Sharing Our Own Experience: A Qualitative Study of Black Women Diagnosed with Triple-Negative Breast Cancer

San Antonio Breast Cancer Symposium December 5-9, 2023

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Background and Significance

- > Triple-negative breast cancer (TNBC) is an aggressive subtype of breast cancer that accounts for 15-20% of all breast cancers and is disproportionately prevalent among U.S. Black women¹
- > Due to these racial disparities in TNBC, previous research suggests that Black women with TNBC likely face unique barriers to care and have unmet psychosocial needs^{2,3}
- > Thus, there is a need for greater understanding of the treatment experience and unique needs for information and support that Black patients with TNBC may have

Study Goal

To explore the perspectives, needs and experiences of Black women diagnosed with TNBC

Methods

- > Our multi-method study was guided by the transformative paradigm⁴ and core principles of Black Feminist Thought⁵
- > Study-eligible participants self-identified as a) Black/African American; b) 18 years or older; c) being diagnosed with TNBC; d) receiving TNBC treatment in the U.S.; and e) English-speaking
- ➤ Quantitative survey data from SHARE Cancer Support's registry (n=49) was collected and analyzed (Aug-Oct 2022) followed by qualitative interviews (November 2022-February 2023)
- > We recruited a stratified, purposeful sample of 20 Black women from SHARE's registry
- > Two Black researchers conducted virtual interviews with the participants via Zoom
- Participants were compensated \$175 for their time
- > We used the text analysis software NVivo® 12 for data management and thematic analysis⁶
- > A Black Feminist lens was used to analyze codes and interpret emerging themes present across the interviews

Results

50%

were between the ages of 35

reported being diagnosed as

85%

received chemotherapy received

received radiation

1 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

2 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

3 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

4 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







Eight main themes emerged from the qualitative research and subsequent data analysis

*Names listed as authors of each quote are participant pseudonyms

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

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

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

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

Recommendations: What you can do as a...

HEALTH CARE TEAM MEMBER

- Avoid color blindness
- Clinicians need to be better educated about TNBC in Black women
- Acknowledge the mental exhaustion of structural racism and its potential additional impact on Black women

BLACK WOMAN DIAGNOSED WITH TNBC (SURVIVOR)

- 1 Recognize that it's okay to not be okay
- Conversations about the future are necessary
- Surround yourself with positive others

SUPPORT ORGANIZATION

- 1 Increase awareness about TNBC, especially in Black spaces
- 2 Black women want tailored support groups
- Advocate for more research with Black women about TNBC

REFERENCES

1. Bollinger, S. (2018). Biopsychosocial challenges and needs of young African American women with triple-negative breast cancer. Health & Social Work, 43(2), 84-92. 2. Siddharth, S., & Sharma, D. (2018). Racial Disparity and Triple-Negative Breast Cancer in African American Women: A Multifaceted Affair between Obesity, Biology, and Socioeconomic Determinants. Cancers, 10(12), 514. 3. Turkman, Y. E., Kennedy, H. P., Harris, L. N., & Knobf, M. T. (2016). "An addendum to breast cancer": the triple negative experience. Supportive Care in Cancer, 24, 3715-3721.

4. Mertens, D. M. (2007). Transformative paradigm: Mixed methods and social justice. Journal of mixed methods research, 1(3), 212-225.

5. Collins, P. H. (1986). Learning from the outsider within: The sociological significance of Black feminist thought. Social problems, 33(6), s14-s32. 6. Clarke, V., & Braun, V. (2021). Thematic analysis: a practical guide. Sage Publications.

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