

Exploring Differences in Cancer Care Values, Needs, and Preferences among Black and White Patients using Thematic Content Analysis



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Background

The National Academy of Medicine (NAM), formerly known as the Institute of Medicine, defines care quality as "the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."^{1(p.4)} PCC has been associated with key care outcomes such as improved health status,² treatment adherence,³ lower blood pressure,² reduced distress and pain,⁴ and lower mortality rates.⁵

The literature shows that non-Hispanic blacks (NHB) consistently experience less favorable cancer care outcomes compared to their white counterparts. NHB are less likely than NHW to:

- Have high quality patient-provider interactions/communication^{6,7}
- Receive care or treatment as recommended by clinical guidelines⁸
- Die from cancer for most of the major cancers including breast, lung, and colorectal cancers ⁹

Sub-optimal minority care experiences have been attributed to: low trust in providers,¹⁰ low health literacy,¹⁰ patient aversion to certain treatment modalities,¹¹ and provider biases.¹² These contributing factors may be addressed by eliciting and attending to key PCC concepts that have been identified by the NAM: patient values, needs, and preferences.

New insights on how to mitigate the racial differences in care outcomes may be obtained by identifying and comparing the values, unmet needs, and preferences of NHB and NHW cancer patients. We anticipated that these PCC factors would vary by race, possibly influencing patient care priorities and their evaluation and participation in care. Furthermore, failure to address values, unmet needs and preferences in oncology may partially explain the observed disparities

Research Aim:
 To explore in differences patients' values, needs, preferences, priorities between NHB and NHW to understand their influence on patient priorities and NHB care outcomes.

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Methods

Sample
 NHB (all) and NHW (purposively selected to match NHB) participants from a 2016 individual interview study (n=29) were included in the analysis. Patients were recruited from the breast, gynecology, lymphoma, thoracic, colorectal, and sarcoma services at an NCI-designated comprehensive cancer center in the Southwestern U.S. This study had IRB approval.

Study Design
 We used a semi-structured interview guide with open-ended questions exploring patients' values, unmet needs and preferences relevant to their entire cancer care experience. Interviews lasted approximately one hour and were audio-recorded and transcribed. A thematic content analysis was conducted by two researchers trained in qualitative methodology.

Results

The sample consisted of 10 cancer patients, 4 NHB and 6 NHW aged 25 to over 60 yrs old, 50% females in both groups. The following themes emerged as patient priorities: a) highest quality of care, b) care experience, c) outcomes, and d) family. No racial differences were observed. The themes or values, needs and preferences are below:

Table 1: Themes for Cancer Patient Values, Unmet Needs, and Preferences that were Exclusive to a Single Racial Group

Values	Needs	Preferences
Social roles <ul style="list-style-type: none"> • Working • Protecting family Social interactions <ul style="list-style-type: none"> • Openness to communication • Honesty • Being outgoing • Helping others (non-family) • Treating others with respect • Professionalism • Being treated like family Religious/spiritual beliefs <ul style="list-style-type: none"> • Belief in God/Religious affiliation • Finding meaning in the illness • Optimism (NHW)* 	Timely access to care <ul style="list-style-type: none"> • Timely initiation of care • Issues with long wait times • Finding and obtaining affordable coverage • Accurate diagnosis and associated care Emotional social support <ul style="list-style-type: none"> • Mutual understanding Informational social support <ul style="list-style-type: none"> • Understanding the rationale and results of procedures/treatment • Preparation for care, experience, treatment and possible side effects • Patient resource information • Long-term treatment plan (NHB)* Instrumental social support <ul style="list-style-type: none"> • Provider interaction between visits • Time to make decision 	Level of healthcare engagement <ul style="list-style-type: none"> • Provider-directed care • Patient-directed care • Minimal interaction • Research participation (NHW)* Types of provider support <ul style="list-style-type: none"> • Provider time usage • Receiving care from a specific or new provider • Spiritual support Treatment <ul style="list-style-type: none"> • Types of treatment • Amount of treatment Care logistics <ul style="list-style-type: none"> • Use of Equipment • Location of care

*Themes that differed by race are presented in orange font with the associated racial group in parentheses.

Results

Patient Sample Quotations for Themes that Differed by Race:

Values – Optimism (NHW)

"And even if the doctors says that something showed up on the test today, I'm not going to give up, you know? That could happen, I don't know, but we'll go on, whatever obstacles should come."
 - NHW Male, Sarcoma, Over 60 yrs old

"I've had a lot of cancer experiences in my family, ah, I'm a glass half full kind of guy, and so it didn't really scare me so much as, "Okay, let's get on, what's the next step? Let's get it out of there."
 - NHW Male, Colorectal, 45-60 yrs old

Unmet Needs - Long-term treatment plan (NHB)

"Cause he was getting ready to get switched down to I think, one day a week, and so I was like, "What's the, what's the plan? What's the next step?" And you know, it was just kind of in the air."
 - NHB Female, Breast, 25-45 yrs old

"...I'm not, I'm not cancer free, quote, unquote so...um, I guess my concerns are you know, how long and how sustainable is what I'm doing now?"
 - NHB Male, Lymphoma, 25-45 yrs old

Preferences - Research participation (NHW)

"Yeah, I did [enroll in clinical trial] and I also signed up to donate extra tissues and blood samples and all that stuff to see if it would help anyone else because, why not, you know, you're here."
 - NHW Male, Lymphoma, 25-45 yrs old

"you know, if...you needed some... they, they asked you for, you know, extra blood and things like this for their research, you know, that they needed, anything like that, I would probably do that."
 - NHW Female, Lung, Over 60 yrs old

Conclusion

We observed differences in values, unmet needs, and preferences between NHB and NHW; however, these racial differences were not reflected in patient priorities for care. This suggests that it may not be enough to focus solely on overarching priorities.

These study findings are limited by a small sample but provide support for further investigation of how racial differences in PCC factors may affect evaluations of and engagement in cancer care, and potentially care outcomes.

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