Review article

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Racial Disparities in Breast Cancer and Genomic Uncertainty: A QuantCrit Mini-Review

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Abstract: African American women are 39-44% more likely to die from breast cancer than white women. This stable racial disparity in mortality rates has persisted since the 1980s and is unlikely to improve unless specific factors leading to disparities are discovered. Racial health disparities should be understood in the context of stable racialized social structures that determine differential access to information. The purpose of this study is to consider how recent quantitative studies using HINTS data might benefit from a critical race agenda to capture the nuances of African American women's information behaviors, genetic testing awareness, and testing for BRCA1 and BRCA2 gene mutations.

Keywords: health information behavior, quantitative analysis, critical race theory, disparities

1 Introduction

In the United States, African American women have the highest death rate from breast cancer despite having lower incidence rates, when compared with white women (Ramirez & Thompson, 2017; Richardson, 2016). African American women diagnosed with breast cancer represent a disparity population as defined by the National Institute on Minority Health and Health Disparities (NIMHD) due to this poor health outcome (Alvidrez et al., 2019). For several decades, researchers have documented breast cancer disparities; however they are unlikely to improve mortality rates unless the specific factors leading to disparities are discovered and an understanding of the disparity population is achieved (Bigby & Holmes, 2005). The persistence of racial health disparities should be understood in the context of relatively stable racialized social structures that determine differential access to information and resources that drive health (Williams et al., 2019).

1.1 Breast Cancer

Most breast cancers are associated with mutations that are acquired throughout one's lifetime and do not cluster in families (U.S. National Library of Medicine, 2019). However, some breast cancers are hereditary and related to deleterious mutations in genes that are inherited from a biological parent (Ademuyiwa et al., 2019). The abbreviation "BRCA" refers to two well-known "BReast CAncer" genes. The BRCA 1 and BRCA 2 genes, when functioning properly, suppress tumors (Scully, 2000). Mutations in BRCA1 and BRCA2 genes were first discovered in the mid-1990s in families with multiple cases of breast and ovarian cancer (Levy-Lahad et al., 2015). BRCA1 and BRCA2 mutations remain a major risk factor for developing breast

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cancer. About 72% of women who inherit a harmful BRCA1 mutation and about 69% of women who inherit a harmful BRCA2 mutation will develop breast cancer by the age of 80 (Kuchenbaecker et al., 2017). In one of the largest population-based studies of young African American women, a BRCA mutation prevalence of 12.4% was observed, which is approximately double the BRCA mutation prevalence among white women (Pal et al., 2015). African American women diagnosed with breast cancer tend to have more aggressive tumors than white women (Wheeler et al., 2013) and are twice as likely to be diagnosed with triple negative breast cancer (TNBC), an aggressive form of breast cancer associated with a BRCA1 gene mutation (Dietze et al., 2015; Pal et al., 2008). Many studies support the hypothesis that breast cancer in African American women is biologically different, but biological factors cannot explain all of the racial disparity in morbidity and mortality (Bigby & Holmes, 2005; O'Brien et al., 2010; Wheeler et al., 2013).

Advances in genomic research can help define cancer risks for individuals and families and facilitate decision making about risk management options (Kaphingst et al., 2019). Genetic tests for hereditary breast cancer permits high-risk individuals to be identified and offered risk-reducing pharmacological or surgical treatment options (Machirori et al., 2018). Genetic testing for BRCA1 and BRCA2 mutations allow women to be better informed and proactive about future health decisions (Kolor, 2017; Miron-Shatz et al., 2015). In 2013, actress, Angelina Jolie, announced in a New York Times opinion piece, that through genetic testing she learned she carried a BRCA1 gene mutation and elected to undergo a risk-reducing bilateral mastectomy (Jolie, 2013). The subsequent media attention followed, called the "Angelina Jolie effect", generated enormous interest and awareness on the topic of genetic counseling and testing (Staudigl et al., 2016). Although genetic testing has become more prevalent, racial disparities in BRCA1 and BRCA2 genetic testing persist (Jones et al., 2017; Mai et al., 2014; McBride et al., 2015). Several studies have demonstrated that BRCA1 and BRCA2 testing rates are substantially lower among African American women due to numerous barriers (Jagsi et al., 2015; Levy et al., 2011; Lynce et al., 2015; Susswein et al., 2008). African American women have lower odds of being offered referrals to genetic counseling (Jones et al., 2017), minority-serving physicians are less likely to order genetic testing (Shields et al., 2008), and African American women may have specific concerns regarding genetic testing reflecting historic injustices in medical research and genetics (Bliss, 2012; Cooper Owens, 2017; Dusenbery, 2018; Hogarth, 2017; Jackson, 1999; Lee et al., 2008; Nelson, 2016; Washington, 2008). Despite these barriers, racial differences in attitudes were found to have little impact on African American women's BRCA1 and BRCA2 testing uptake (Jones et al., 2017). Social disparities (discrimination, lower income, poorer education) may have more influence on predicting genetic testing awareness and uptake (Levy et al., 2011), and African American women who experience social disparities also experience worse health outcomes and are likely to have lower levels of health literacy (Mantwill et al., 2015).

