with anxiety, post-traumatic stress disorder (PTSD), and "chemo brain" directly resulting from their TNBC diagnosis and treatments.

"I ended up actually going back to the hospital several times because I couldn't breathe. They came down to mostly it was my anxiety. I mean given yeah the diagnosis pushes you into a state of PTSD no matter what happens with you. I did all on my own, so when I finally grasped okay, I started anxiety meds."
– Jay, 35-44 years old, Stage 4

"I think I'm a lot better than I used to be because as you get older you learn things. So yes, he [her husband] is always worrying I guess just making sure I'm mentally all right because it is a lot, a lot going on."
– Power, 45-54 years old, Stage 1

Many women noted the mental exhaustion from having to code-switch, overthink or second-guess their treatment decisions or care experiences due, in part, to receiving care from predominantly White care teams.

"I feel like you know as a Black woman you don't want to just always assume that people not giving you the care that you need, but I just feel like I'm not getting what I need sometimes. You know what I mean? There's always that feeling that you just have like do you do this to everybody or is it just like me? But the experience I just wish that I could have been cared for by people who look like me a little more. But I don't

trust them. I don't trust my experience. I'm always questioning things, but I just feel like they don't care." – *Mel, 35-44 years old, Stage 3*

"I think it's important because it's just so, you know, I just feel like we don't want to have to code switch or we don't want to have to overthink what we're thinking or how we're sharing our own experience, our own lived experience." – *Chavi, 35-44 years old, Stage 4*

While some women were offered or had access to mental health support (e.g., counselors, therapists) during treatment, some did not use the help due to a cultural mismatch (e.g., White male therapists).

"I [don't] understand why they are assigning male doctors or psychiatrists to talk to me. To me you don't have breasts, you know. That, to me, I think they need to change that up a little bit and also get someone who looks like me in there to talk with me." – *Kim, 55-64 years old, Stage 3*

"I met with a therapist one time. I didn't connect with him. He was like a middle-aged White guy and I just did not feel like talking to him." – *Kay, 25-34 years old, Stage 2*

The women also discussed the importance of needing access to mental health resources, particularly after treatment.

"I have been thinking about going to counseling now. I really didn't need it at first but probably now." – *Si, 35-44 years old, Stage 2*

7. Support looks different for everyone:

“But I’m kind of – it’s like I share information, and then I’m also kind of private. Like I really didn’t give a lot of people information about my diagnosis, so I didn’t really have a big support system per se... they were willing to help, but I just really wasn’t open to that.”
– Fari, 35-44 years old, Stage 2

All participants reported receiving varying levels and types of support (e.g., informational, emotional) from family, friends, co-workers, church members, online support, and support groups **(Figure 4)**. Support groups and family were the most frequently discussed sources of support. Support groups were great sources of information and emotional support for women.

“Oh man. Still three years later helping me get through treatment so much. I would probably call the support groups, like the biggest support that I have, you know, because nobody gets it like they do. But for me I felt like the support groups were just really empowering.” – Chavi, 35-44 years old, Stage 4

“Like most of the time on Fridays we meet like for a coffee. Most of the time the people like you know the people who are diagnosed a long time ago, a long time ago and they are still surviving, like they want to push us like you know, we are here for you and your testimony, so you keep on...” – Evvah, 18-24 years old, Stage 2

Some women expressed their appreciation for practical and emotional support that was given to them without them having to ask:

“I would be home but my friends and them they would come. I’m like, “I didn’t tell you to come clean-up my house.” She was like, “Girl let’s sit down.” But I thank God for those people that were put in my life to come. You are always helping other folks but when you need help you really see who your true friends are because once you have cancer or a sickness people disappear like they’re scared to talk to you or something.”
– Portia, 35-44 years old, Stage 2

“So my church family, my work family, and my family, we all had a holiday dinner at my house. Like I said it was a harness. Like I was on the ropes. I was down and out. I couldn’t do for myself, the person who does

for everybody, but that was the moment for everybody to like really stand up and just really show their support and it meant a lot. It meant a lot."
– Sonya Blade, 45-54 years old, Stage 0

Given the "strong Black woman" trope, some participants encouraged Black women diagnosed with TNBC to accept and seek support.
"So there are things that we went through that we were doing culturally, the stubbornness or this unrealistic way that we have been socialized that I can get through this. I'm a strong Black woman. No. No. This is the time to receive tenderness." – Sage Thriver, 45-54 years old, Stage 3

