Evaluating Racial Differences in Patient-Provider Decision Making Regarding Treatment-Related Symptom Management to Advance Supportive Cancer Care

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BACKGROUND

- Black breast cancer patients report worse treatment-related symptom management compared to their White counterparts.
- Previous studies also indicate that Blacks report less shared decision making regarding treatments. However, little is known about whether racial differences in shared decision making are associated with racial inequities in treatment-related symptom management.

STUDY OBJECTIVE

As part of the Cancer Health Accountability for Managing Pain and Symptoms (CHAMPS) study, We examined racial differences in shared decision making regarding use of treatment changes (switching, stopping, prolonging, or delaying treatment) to manage treatment-related symptoms in breast cancer patients (BCPs).

CHAMPS STUDY

- Community-based participatory research (CBPR) study addressing racial differences in treatment-related symptoms, symptom management, and treatment completion among Black and White breast cancer patients
- Supplemental study to the Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) study, an NCI-funded systems change intervention to improve racial equity in treatment quality and completion among Black and White breast and lung cancer patients
- Research team included community, academic, and medical partners from the Greensboro Health Disparities Collaborative, Sisters Network Greensboro, UNC Chapel Hill, University of Pittsburgh Medical Center-Cancer Center (UPMC-CC), and Cone Health Cancer Center (CHCC)

METHODS

Participant Eligibility

- Black or White woman
- ≥ 18 years of age
- First or recurrent diagnosis of stage 1-4 breast cancer
- Completed primary treatment for breast cancer at CHCC or UPMC-CC from Jan 1, 2013 to Dec 31, 2014
- Exclusion criteria: cognitive impairments or limited English proficiency

Study Design

- Conducted six focus groups (3 Black and 3 White) and six semi-structured interviews with 22 stage 1-4 breast cancer patients
- Evaluated treatment-related symptoms and symptom management experiences across five symptom categories: physical, psychological/emotional, social, financial, and spiritual
- Using a CBPR process, our team of community, academic and medical partners coded and analyzed focus group and interview transcripts

RESULTS

Participant Characteristics (N = 22)

	Black	White
Total # of Participants (N)	10	12
Mean Age, years (SD)	66 (10.9)	65 (13.1)
Stages (n)		
Stage 1	3	3
Stage 2	3	4
Stage 3	2	5
Stage 4	1	0
Time Since Diagnosis, months (SD)	31 (5.4)	31 (8.6)
Insurance Status (n)		
Medicaid	0	1
Medicare	2	4
Private	5	5
No Insurance	1	0
Multiple (Medicare + Medicaid or Private)	2	2

Numbers may not add up to total N due to missing data

Key Themes

Both Black and White breast cancer survivors reported:

Providers (e.g., oncologists, nurses, and surgeons) switched cancer related treatments to address treatment related symptoms and side effects.

- ➢ *"he was gonna put me on the Arimidex…everything in my bladder went up and I said well, you know, you better look into this…. he finally put me on the Arimidex saying that it was not going to affect what was going on"*

Providers stopped or delayed treatments to address treatment related symptoms and side effects.

- ➢ *"And I ended up talking with the doctor, and I stayed off the medicine for six months. It may have been a little"*
- ➢ *"And I had to delay the radiation, and they had to keep giving me different x-rays"*

RESULTS (Cont'd)

Key Themes

Compared with Blacks, White breast cancer survivors more frequently reported:

More shared decision making with providers.

- ➢ *"they delayed radiation to tell me that, well, I could get chemo….She said, "Well, I knew you were gonna say no. "So I was like, "Well, why did we bother with this?" But anyway, I just – I didn't think it was the worth the five percent.*
- ➢ *"And then I opted not to do chemo. It was offered, but I didn't. It was only like a five percent benefit, and I didn't want to lose my hair…..So we did radiation, 33 treatments of radiation starting after Christmas through February 12"*

Compared with Whites, Black breast cancer survivors more frequently reported:

Stopping or refusing to take treatments/ medications because of medical mistrust, patient dissatisfaction or reliance on spiritual guidance.

- ➢ *"before my hot flashes was getting better, but I notice how all of a sudden it's just came back into – I'm not taking that medicine that they gave me."*
- ➢ *" I forget, 'cause I stopped taking that[medication/treatment]. I didn't trust it"*
- ➢ *" But the oxycodone, he's like, well, you're gonna have pain. You didn't tell me I was gonna lose my hair. How you know I'm gonna have pain? See that's why I think, like, you're belittling my intelligence and I don't take drugs like that. If I have a major pain issue, the worst thing I want is some Tylenol with codeine. I don't want no oxycodone."*
- ➢ *"And I was sitting in my living room and this voice came in my head and it said do not put any more of that poison in your body. And I said, oh, okay. I never ignore anything that occurs around Ramadan. So I was like okay. The law has said don't put no more of this poison in your body.."*

CONCLUSIONS

- Treatment changes as a form of symptom management is a common practice. However, stopping or delaying treatments, without provider consultation, may jeopardize supportive cancer care quality and lead to worse cancer care outcomes (e.g., worse quality of life, treatment incompletion) among Black BCPs.
- Future studies should further examine barriers to and strategies for improving equity in shared decision-making regarding cancer treatment-related symptom management.

Acknowledgements: We thank the study participants, staff, co-investigators, and our community partners for their contributions to the CHAMPS study. This work was funded by the National Cancer Institute Award # 3R01CA150980-04S2 and UNC TraCS Pilot Award # (2KR691512) under UNC CTSA Grant Award # UL1TR001111.

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