1.2 Literacy & Decision-making

Health literacy is the ability to understand, use, and interpret basic health information necessary to make decisions (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010). Strong numeracy skills increase an individual's ability to interpret complex information related to cancer risk, which is essential to making decisions about prevention and treatment (Fagerlin et al., 2011; Lea et al., 2011; Malloy-Weir et al., 2016; Ross et al., 2018). Having the ability to make informed decisions about genetic testing may be impeded by insufficient information, time pressures, and psychological stress from the decisional process (Ersig et al., 2019; Grimmett et al., 2018; Hesse-Biber et al., 2018). Poorly informed decision-making can lead to feeling overwhelmed and poor psychosocial outcomes (Mazzocco et al., 2019; Postolica et al., 2018) including feelings of uncertainty (Han, 2016), decisional conflict (Rini et al., 2019), and questioning of moral values (Reyna et al., 2015; Zikmund-Fisher et al., 2010).

Internationally renowned, poet, activist, and librarian Audre Lorde refused to quietly bear the burden of her 14-year battle with breast cancer. Instead, she chose to share her emotional patient experiences to empower those suffering in silence, invisibility, and without support for decision-making. In *The Cancer Journals*, Lorde wrote, "... I felt almost overwhelmed by pain and fury, and the inadequacies of my tools to

make any meaningful decision, and yet I had to" (Lorde, 2006).When patients prefer an active or collaborative role in making decisions with health professionals, they tend to be more active in their health information search (Davison et al., 2002). Relevant health information is needed to help patients make sense of their situations (Dervin et al., 1982), heighten their self-efficacy (Lukwago et al., 2003), and enable them to make informed health decisions (Brashers et al., 2002; Dean & Davidson, 2018). It should be noted that in the case of genetic testing for BRCA 1 and BRCA 2 mutations, genomic literacy is required in concert with health literacy. Yet, genomic literacy is persistently low in the United States (US) (Haga et al. 2013). Poor genomic literacy can lead the public to misinterpret genomic information and may lead to greater health disparities (Allen et al., 2016). Knowledge about breast cancer genetics is influenced by the quality of the information obtained and individual's ability to comprehend that information (Himes et al., 2019; Lea et al., 2011).

Facilitation of the public's information-seeking activities will be a key aspect of efforts focused on promoting informed decision-making and greater patient involvement in cancer prevention and control efforts (Arora et al., 2008). Public health professionals desire to improve health outcomes and reduce health disparities through better understanding about patients' interactions with complex and rapidly changing health information. Since 2001, the National Cancer Institute's Health Information National Trends Survey (HINTS) has been a rich resource of cross-sectional, national surveillance data to evaluate trends across and within vulnerable populations (Hesse et al., 2017). Public health surveillance systems monitor trends in disease incidence, health behaviors, and environmental conditions in order to allocate resources to maintain healthy populations (Mooney & Pejaver, 2018). HINTS data have been used to explore constructs of health literacy and provide a sentinel view of strategies tailored to meet the needs of disparity populations.

1.3 Purpose

Analysis of data [like HINTS] is most effective when researchers account for complex ideological processes underling the data's impetus, bias and affordances (Brock, 2015). Population-based data like HINTS may be quantitatively analyzed and the results interpreted in ways which insufficiently represent African American women, and their health information behaviors. Although the NCI commitment to population-based data collection has unlocked novel opportunities for understanding public health trends in information behavior and health information literacy, publications based on HINTS data should be critically reviewed for pitfalls of algorithmic thinking, distortions of misnaming differences, reinforced mythical norms, and neutralizing entrapments of colorblindness. Gillbourn and colleagues (2018) urge researchers to draw on the tenets of Critical Race Theory (CRT) in the analysis of quantitative data to reduce these pitfalls (Gillborn et al., 2018). Critical Race Theory has been championed in public health by disparities researchers as an Antiracism Praxis (Ford et al. 2010). The purpose of this study is to consider how recent quantitative analysis and interpretation of HINTS data might benefit from a critical race agenda to capture the nuances of African American women's information behaviors and genetic testing awareness and uptake related to hereditary breast cancer or BRCA1 and BRCA2 gene mutations.