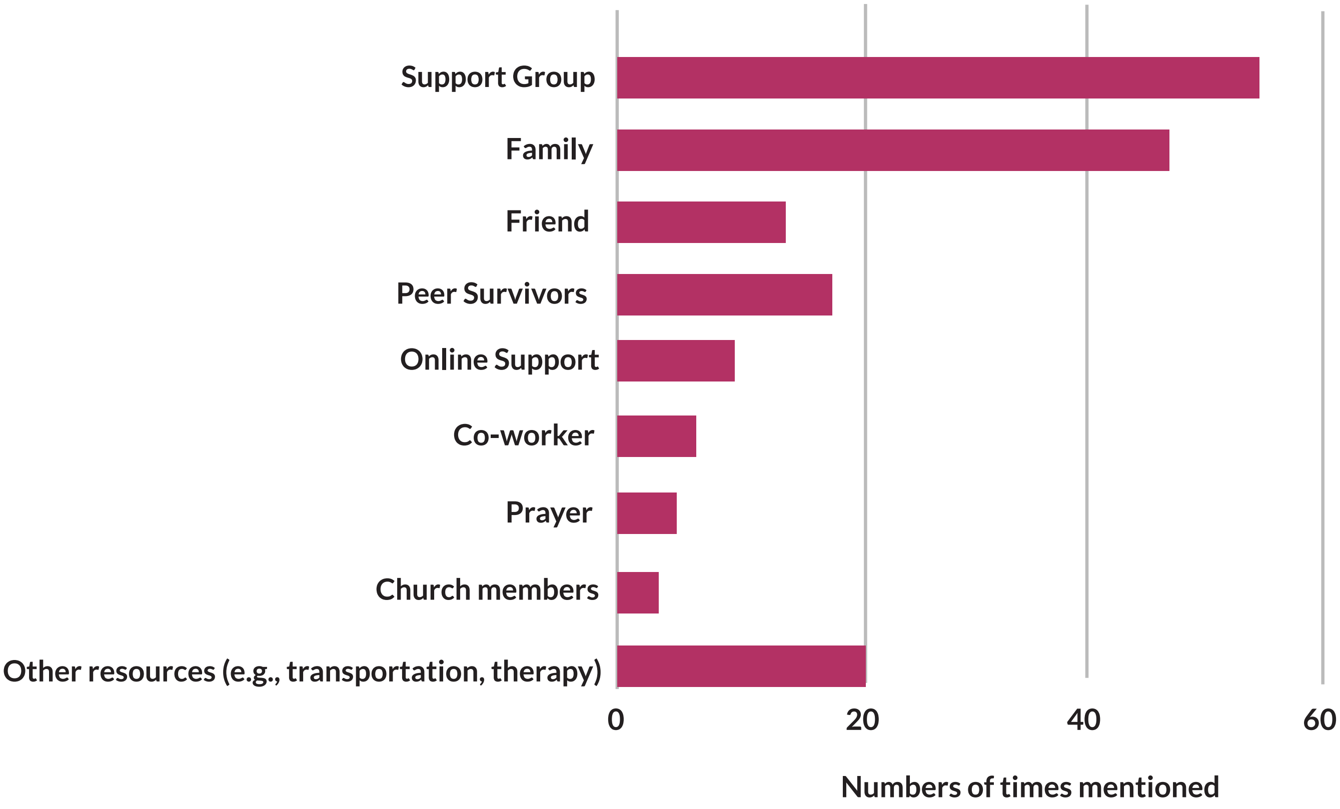

Figure 4. Most Common Forms of Support Mentioned by Interview Participants

8. Support needs to be improved in all its forms:

“So I just know that there’s a lot of things for women of color and triple-negative that needs to be done.”

– Power, 45-54 years old, Stage 1

Once diagnosed with TNBC, most women indicated they did their own research to seek additional TNBC information, resources, and support, particularly regarding Black women. The women desired more information and public awareness about TNBC, as most had never heard of TNBC prior before their diagnosis.

“And I did my own research and wanted to learn the ins and outs of everything that I was going to have to deal with and face.” – Robinette, 35-44 years old, Stage 2

“And even during that oncology visit I asked her what do you know about Black women and cancer and she said to me, “It’s pretty much…there’s not enough

Figure 5. Word Cloud of Our Research Data Describing Support

out there," she said. That was the first thing she said. The second thing she said is, "The stuff I'm telling you is just what I tell everybody," and I was like well that sucks, because even though there might not be a lot out there in my rudimentary research I see more than you're telling me and so my outcomes look very different than a White woman's outcomes."
– Dee, 45-54 years old, Stage 2

They wanted more in-person support groups exclusively for Black women diagnosed with TNBC. They suggested specific support groups for Black women diagnosed as metastatic and groups for caregivers and children.

"I'm looking for people who look like me. So yeah, I'm still out there because the world is starting to open up. I'm interested in joining where we can go in person some groups of women who have been through it, and still because the world is still somewhat shut down it's still hard to find those groups."
– Kim, 55-64 years old, Stage 3

"I think physical can do more better than online because online you don't feel that someone is really talking. It just feels like support. But if you meet with someone face to face and you see the progress face to face then it's going to motivate you more in person."
– Cas, 18-24 years old, Stage 2

"…when I was diagnosed there was no support group in my cancer center, not for me. They had a small support group and they let me know that it is primarily early stagers and so they don't really get metastatic folks because they don't really feel comfortable in it.
– Chavi, 35-44, Stage 4

Women wanted more tangible forms of support, such as transportation and financial assistance. The need for more tailored information and resources to improve sexual health was also discussed.

"We [Black people] are not tycoons, we are not millionaires and we are really struggling to get even a penny for a day… I heard people are not even getting the treatment because of that. They lack the money to take them to the hospital. Because nobody is coming to tell them you are suffering from this because they don't have even that money to go. Yeah. I think they should be there to help us financially. For me, I can testify this thing is so costly, so costly. For you to be there, for you to live more than even five years, it has costed you a lot. – Sur, 25-34 years old, Stage 1

“It’s just making sure that newly diagnosed person can get to their treatments because this may be a long time. So there are women I’m talking to they’re still in treatment. They have radiation, chemo. They might stop and might have to go back, depending on what their issue may be and so transportation is big with treatment. Transportation is big. If they have children making sure that their kids can be picked up, those type of things that’s not interfering, they’ve got to work around it so those things are important – transportation, clinical trials, making sure that they have the things that they need. I feel like medical providers they might have to do a little bit more than they used to.” – Power, 45-54 years old, Stage 1

“While common themes may link Black women’s lives, these themes will be experienced differently by Black women of different classes, ages, regions, sexual preferences as well as by Black women in different historical settings. Thus, there is no monolithic Black women’s culture...”
– Patricia Hills Collins (1986)

Recommendations

To further expand the potential impact of these findings, our team adapted the qualitative themes into recommendations for key interest groups and individuals essential to reducing TNBC disparities and improving the quality of life for Black women diagnosed with TNBC **(Table 3)**. As we developed these recommendations, we found that they aligned well with three constituent groups: Black women diagnosed with TNBC; care team members, such as oncologists, surgeons, nurses, administrative staff, and others; and support organizations, such as SHARE and other health-related organizations (e.g., non-profit, private) or agencies (e.g., governmental) that fund cancer-related research or programs. In this section, we describe the context for each recommendation and provide guidance on potential ways they could be achieved.

Education and Awareness

There is a need for more culturally tailored information about TNBC and its specific impact on Black women. Given the racial disparities in TNBC, there is a need for increased public awareness about TNBC (e.g., risk factors, incidence), as well as targeted education to predominantly Black audiences, such as predominantly Black churches, sororities, and other relevant organizations. Black women diagnosed with TNBC desire more information about their disease and information that provides messages or stories of hope. Once diagnosed, there is also a need for more information about existing supportive resources at national/state/local levels, such as transportation to/from medical appointments, financial support, and fertility options. The recommendations also emphasized the need for educating the caregivers and children of Black women diagnosed with TNBC on how to best care for themselves and their loved ones with TNBC. Best practices for developing effective educational materials or campaigns about TNBC for Black women and caregivers include applying health literacy principles *(AHRQ, 2020)*, inclusive communication strategies *(CDC, 2023)*, and the use of plain language *(PLAIN, 2023)*.

Given the severity of TNBC and the vast disparities noted among Black women experiencing the disease, we were surprised to find such a dearth of extant research about this phenomenon. Further, of the research that has been conducted, it is predominantly clinical in nature. As a whole, we find that if there is to be greater attention, and by extension, successful efforts to eliminate the disparities in TNBC, more research, including social and behavioral, must be conducted with Black women about TNBC. Further evidence of this emerged during the interviews in which women described either deficits in their clinical team not understanding how the disease impacts Black women, women desiring to participate in studies about TNBC, or women expressing sincere gratitude that our team was conducting this study.

Cultural awareness and cultural humility

There is a cross-cutting emphasis on the importance of and need for increased cultural awareness and cultural humility among individuals and organizations who care for and support Black women diagnosed with TNBC. While cultural competence has been the standard for healthcare professional education and training, cultural humility extends cultural competence beyond cultural awareness and knowledge to understanding power imbalances and holding systems accountable for addressing those imbalances (**Figure 6,** *Project READY: Reimagining Equity & Access For Diverse Youth, 2020)*. For example, in instances when Black women expressed feelings of being invisible (i.e., not feeling “seen”), concerns about equity in treatment, and were discouraged by providers who acknowledged that they were unfamiliar with the prognosis and treatment options for Black women with TNBC, some of these challenges could be mitigated by having more diverse care teams. There are noted benefits to increasing diversity in the healthcare workforce such as promoting health equity, improving patient care quality, inviting diverse thoughts and experiences to devise effective solutions, and ultimately reducing disparities. Moving toward cultural humility means care team members could work toward “avoiding color blindness” by completing foundational health or racial equity training and remaining curious by asking their patients if they have any specific needs for information or support. Further, care team members must also recognize the power differential of Black women diagnosed with TNBC receiving care from primarily White oncology care team members. The women explained how this differential may lead them to self-advocate in ways that could be misunderstood by care team members. It is critical for care team members to reject negative

stereotypes about Black women (e.g., angry Black woman, strong Black woman schema), be self-reflective and treat them with tenderness.

Patient Support

Common forms of social support include informational, instrumental and emotional support. When discussing a variety of forms of support, such as family and friends, support groups were mentioned the most. When women were asked about the type of support that they received to help get them through treatment, many remarked about their concerns about how important members of their support networks and caregivers were coping with their new roles. The women mentioned parents, spouses, and children as persons of concern regarding how their mental health and the impact that caring for their loved one may be having. They also noted clear gaps in resources for supporting caregivers. Care teams and support organizations should be thoughtful about how to support caregivers as they develop resources for Black women diagnosed with TNBC and their families. Even in cases when

Image adapted from “Module 8: Cultural Competence & Cultural Humility - Project READY: Reimagining Equity & Access For Diverse Youth”. 2023. Ready.Web.Unc.Edu.

Figure 6. Cultural Competence as a Foundation for Cultural Humility

women were made aware of support services and resources, they noted having to pull this information from a variety of different sources or receiving information at different points along their TNBC journey. From an infrastructure perspective, it could be more efficient and effective if support were formally integrated into the treatment plan rather than a disjointed aspect of the treatment process.

We also identified differences in the amount of information that some women had about resources that existed in their health care system, through their insurance coverage, or even locally to support their daily needs. While support groups and networks were often identified as common resources, some desired resources were financial in nature. Black women diagnosed with TNBC who have successfully navigated these systems and many grassroots organizations can be excellent sources of this information. Care team members and support organizations should seek to have ready access to this information to provide Black women early and often during their TNBC experience.

Mental Health

Participants were consistent about the physical toll that TNBC and the treatment regimen had on their bodies. However, they also noted that their physical space and the energy that they received from positive others was a great help in their healing journey. For women diagnosed with TNBC, care teams, and support organizations should be aware of the value of keeping a positive atmosphere to enhance Black women's physical and mental health.

In line with cultural awareness and humility, Black women shared their experiences with "code-switching," "second-guessing" themselves and mentally having to wonder if they can trust they are receiving the best care for their TNBC during their cancer care encounters. All of this ruminating adds an additional mental burden and exhaustion on these women, often stemming from their cumulative experiences with discrimination and racism as Black women. It is important for care team members to recognize this and ensure that Black women with TNBC have the mental health support that they need. We also emphasize that when connecting these women to mental health support, care team members must assess Black women's preferences for the type of mental health professional they feel comfortable meeting with. Some participants mentioned discontinuing mental health support due to cultural mismatches, such as differences in age, racial, and gender identity.