2 Method

Scientific literature on the health information behaviors related to genetic testing for breast cancer is relatively low. Therefore, the researcher conducted a mini-review of the literature to explore recent publications analyzing HINTS data and addressing the topic of African American women's genetic breast cancer (BRCA) screening decisions. A bibliometric search was conducted using three electronic databases, ProQuest, EBSCO, and Google Scholar, for articles published from 2013 through September 14, 2019 using the terms ''Health Information National Trends'' and ''brca''.

The research included only peer-reviewed articles published in scientific journals. Articles had to (a) be written in English, (b) include an abstract, (c) include an analysis of HINTS data in the method, (d) focus on breast cancer, and (e) focus on genetic or BRCA testing.

The researcher reviewed all abstracts and methods for eligibility. As documented in Fig. 1, the initial search resulted in the identification of 275 records for review. After exclusion of duplicate records and articles that failed to meet the study's inclusion criteria, 11 articles remained for evaluation (Table 1).

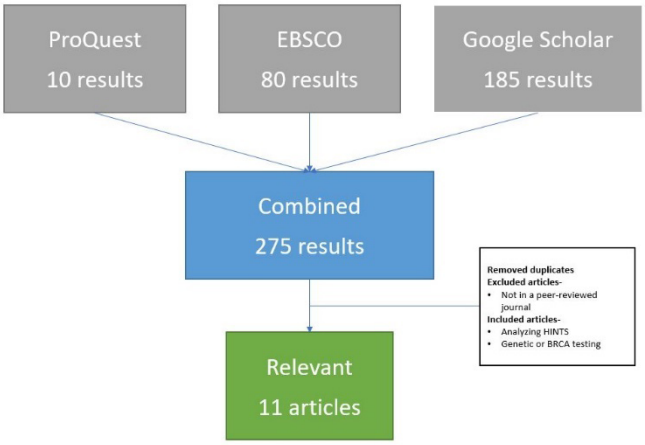

Figure 1: Articles Reviewed

Table 1: Selected Peer-Reviewed Articles

1	Agurs-Collins, T., Ferrer, R., Ottenbacher, A., Waters, E. A., O'Connell, M. E., & Hamilton, J. G. (2015). Public Awareness of Direct-to-Consumer Genetic Tests: Findings from the 2013 U.S. Health Information National Trends Survey. *Journal of Cancer Education*, *30*(4), 799–807. https://doi.org/10.1007/s13187-014-0784-x	Awareness
2	Arora, N. K., Hesse, B. W., & Clauser, S. B. (2015). Walking in the shoes of patients, not just in their genes: A patient-centered approach to genomic medicine. *The Patient-Patient-Centered Outcomes Research*, *8*(3), 239–245.	Patient Centered Care
3	Huang, H., Apouey, B., & Andrews, J. (2014). Racial and Ethnic Disparities in Awareness of Cancer Genetic Testing Among Online Users: Internet Use, Health Knowledge, and Socio-Demographic Correlates. *Journal of Consumer Health on the Internet*, *18*(1), 15. Retrieved from edb.	Awareness
4	Krakow, M., Ratcliff, C. L., Hesse, B. W., & Greenberg-Worisek, A. J. (2017). Assessing genetic literacy awareness and knowledge gaps in the US population: Results from the Health Information National Trends Survey. *Public Health Genomics*, *20*(6), 343–348.	Awareness
5	Kushalnagar, P., Holcomb, J., & Sadler, G. R. (2019). Genetic testing and eHealth usage among Deaf women. *Journal of Genetic Counseling*. https://doi.org/10.1002/jgc4.1134	Usage
6	Quillin, J. M. (2016). Lifestyle Risk Factors Among People Who Have Had Cancer Genetic Testing. *Journal of Genetic Counseling; New York*, *25*(5), 957–964. http://dx.doi.org.proxy.lib.fsu.edu/10.1007/s10897-015-9925-6	Health Behavior
7	Roberts, M. C., Taber, J. M., & Klein, W. M. (2018). Engagement with Genetic Information and Uptake of Genetic Testing: The Role of Trust and Personal Cancer History. *Journal of Cancer Education; New York*, *33*(4), 893–900. http://dx.doi.org.proxy.lib.fsu.edu/10.1007/s13187-016-1160-9	Usage
8	Roberts, M. C., Turbitt, E., & Klein, W. M. P. (2019). Psychosocial, attitudinal, and demographic correlates of cancer-related germline genetic testing in the 2017 Health Information National Trends Survey. *Journal of Community Genetics*. https://doi.org/10.1007/s12687-018-00405-4	Psychosocial
9	Ross, K., Stoler, J., & Carcioppolo, N. (2018). The relationship between low perceived numeracy and cancer knowledge, beliefs, and affect. *PLOS ONE*, *13*(6), e0198992. https://doi.org/10.1371/journal.pone.0198992	Numeracy
10	Salloum, R. G., George, T. J., Silver, N., Markham, M.-J., Hall, J. M., Guo, Y., … Shenkman, E. A. (2018). Rural-urban and racial-ethnic differences in awareness of direct-to-consumer genetic testing. *BMC Public Health; London*, *18*. http://dx.doi.org.proxy.lib.fsu.edu/10.1186/s12889-018-5190-6	Awareness
11	Taber, J. M., Chang, C. Q., Lam, T. K., Gillanders, E. M., Hamilton, J. G., & Schully, S. D. (2015). Prevalence and Correlates of Receiving and Sharing High-Penetrance Cancer Genetic Test Results: Findings from the Health Information National Trends Survey. *Public Health Genomics; Basel*, *18*(2), 67–77. http://dx.doi.org.proxy.lib.fsu.edu/10.1159/000368745	Information sharing