Recommendations for health care providers

We identified health care providers as critical to implementing 12 of the 15 recommendations **(Table 3)**. While most of the participants reported very positive experiences with their providers, the women expressed a collective desire for their providers to see and understand them as Black women. Much of this understanding will grow from a genuine commitment to cultural humility, which includes not only increasing cultural awareness but also, becoming a champion for diversifying the oncology workforce and advocating for more research with Black women diagnosed with TNBC. Providers can contribute towards these goals by aligning with professional organizations who are committed to cancer health equity and by being formally trained in patient-centered communication methods.

Recommendations	Black Women Diagnosed with TNBC	Care Teams	Support Organizations
1. Increase awareness about TNBC, especially in Black spaces.		✓	✓
2. Diversify the oncology care team.		✓	
3. Avoid color blindness.		✓	✓
4. Strive for equity, rather than equality, in treatment and care.		✓	
5. Black women should be treated with tenderness.		✓	
6. It is okay not to be okay.	✓		
7. Clinicians need to be better educated about TNBC in Black women.		✓	✓
8. Black women want tailored support groups.		✓	
9. Coversations about the future are necessary.	✓	✓	✓
10. Acknowlegde the mental exhausion of structural racism and its potential additional impact on Black women.	✓	✓	✓
11. Don’t forget the caregivers.	✓	✓	✓
12. Surround yourself with positive others.	✓		
13. Formally integrate pathways for support.		✓	✓
14. Increase awareness about instrumental support resources.		✓	✓
15. Advocate for more research with Black women about TNBC.	✓		✓

Table 3. Recommendations for Key Interest Groups Essential to Reducing the Burden of Triple-Negative Breast Cancer among Black Women

Conclusion

This study aimed to better understand the health care experiences, support, and information needs of Black women diagnosed with TNBC. By centering Black women’s voices across all phases of this research study, their lived experiences uncovered major themes and practical recommendations for key interest groups and individuals to contribute to reducing persistent racial disparities in TNBC among Black women. Across themes and recommendations, the women’s identity as Black women and how their identity as Black women intersects with their other identities (e.g., age, socioeconomic position) significantly shaped their perceptions of their TNBC diagnosis and treatment experiences and their preferences for more tailored support.

[Photos (L to R) by Caique Silva, Eye for Ebony, Jessica Felicio on Unsplash]

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Tables

Table 1. Personal and Professional Characteristics of Research Team

Team Member	Professional Credentials & Discipline(s)	Occupation	Racial & Gender Identity	Training & Expertise	Study Role	Personal Connection to Study Topic
SHARE Cancer Support *(National Non-Profit Organization)*						
Christine Benjamin	BA (Psychology), MSW (Master of Social Work), LMSW (Licensed Master of Social Work)	Vice President of Patient Support & Education	White woman	20+ years as breast cancer patient advocate; served as Vice Chair & Chair of the Metastatic Breast Cancer Alliance; Patient experience advisor; Research contributor; author	Study design	Triple-negative breast cancer survivor (23 years)
Victoria Burke	BA (Comparative Womens’ Studies)	Program Assistant	Black woman	Worked in the cancer space for one year	Study design, recruitment, data collection, and analysis	College advisor was breast cancer advocate
Megan-Claire Chase	BA (Communications)	Breast Cancer Program Director	Black woman	Patient advocate and invasive lobular breast cancer survivor	Study design, data collection	Invasive lobular breast cancer survivor - 7 years; patient advocate
Stephanie Poland	BA (Political Science), MS (Master of Science, Business Management)	Sr. Program Manager and Project Director	White woman	Worked in the breast cancer space for five years; breast cancer policy advocate	Study design	Mother died of metastatic breast cancer
University of South Carolina *(Academic Institution)*						
Megan Austin	MPH (Master of Public Health Promotion, Education, and Behavior)	PhD Student	White woman	Women’s health, Health equity, qualitative research	Data analysis	Supporter of women; family history of breast cancer
Lucy Ingram	MPH (Master of Public Health in Behavior), PhD (Health Education & Health Behavior)	Associate Professor, Associate Dean	Black woman (Ghanaian heritage)	Health equity, women’s health, community-engaged and qualitative research	Data collection and analysis	Supporter of women; Best friend’s mother died of breast cancer; Exploring family history of cancer
Tisha Felder	BA (Sociology), MSW (Master of Social Work), PhD (Behavioral Science in Public Health)	Associate Professor	Black woman	Breast cancer, health equity, women’s health; mixed methods research	Principal Investigator, study design, data collection and analysis	Best friend’s mother died of breast cancer

Table 2. SHARE Participating Organizations

Thank you to the following organizations who helped share our screener survey, partnered on a program, or shared our TNBC postcard to get feedback from the Black breast cancer community.

Amplify Black Voices
Ancora.ai
Cierra Sisters
Diverse Health Hub
FORCE- Facing Hereditary Cancer Empowered
For the Breast of Us
Keep-A-Breast
My Style Matters
SHARE Cancer Support's Ambassadors
The Chrysalis Initiative
The Patient Story
Tigerlily Foundation
TOUCH, The Black Breast Cancer Alliance
Triage Cancer
Unite for HER

Appendices

Appendix 1. Methodology

Study Paradigms

The transformative paradigm served as the underlying framework to guide the study. The central tenet of the transformative paradigm is that "power is an issue that must be addressed at each stage of the research process" and that the research be inclusive and culturally responsive *(Mertens, 2007)*. Core principles of Black Feminist Thought also informed the research process and data analysis *(Collins, 1989)*. These paradigms were selected to expose potential inequities and unmet needs of Black women with TNBC that must be addressed along the cancer care continuum.