2.1 Synthesis and thematic analysis

The papers identified for review were read in depth. First, the researcher summarized the quantitative outcomes for each study using a narrative summary technique to describe the trends associated with African American women and genetic breast cancer (BRCA) testing. The quantitative outcomes (P values and estimates of precision) are reported on a study by study basis in Table 2. Second, the researcher conducted a thematic analysis of the interpretation of the quantitative results described in the discussion and conclusion of each article using an a priori coding schema based on the five tenets of critical race theory applied to quantitative critiques also known as QuantCrit (N. M. Garcia et al., 2018; Gillborn et al., 2018): (1) the centrality of racism as a complex and deeply-rooted aspect of society that is not readily amenable to quantification; (2) numbers are not neutral and should be interrogated for their role in promoting deficit analyses that serve White racial interests; (3) categories are neither 'natural' nor given and so the units and forms of analysis must be critically evaluated; (4) voice and insight are vital: data cannot 'speak for itself' and critical analyses should be informed by the experiential knowledge of marginalized groups; (5) statistical analyses have no inherent value but can play a role in struggles for social justice.

3 Results

The current mini-review characterizes the quantitative analysis of HINTS data described in a sample of 11 studies related to genetic or BRCA testing (Table 1). The studies were published between 2013 and 2019 and were conducted in the United States. Several (n = 4) of the 11 studies focused on the concept of genetic testing awareness. The other studies had diverse topics related to information behaviors or genetic testing uptake, such as the role of genetic counselors (n = 1), psychosocial factors like trust and worry (n = 2), numeracy (n = 1), and the sharing of results (n = 1) (Table 1). All studies presented frequencies of correlates to characterize subpopulations. Several of the studies used chi-square tests (n= 4) to compare associations between correlates and all but one used logistic regression for statistical analysis (n=10).

3.1 Race as a social construct

There has been a longstanding system of government classification by defined racial categories. In 1977, the Office of Management and Budget (OMB) issued directive No. 15, which instructed federal agencies to use the U.S. Census racial taxonomy to collect and monitor minority participation in public services (*OMB DIRECTIVE 15: RACE AND ETHNIC STANDARDS FOR FEDERAL STATISTICS AND ADMINISTRATIVE REPORTING*, n.d.). Directive No. 15 was revised in 1997 to issue standards for the following basic racial categories and organizing data: American Indian or Alaska native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander and White. The revision also defined two ethnic categories, which are "Hispanic or Latino" and "Not Hispanic or Latino" (*Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*, 2016). Every cycle of HINTS includes questions to ascertain race and ethnicity, which map to the federal standards (*Survey Instruments | HINTS*, 2017). Scientists routinely use these racial categories in their research and make health comparisons between races (Kahn, 2008). Often scientists find themselves oscillating between social, biological, and genomic definitions of race (Bliss, 2012). Socially constructed definitions of race may be useful in medical contexts, as a means for providing information about social circumstances and lifestyle conditions of patients, particularly discrimination (Feldman & Lewontin, 2008). However, use of social constructs like race in the descriptive assessment of health outcomes often result in attribution of causality to those categories, which is unjustified and potentially harmful (Caulfield et al., 2009) .

Several scientists analyzing HINTS data used race classifications to describe and predict the behaviors and characteristics of categories of people. Agurs-Collins et al. indicated race and ethnicity as a predisposing background factor in their conceptual framework used to assess demographic correlates with genetic

testing awareness (Agurs-Collins et al., 2015). Huang et al. described race and ethnicity as predictors for genetic test awareness (Huang et al., 2014). Roberts et al. (2019), adapted the Multiplex Genetic Testing Model, which included race as a factor directly related to intentions. These interpretations are often devoid of subjective singularities and represent a statistical body that ignores the embodied individuals (Cheney-Lippold, 2017). According to Critical Race Theory, race is socially constructed and is a marker for racism-related exposures (Ford & Airhihenbuwa, 2010). Racism (not race) is considered a fundamental cause of adverse health outcomes and health disparities for racial and ethnic minorities (Williams et al., 2019). Racism is an organized social system in which the dominant racial group categorizes and ranks people into social groups. The dominant racial group defines inferior groups through disenfranchisement, segregation, and devaluation through controlled allocation of societal resources and opportunities (Bonilla-Silva, 1997). The negative normative beliefs (stereotypes) and attitudes (prejudice) toward stigmatized racial groups become normalized throughout society and operate through institutional and cultural domains (Williams et al., 1997), as predisposing factors for racial health inequalities (Phelan & Link, 2015).

The Everyday Discrimination Scale (EDS) was developed by Williams, Yu, Jackson, and Anderson for use in a study of racial discrimination (Williams et al., 1997) and has become a widely used tool to measure perceived discrimination and poorer health outcomes (Kim et al., 2014; Mouzon et al., 2019; Peek et al., 2011). The EDS measures have been tested by two large-scale population studies, first by Kessler and colleagues in 1999 and then by Ryff, Keyes, and Hughes in 2003. Only one (Huang et al., 2014) of the three studies that mentioned race as a predisposing factor for awareness, reported race as being significantly associated with genetic testing awareness. The HINTS instrument does not include measures of racial discrimination.

3.2 Numbers are not neutral

Population data represents 'a political process involving questions of power, transparency and surveillance' (Tufekci, 2014), it is not neutral or complete (Hannah-Moffat, 2018). Often 'hidden assumptions frequently encode racist perspectives beneath the façade of quantitative objectivity' (Gillborn et al., 2018). In 2018, Roberts et al. reported missing data for the dependent variable among respondents who were African American, Hispanic, or Female. When data is missing, it may translate into a form of colorblindness and inability to report on outcomes stratified by race. Failing to secure a study population that is representative of diverse peoples may result in oversampling of white people and lead researchers to ignore the specific needs of African American women. Also, HINTS data are weighted to align with population data from the American Community Survey conducted by the U.S. Census (*Methodology Reports | HINTS*, n.d.). If the study population underrepresents African American women, statistical analysis with weighted data may be invalid. Quillin et al. described a study population of 135 who reported having had genetic testing for BRCA or Lynch syndrome. The weighted percent of white respondents in this study population was 82.17, while all other racial classifications were combined to represent a weighted 17.6 percent of the population (Quillin, 2016). Krakow et al. reported statistically significant lower odds of having heard of genetic tests among black people when compared to white people where Non-Hispanic African American people represented a weighted percent of 10.28 (409 respondents) and Non-Hispanic white people represented a weighted percent of 65.69 (1868 respondents). Without weighting the percent of Non-Hispanic African American respondents is greater (12.45) and percent of Non-Hispanic white respondents is lesser (56.86).