Study Design

All aspects of the study were designed and carried out by a multidisciplinary and multisectoral team of self-identified, racially diverse women working for SHARE Cancer Support, a national nonprofit focused on cancer, and the University of South Carolina **(Table 1)**. The team reflected personal and professional connections to breast cancer, and collectively had combined expertise in breast cancer, quantitative and qualitative research, and cancer advocacy. The study used a multi-method approach to gain a more comprehensive understanding of the perspectives and experiences of Black women with TNBC. Quantitative data from a survey was collected and analyzed followed by virtual, qualitative interviews to explore in greater depth Black women's experiences with TNBC.

Development of SHARE Participant Registry

From July to August 2022, team members developed a pre-screener survey to create a registry of self-identified Black TNBC patients and survivors who expressed interest in participating in a qualitative interview. The final survey **(Appendix 2)** consisted of 22 questions that asked participants about their characteristics, such as sociodemographic information (e.g., self-identify as Black, age, income, relationship status), TNBC diagnosis (e.g., stage at diagnosis, treatments received, insurance status at time of diagnosis) and where they received information about TNBC (e.g., oncologists, cancer organizations, support groups). To be eligible to complete the

- Age: 18 – 80 years old
- Can be early-stage or MBC
- Diagnosed within the past 5 years

Figure 1. Recruitment Flyer

full survey, participants had to self-identify as being 1) Black or African American; 2) 18 years or older; and 3) diagnosed with TNBC, preferably within the previous five years. If they did not meet one or more of these criteria, a disqualification statement was provided to the participant at the end of the survey. From August to October 2022, SHARE posted a flyer **(Figure 1)** with information about the opportunity to participate in a paid interview about TNBC and weblink to the survey on social media (Facebook, Twitter, Instagram) and distributed this information directly to 15 partner organizations **(Table 2)**. This combined recruitment effort yielded 49 eligible individuals for the study.

Setting and Recruitment Procedures

The study was approved by the University of South Carolina Institutional Review Board (Protocol #: Pro00123881). Potential TNBC breast cancer survivor participants were recruited from the SHARE Cancer Support participant registry. The team used a stratified purposeful sampling approach to identify potential interview participants who reflected a range of characteristics that likely influence the TNBC diagnosis and treatment experience (e.g., stage at diagnosis). A staged recruitment process was then used to email invitation letters to selected participants. The invitation letter **(Appendix 3*)*** included an overview of the purpose and potential impact of the study, how interviews will take place, interviewer bios, and the amount of compensation for participation. Participants who responded to the email and agreed to participate in the study also received a FAQ document **(Appendix 4)** to give them more information about the study and give them an opportunity to ask any questions or address any concerns. Prior to scheduling their interviews, SHARE staff ensured that participants understood that audio recording of the interviews was required but they had the option to agree to or decline being video recorded. Participants who did not respond to the email invitation letter received a follow up phone call from the SHARE staff to confirm if they were interested and/or had any questions before agreeing to participate. Interested participants were scheduled for the virtual interview appointment. Each confirmed participant was emailed a private, password protected, Zoom meeting room link.

As each “batch” of participants (about 3-4) were contacted and scheduled, a subsequent set of selected participants were sent email invitation letters. As participants were accrued and completed interviews, the team continued to review participant pre-screener data to ensure that the sample reflected various participant characteristics, such as age, stage of diagnosis, and insurance status. At the end of the eighteenth interview, the study team identified the need to ensure a greater representation of participants who had received a metastatic (Stage 4) TNBC diagnosis. Thus, in March 2023, SHARE reopened the pre-screener survey for two weeks and successfully recruited and interviewed two additional individuals who self-reported as being Stage 4 at the time of diagnosis.

Data Collection Procedures

Two Black women researchers (TMF, LAI) conducted virtual, semi-structured interviews

with 20 participants between November 2022 and March 2023. All interviews were scheduled and conducted via Zoom at a time that was convenient to the participant. To facilitate comfort, each participant was asked to identify a pseudonym or "nickname" to be referred to and decided on their preference for turning their video camera on or off at any point during the interview.

Prior to beginning the interviews, interviewers used a script to guide an informed consent process with each participant to ensure participant understanding of key elements of the study, such as the goals of the study, why they had been asked to participate, a description of the study procedures, how their confidentiality would be maintained, potential risks and/or any benefits and contact information for the study team members. Following the consent process, when each participant agreed to participate and be audio and/or video recorded, the interviewer asked each participant to type their nickname in the chat feature of Zoom in the place of signing a physical copy of a consent form. Participants were provided the option to receive a written copy of the consent script via email or mail upon request.

Interview Guide Development

All interviews were conducted using a semi-structured interview guide. The initial interview guide was informed by interview questions previously used in Dr. Felder's study of African American women with breast cancer *(Felder et al., 2019)*. The research team used an iterative and interactive process of discussing and revising the interview guide to ensure the questions and related probes aligned with the overall study goal and aims. Once a final draft guide was developed, SHARE staff sent a request to their TNBC survivor support group email listserv to invite interested survivors to attend a virtual, focus group meeting about the qualitative interview and guide. In October 2022, two team members (MCC, TMF) facilitated a brief discussion and pre-testing of the interview guide with three Black TNBC survivors. The survivors responded well to the questions, expressed enthusiasm for the study, and did not provide any suggestions for revisions to the interview guide **(Appendix 5)**.

Interviews began with a broad question, "Tell me about your breast cancer diagnosis experience," followed by more broad questions and specific probes to obtain more specific information about each participant's treatment experience, the role of support and information sources in their decision-making processes, their perspective as a Black woman on how they were treated by their cancer care team, and their current needs and concerns as a TNBC survivor. At the end of each interview, the interviewers wrote reflexive memos about their insights and thoughts about their experiences. All participants were compensated with a $175 stipend via e-gift card or check for their time and effort.