3.3 Categories are not natural

Health inequalities along racial are attributed to systemic racism and the ensuing unequal life chances across myriad domains (Brown, 2018). Most researchers analyzing HINTS data typically examined health disparities separately for racial groups rather than using an intersectional lens to identify the contingent health consequences of race and other factors such as ethnicity, nativity, gender (and gender

identification), disability, and rurality. However, several championed intersections with race, disability, and rurality. Kushalnagar et al. demonstrated that disparities between African American women and white women deepen when the women are deaf (Kushalnagar et al., 2019). While Salloum et al. observed rural/urban differences across racial and ethnic groups (Salloum et al., 2018). Multiple interacting dimensions of inequality are articulated by the theory of intersectionality, which emphasizes the fundamental interconnections and interdependence between categories of gender, race and class (Crenshaw, 1991). Intersectionality approaches for health disparities highlight how intersecting social statuses result in unique social contexts that differentiate the lived experiences and health pathways among broadly defined social groups (Ailshire & House, 2011).

3.4 Data cannot speak for itself

Society is collecting unprecedented volumes of data and has subtly grown into an "algorithmic age" fueled by using computer science, technology, and information in powerful new ways. Scholars from diverse disciplines are examining how big data varies, how it is being assembled and who is accessing said data for analysis, manipulation and (re)presentation (Dalton, Taylor, & Thatcher, 2016). Thin data from HINTS may need to be supported with thicker data and narratives to piece together a story richer than the data originally collected. Quillin et al. mapped HINTS responses with American Cancer Society recommendations as a means of assessing lifestyle factors like smoking (Quillin, 2016). The researchers found the prevalence of smokers among those who had genetic testing to be no different from those who did not. This finding leads to more questions about the role of genetic counselors and their impact on lifestyle factors. In 2019, Roberts et al. found that people who had genetic testing and avoided cancer information demonstrated a paradox between their attitudes and their testing behaviors (Roberts et al., 2019). Taber et al., found no significant association between race and sharing genetic testing results with health professionals but they also found that respondents were more likely to share their results if the respondents also reported higher optimism, greater self-efficacy for health management, and greater trust in health information from doctors (Taber et al., 2015). The psychosocial factors fatalism, trust, and self-efficacy have been found in other studies to be lower among African American patients (Powe & Johnson, 1995; Strekalova, 2018; Yang et al., 2010). There is a need to better understand the act of sharing or not sharing genetic testing results among African American women. Some studies have demonstrated that those who considered the test result as diagnostic were significantly more likely to consult a physician post-test, and the majority thought that physicians had an obligation to help interpret the results (Goldsmith et al., 2012).

3.5 Struggles for social justice

Many of the trends observed when analyzing the HINTS data underscore the relationships between socio-demographic characteristics and longstanding struggles for economic and educational justice. Agurs-Collins et al. report the estimated cost to purchase direct to consumer genetic testing ranges from less than $100 to more than $1000 depending upon the test ordered (Agurs-Collins et al., 2015). It is not surprising that researchers have found income to be associated with awareness of genetic testing (Agurs-Collins et al., 2015; Huang et al., 2014; Jones et al., 2017; Krakow et al., 2017; Platt et al., 2014; Rini et al., 2019). While racial and economic disparities in mortality are well known (Abnousi et al., 2018; Freeman, 2004; Murray et al., 2006), several social conditions associated with health may unequally affect African American people in poverty in the United States (Mode et al., 2016). Although spatial racial segregation has decreased (Rugh & Massey, 2014), wage gaps for African American women have increased (Daly et al., 2017). Health disparities can reproduce and reinforce gaps in income and wealth, with negative feedback loops creating a health poverty trap (Bor et al., 2017).

Numeracy is related to income and educational attainment (Peters & Bjalkebring, 2015). Low numeracy has also been identified as a problem because patients with low numeracy will have difficulties assessing

the risks and benefits of screening or treatment options and even medication management (Mantwill et al., 2015). Health professionals with low numeracy may have difficulties communicating numerical data to patients (Malloy-Weir et al., 2016). Ross et al. used the HINTS data to examine associations between racial and ethnic categories with measures of perceived numeracy (Ross et al., 2018). The researchers found that respondents who reported low understanding of and low comfort with numeric information were more likely to be non-white, lower income, and of lower educational attainment (Ross et al., 2018).

Finally, five studies in the sample measured "awareness" of genetic testing using a yes/no response to any of the following questions:

"Genetic tests that analyze your DNA, diet, and lifestyle for potential health risks are currently being marketed by companies directly to consumers. Have you heard or read about these genetic tests?"
"Have you heard or read about any genetic tests?"
"Doctors use DNA tests to analyze someone's DNA for health reasons. Have you heard or read about this type of genetic test?"