Data Analysis

As each interview was completed, the data was transcribed verbatim by a professional transcription service. Each participant's audio file and transcript were assigned the participant's preferred nickname and unique identifier as their corresponding pre-screener survey. Transcripts were independently read by the investigator and reviewed to check for accuracy and authenticity. Transcripts were imported into the qualitative data analysis software NVivo® 12 for data management, analysis, and thematic analysis *(Clarke & Braun, 2021)*. Three team members each independently coded two transcripts to identify preliminary codes. The team members then met to compare individually identified codes and developed the initial codebook before each transcript was coded utilizing an inductive coding method to finalize the codebook. All transcripts were then double coded by two team members. After coding was complete, three team members met to discuss and analyze the codes using Black Feminist Thought *(Collins, 1989)* as a lens to interpret thematic patterns present across the interviews.

Study Limitations

The primary limitations of this study are that we recruited a sample with relatively high socioeconomic representation (e.g., private insurance, higher incomes) and a limited number of participants diagnosed with metastatic disease. Thus, since we recruited online and through partner organizations, our study participants may differ from other Black women living with TNBC, who may not be as engaged with social media or nonprofit organizations. However, because there is extremely limited research focused on Black women diagnosed/living with TNBC, our findings offer new and meaningful insights about this patient population.

Key Qualitative Research Study Questions:

1. **What was their diagnosis experience?**
2. **How involved were they in making treatment decisions?**
3. **Did they experience racism or discrimination in healthcare settings? If so, how did it impact their communication and relationship with their cancer care team?**
4. **What types of sources and support did they receive and/or need along their TNBC journey?**

Research Presentation: TNBC and Black Women: Exploring Perspectives, Needs and Experiences by Dr. Lucy Ingram, PhD, MPH at Getting Our Fair SHARE: 2023 Conference to End Health Disparities

TNBC Impact Program

Thank you for your interest in participating in the Triple-Negative Breast Cancer (TNBC) Impact Survey. SHARE Cancer Support is looking to interview 20-25 people diagnosed with TNBC within the last 5-10 years. We want to learn more about your experience with being diagnosed, the information you may have received about your diagnosis, what you understood about TNBC at the time of your diagnosis and more. This survey will tell us a little bit about you and help us identify potential participants for the interview.

This survey will take about 5-10 minutes to complete, and all responses will be kept confidential. A summary of responses will be prepared with no personal or identifying information as part of our research. If you decide to participate, you can stop at any time.

If you have any questions about this survey, please contact SHARE at shareresearch@sharecancersupport.org.

You may begin the survey by clicking on the button below:

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[Photos (L to R) by Caique Silva, Eye for Ebony, Jessica Felicio on Unsplash]

TNBC Impact Program

*1. What is your current age?

☐

TNBC Impact Program

*2. Do you identify as African American or Black (e.g., Black American, Afro-Latina, Caribbean-descent)?

- ○ Yes
- ○ No

TNBC Impact Program

*3. In what month and year were you diagnosed with TNBC?

☐

4. What was the stage of your breast cancer?

- ○ Stage 0
- ○ Stage 1
- ○ Stage 2
- ○ Stage 3
- ○ Stage 4
- ○ I do not know or do no remember
- ○ Other (please specify)

☐

5. What treatment did you receive for your TNBC? Select all that apply.

- ☐ Surgery
- ☐ Chemotherapy
- ☐ Radiation
- ☐ Other additional treatments (please specify)

☐

6. Before you were diagnosed with TNBC, were you aware if you had a family history of cancer?

○ Yes

○ No

○ I do not know or do not rememeber

7. When you were diagnosed with TNBC, what type of health care insurance did you have? (select all that apply)

☐ Private (obtained through an employer or purchased yourself, such as “Obamacare”)

☐ Medicare

☐ Medicaid

☐ I do not have any insurance at that time

☐ I don’t remember

8. When you were diagnosed, with TNBC, which of the following best described your living situation?

○ I was living alone.

○ I was living wih other adults and/or children.

○ Other

9. Where have you received information about TNBC? (Select all that apply)

☐ I have not received or reviewed any information

☐ Oncologist

☐ Primary care doctor or other MD

☐ Cancer organizations (e.g., SHARE Cancer Support, American Cancer Society)

☐ Mobile app

☐ Family or friends

☐ Support group

☐ Internet

☐ Television

☐ Social media (e.g. Twitter, Facebook, etc.)

☐ Written materials (e.g. Books, Magazines, etc.)

10. What gender do you identify with? Select all that apply.

- ☐ Woman
- ☐ Man
- ☐ Non-binary/non-conforming
- ☐ Transgender
- ☐ Prefer not to share
- ☐ Additional gender category/indentity not listed (please specify below)

*11. In what country do you currently live?

- ○ United States
- ○ Other (please specify)

TNBC Impact Program

12. What is your zip code?

*13. Were you born in the United States?

- ○ Yes
- ○ No

TNBC Impact Program

14. How many years have you been living in the United States?

- ○ Less than 1 year
- ○ 1-2 years
- ○ 3-5 years
- ○ More than 5 years

15. Were you treated for your breast cancer in the United States?

- ○ Yes
- ○ No

*16. Is English your first language?

○ Yes
○ No

TNBC Impact Program

*17. Do you have difficulty speaking or reading English?

○ Yes
○ No

TNBC Impact Program

18. How did you hear about this survey? (Check all that apply)

☐ Twitter
☐ Facebook
☐ Instagram
☐ Website
☐ Other (please specify)

☐ Friend or Family Member
☐ Email
☐ Newsletter
☐ My doctor or other health care professional

19. Which of the following currently describes your relationship status?

○ Married
○ Widowed
○ Divorced
○ Separated
○ Single, Never Married
○ Single, but living with a significant other
○ Domestic Partnership or civil union

20. What is your highest level of education?

- ○ Some grade school
- ○ Some high school
- ○ High School Graduate
- ○ Some College, No Degree (1-3 years)
- ○ Associates Degree (2 yrs)
- ○ Bachelor’s Degree (e.g. BA, AB, BS)
- ○ Master’s Degree (e.g. MA, MS, MBA)
- ○ Doctorate or Professional Degree (e.g. PhD, MD, JD)

21. What is your current employment status?

- ○ Full-time
- ○ Part-time
- ○ Self-employed
- ○ Unemployed/not working
- ○ Retired, not employed
- ○ Student
- ○ Disabled, not able to work
- ○ Full-time homemaker

22. What was the current total household income of all your members in your home?

- ○ $0 to $9999
- ○ $10000 to $24999
- ○ $25000 to $49000
- ○ $50000 to $74999
- ○ $75000 to $99999
- ○ $100000 to $124000
- ○ $125000 to $149000
- ○ $150000 to $174000
- ○ $175000 to $199999
- ○ $200000 and up
- ○ Prefer not to answer

TNBC Impact Program

23. Based on your responses *you have qualified* as a potential participant for this study. We will select a total of 20-25 people from across the U.S. to participate. Please submit the following information so that we can contact you when the study begins. You will be notified via email and phone. Thank you for your willingness to participate.

Name

Email Address

Phone Number

TNBC Impact Program

Thank you so much for your interest in the TNBC Impact Study. Based on your responses, we regret that you do not meet the requirements to participate in the study.

If you would like to remain informed about the TNBC Impact Program and future studies, *and* other opportunities you may be eligible for, please provide us with your email below and follow us on social media. If you have any questions or need additional information about TNBC, please call SHARE's *Toll-Free* Helpline at 844-275-7427.

24. Email:

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[Insert date]

Dear [insert name],

My name is Victoria Burke, and on behalf of SHARE Cancer Support, we want to thank you for completing our previous screener survey. We invite you to participate in an on-line interview via Zoom for Black Triple-Negative Breast Cancer (TNBC) patients and survivors. In this study, we want to learn more about your experience being diagnosed and treated for TNBC.

Your information will help us determine how to improve support and information needs for women with TNBC in the future.

There is no cost for you to be in this study. If you decide to be in the study, I will set up a time for your interview. Then, as a way of saying "thank you" for sharing your story with us, you will receive $175. You can choose to have a check or gift card mailed or receive an E gift card through email.

We are partnering with professors Dr. Tisha Felder and Dr. Lucy Annang-Ingram at the University of South Carolina, who will be conducting the interviews with you and other participants. All interviews will be virtual using Zoom.

Please note that your interview will be both Audio and Video recorded on Zoom. The recording will be kept confidential on a password - protected computer and secure server.

If you are interested in participating, please reply to this email indicating your preferred time of day to schedule an interview. We will do our best to accommodate your schedule.

I look forward to talking with you!

Kind regards,
Victoria Burke

[Photos (L to R) by Caique Silva, Eye for Ebony, Jessica Felicio on Unsplash]

What is this study about?

SHARE Cancer Support is working with researchers from the University of South Carolina to interview Black women who have been diagnosed with Triple-Negative Breast Cancer (TNBC). During the interview, we will ask questions to explore perspectives, needs, and experiences relating to being diagnosed with TNBC. The information provided during these interviews will help SHARE determine what support services and educational information are needed that may help Black women get the best possible care and improve outcomes when diagnosed with TNBC.

IRB #: Pro00123881

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South Carolina

Frequently Asked Questions

Who can be in the study?

Adult Black women ages 18 and above, diagnosed with TNBC in the past 5 years.

Why your participation is important?

TNBC is a very aggressive type of breast cancer that often negatively affects Black women. By participating in this study, you can help us better understand how SHARE Cancer Support can better help Black women diagnosed with TNBC in the future.

What will I be asked to do?

You will be asked to participate in an interview about your perspectives, needs, and experience of being diagnosed with TNBC. The interview will take about 1 hour and 30 minutes on one day and will take place virtually via Zoom.

All interviews will be audio and video recorded with your permission.
You will be asked to allow SHARE Cancer Support to utilize segments from the video and audio recording to create messaging to raise awareness about TNBC. You can still participate in the interview even if you do not want your image (video) to be utilized in messaging.

No identifying information will be collected about you at any time during the interview.

Where will the study take place?

All interviews will take place virtually via Zoom.
You are welcome to bring a family member or friend if that makes you more comfortable.

How much will it cost?

There is no cost for you to participate in this study.

Will I be paid to participate?

Yes, you will be paid $175 after your interview. We will mail/email you a gift card or check 2-3 weeks after your interview.

Will my insurance be billed?

No. We will not ask you for your insurance information and you will never be billed.

What happens to the information you get from me?

The information you share with us will be kept confidential as required by law. We will not share the information you give us with your doctor or health insurance.

The audio and video recording from your interview will be stored on password protected computers on secure servers.

The overall results will be distributed via a written white paper, as well as a video with highlights from the interviews. SHARE will disseminate both the written and video summaries via social media, through community and corporate partners, as well as through the press.

What if I don't want to participate in this study?

If you choose not to participate in this study, you may do so at any time without any penalty.

What if I have more questions before I agree to participate?

You are welcome to reach out to Victoria Burke at vburke@sharecancersupport.org or call Victoria at 332-600-1059.