Individuals who responded "yes" to any of these questions were considered to be aware of genetic testing. Then only individuals who responded yes to genetic testing awareness were also asked if they had ever received any of the following types of genetic tests: ancestry, paternity, DNA fingerprinting, Cystic Fibrosis carrier, BRCA 1/2 and/or a Lynch Syndrome test. With the plethora of tremendously successful shows like The Maury Povich Show or Maury, a controversial talk show, which has aired over 2,900 episodes, boasting paternity testing as the secret for ratings success (Seemayer, 2019), it is hard to imagine so many people are unaware of genetic testing. Could it be that they refer to it by another name and are simply unaware of its use for health? Perhaps a more accurate measure of awareness would be ascertained if volunteers were first asked if they had ever received any type of genetic test such as paternity, ancestry, etc. Researchers who examine racial-ethnic discrimination should move beyond thinking of discrimination as simply statistically-based and should question whether racial discrimination is driven by explicit versus implicit bias (Gaddis, 2019).

4 Discussion

Since the 1980s, a stable racial disparity in mortality rates between African American women and white women has persisted. African American women are 39-44% more likely to die from breast cancer than their white counterparts (DeSantis et al., 2017). This mini-review uses Critical Race Theory to summarize themes in recent quantitative analyses of the Health Information National Trends Survey (HINTS) data related to genetic and BRCA testing. The literature included in this study has been used to gain population level insights into the health information behaviors of disparity populations including African America women. Publicly available sources of data like HINTS have dramatically improved over the years and provide population-level data for secondary data analysis by diverse researchers. Yet, there remains considerable opportunity to advance our health information research agendas by addressing racial breast cancer disparities through the lens of information studies to improve population data collection, center African American women when analyzing trends in breast cancer disparities, and leverage core competencies of information science to inform classification, privacy, and use of genetic information.

4.1 All of Us

In October 2019, Mathew Knowles, the father of celebrity singers Beyoncé and Solange, shared that he had urged his daughters to receive genetic testing for the BRCA mutation because he has a BRCA2 mutation ("Mathew Knowles reveals he is battling breast cancer," 2019; McCullough, 2019; Tracy, 2019). Whether this results in the same celebrity effect comparable to Angelina Jolie has yet to be seen. The HINTS program is being eclipsed by a rock star of a surveillance effort. In January 2015, President Obama announced the Precision Medicine Initiative (PMI), which includes a charge to recruit a cohort of 1 million volunteers In

the All of Us Research Program and collect genetic samples (Sankar & Parker, 2017). The All of Us Research Program plans to enroll volunteers who are diverse in many respects, including socioeconomic status, age, geography, health status, health literacy, and personal competence with information technologies. In particular, the enrollment of racial and ethnic minorities will be a priority. With the trust of this diverse cohort of potentially 1 million All of Us volunteers, researchers are beholden to ensure equity by granting individual access to research findings and genetic testing results as an incentive to participate (Crawford et al., 2019). Web-based tools, like My46 (Tabor et al., 2017), will be made available for non-scientists to manage their genetic testing results.

4.2 Translation

In breast cancer patients, mutations and/or variants of uncertain significance (VUS) in genes results have resulted in a negative impact on recipients' risk perceptions, surgical decisions, and disease-specific distress (Lawal et al., 2018). For African American women this is alarming because the genetic test for BRCA mutations, often results in receiving a variant of unknown significance (VUS), meaning that even though a mutation had been discovered, its significance could not be determined (Saulsberry & Terry, 2013). Researchers have identified VUS occurred ten times more often in African American women than white women in a 2006 study (Opatt et al., 2006) and in 2013, the National Cancer Institute reported that 16.5% of people of African descent who underwent genetic testing had a BRCA mutation classified as VUS (National Cancer Institute, 2013). Therefore, there may be a much higher level of numeracy required to understand African American women's genetic testing results and justification of potentially higher rates of fatalism and worry among them. Health professionals and genetic counselors may serve as information intermediaries to provide guidance and assistance to volunteers attempting to translate their results. Genetic counseling supports patients to make informed decisions about their health and treatment, improves knowledge of cancer genetics, modifies cancer risk perceptions, and reduces cancer associated anxiety (Febbraro et al., 2015). Genetic counselors will face the added burden of interpreting VUS results with an unclear relationship to the volunteer's clinical presentation (Hall et al., 2015). Unfortunately, compared with white non-Hispanic women, fewer African American women receive genetic counseling from a genetic counselor prior to genetic testing, which suggests another dimension of health information disparity (Armstrong et al., 2015; Buchanan et al., 2016).