IRB role is to protect people in studies
IRB = Institutional Review Board

Semi-Structured Interview Guide [Sample Questions]

There are no right or wrong answers. You may share as much of your thoughts and feelings as you feel comfortable.

Tell me about your breast cancer diagnosis experience.

- What did your doctor tell you about the disease?
- Tell me about your understanding of TNBC.
- What kind of information did you receive about your diagnosis?

Tell me about your experience with treatment for your TNBC.

- What treatments did you receive?

- How did you make decisions about your cancer treatment?
  - To what extent were you involved in making decisions about your cancer treatment?
  - How involved was your family, friends or other breast cancer patients in making treatment decisions.

- What kind of information did you receive about your cancer treatment?
  Probe about the amount, sources and pace of the information received
    - *How much information did you receive?*
    - *How was the information delivered: online? pamphlets? in-person class?*
    - *When did you receive the information? e.g., before treatment, during, after.*

- What kind of support or advice did you receive to help you get through treatment?
  Probe about the types of support and services that were provided/used
    - *What types of support or services were offered to you from your oncologist or health care team members? e.g., patient navigation, counseling, etc.*
    - *What types of support services did you use? e.g., navigation, counseling, support groups, etc.*

  Probe about from doctor, nurses, social workers and other professionals; family, friends and other people with TNBC
    - *How did the information or support (from the persons named above) given to you make a difference in your treatment experience?*
    - *If no information or support was provided, is there any specific type of support or information you wish you would have had?*

- Are you experiencing any issues in your body as a result of your treatment?
  - What support or assistance are you receiving or need to address these issues?

As a Black woman, what was your relationship like with your doctor, nurses and other cancer care team members?

- How did you feel about your doctor [or other team member]?
- How do you think your doctor [or other team member] felt about you?
- How well did your doctor [or other team member] listen to your concerns? Answer your questions?
- What did you appreciate most about your relationship with your doctor [other team members]?
- Describe any negative experiences you had with your doctor [other team members].
- Describe what you were told about potential risk of breast cancer recurrence?

Now that you have completed your treatments, what would you say are your current needs or concerns?

- What would you say are the current needs or concerns that your family of friends may have about you or your health?
- What is most concerning to you about your TNBC?
- What would help you the most right now?
- What do you know now about TNBC that you wish you knew earlier?
- What do you think would be most helpful to other Black women who are newly diagnosed with TNBC?
    - What specific types of resources or programs do you think would be helpful to them?

What would you like to share with me that I did not ask about?

Appendix 6. Educational Conversation Card

Educational Conversation Card to provide culturally relevant TNBC- specific information for the Black community. This card can help start conversations with the general public and can provide needed information for those diagnosed.

If you would like to order cards please email *shareprograms@sharecancersupport.org*

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Treatment for TNBC may include, surgery, chemo, radiation, immunotherapy or other approved medications.

Your doctor will discuss your treatment options. Always remember it is a personal choice that should be made together with your doctor.

Treatment can be hard - develop your care team of family and medical professionals to help with side effects and any issues you may experience.

Once you receive a breast cancer diagnosis: One of your next steps is genetic testing.

Genetic testing is safe, your data is protected, it can help determine your treatment plan, and family members can be tested to see if they are at high risk for developing breast and other cancers.

TNBC can be more aggressive because it grows more quickly, is more likely to spread, come back and has fewer receptors (Estrogen/Progesterone/HER2) than other subtypes.

Although TNBC is more aggressive - MANY do survive. There is hope.

“I can’t emphasize enough how important community is. Having those connections is the most important key for surviving cancer.” – Chavi, TNBC Survivor

To better understand the experience of being diagnosed with TNBC as a Black woman, SHARE conducted a research study. Eight major themes and 15 recommendations emerged from the deeply personal stories shared by these brave women diagnosed with TNBC.

Scan to hear their experiences and learn more about the study.

What Black Women Need to Know About Triple-Negative Breast Cancer (TNBC)

Staying on top of your annual breast/chest screenings is important. Know what’s “normal” for your body.

If you are experiencing something outside of your “normal” - don’t wait - get it checked out.

Ask your aunties, and elders about your family history. Knowing this can help protect your health.

Hey Sis - we gotta make talking about health and family history a MUST in our community.

Did You Know?

All breast cancer is not the same.

Black women are more likely to get a certain type of breast cancer called TNBC.

Some people have a higher risk of developing breast and other cancers. That’s why it’s important to know your family history.

Ways to stay on top of your health:

Get annual screenings, don’t be afraid to ask questions, and speak up for yourself - it’s your right as a patient.

SHARE CANCER SUPPORT

Acknowledgments

We deeply appreciate each of the Black women who took the time to share their stories with us. Their stories are impactful and will bring healing and validation to many.

A Heartfelt “Thank You” to Dr. Tisha Felder, PhD, MSW for her role as Principal Investigator, her leadership, collaboration, insights, vast knowledge and wisdom in designing this research and authoring the report.

SHARE greatly appreciates Dr. Lucy Ingram, PhD, MPH for her role as co-investigator and presenter of the research methods and findings at SHARE’S 2023 Conference to End Health Disparities.

SHARE acknowledges the significant contributions of Megan Austin, Graduate Research Assistant at the University of South Carolina.

“If you have been diagnosed with TNBC and need support and resources; SHARE has Helplines, support groups and educational programs for breast and metastatic breast cancer.”

Scan to visit www.sharecancersupport.org

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sharecancersupport.org

SHARE is a national nonprofit that supports, educates, and empowers anyone who has been diagnosed with women's cancers, and provides outreach to the general public about signs and symptoms. We are a compassionate community of knowledgeable survivors, women living with cancer, and healthcare professionals. All of SHARE's services are free, and we are dedicated to serving women of all races, cultures, backgrounds, and identities. Because no one should have to face cancer alone.

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