4.3 Information Concerns

Genetic testing can provide powerful predictive information in the fight against breast cancer but there are many ethical, legal, and social issues to consider. A consequence of encouraging disparate populations to be genetically tested may be the proliferation of private and open source databases with genomes of diverse ancestries, widening privacy concerns to an even greater number of participants and their relatives (Crawford et al., 2019). African American women may have specific concerns about 'genetic' discrimination, stigmatization, and personal identifiability (Botkin et al., February 7; Catz et al., 2005). Doukas and colleagues reported African Americans were more suspicious regarding the confidentiality of genetic testing results and how they could be misused (Doukas et al, 2004). Although, many African Americans appreciate the preventative advantage of genetic testing, they may find preventive surgery after a positive genetic test for breast cancer (such as prophylactic mastectomy) as 'going too far' with genetic information (Catz et al., 2005).

Information researchers addressing breast cancer disparities are positioned to raise the concerns of patients to inform policy and best practices for genetic research registries and future behavioral interventions. Breast cancer patient information needs reach beyond deficits in awareness and low numeracy. Addressing breast cancer patient concerns about how their genetic information will be de-identified, protected, directly benefit their families may move the needle in achieving representative registries and reducing disparities

in BRCA testing. However, to reduce the risk of reifying the ills of the past, researchers must challenge traditional stratification methods and change how we interpret racial statistics (J. A. Garcia, 2013; Zuberi, 2001).

5 Conclusion

This mini-review introduces a complex and growing area of study for information researchers to explore. It represents the preliminary actions to advance the study of cross-cutting domains of population data, information behavior, health literacy, and genetic testing as a means to address racial health disparities in breast cancer. Informed choices are fundamental to both individual health outcomes and to the reduction of racial health disparities in the population. It is imperative that quantitative data used for the purpose of describing and predicting health information trends be evaluated and interpreted critically.

Table 2: Included Study Characteristics

First Author, Study Year, HINTS Dataset	Objective	Key Findings	CRT Considerations
(Agurs-Collins et al., 2015) HINTS 4, cycle 3 (2013)	To assess the prevalence of awareness of direct to consumer (DTC) genetic testing, identify sources of information regarding DTC genetic testing; and identify demographic, cognitive, and behavioral correlates of awareness of DTC genetic testing.	Income was the only demographic variable significantly associated with awareness of DTC genetic testing. Participants with annual incomes of $99,999 or less had lower odds of being aware of DTC genetic testing (ORs ranging from 0.46–0.61) than did those participants with an income of $100,000 or more. None of the predisposing factors defined by the framework (fatalism, worry, perceived risk, mortality salience and perceive ambiguity about cancer prevention) were found to be significantly associated with DTC testing awareness but awareness was positively associated with enabling factors like internet use and cancer information-seeking behaviors. A significate association between DTC awareness and a measure of objective numeracy was observed.	Race and ethnicity are described as distinct background factors in the adapted conceptual framework but no associations with DTC awareness were observed. Racial and ethnic income inequality represent a persistently entangled disparity.
(Arora et al., 2008) HINTS 4, cycle 1 (2011)	To evaluate "patient-centeredness" or how often (from the perspective of the patient) providers engaged patients in Patient Centered Care (PCC) by fostering healing relationships, exchanging information, facilitating decision-making, responding to emotions, enabling self-management, and managing uncertainty.	Although 45-61% of the population reported that they "always" received PCC, 25% reported they rarely received help dealing with uncertainty about their health care, 23% reported their providers never paid attention to their emotions, 18% were rarely involved in decision making as much as they wanted, and 10% reported being unable to ask their health-related questions during medical visits, they leave the office not understanding what they need to do to take care of their health care needs, or rely on the health care system to take care of them.	Racial characteristics of the population reporting low patient-centeredness are not provided but may be important to employ the six-function framework of PCC in environments enabled by breast cancer genomic medicine.

First Author, Study Year, HINTS Dataset	Objective	Key Findings	CRT Considerations
(Huang et al., 2014) HINTS 2007	To examine the association of race and ethnicity on genetic testing awareness and explore variables of trust, sharing, and health knowledge.	"When considering the variables of ethnicity only, African Americans and Hispanics, compared to whites, had negative impacts on the prediction of genetic test awareness." The authors used the nonlinear Fairlie decomposition method to quantify the awareness gap between racial groups. This method requires a one-to-one matching of cases between groups, which was achieved by selecting a random drawing of whites to match with the African American population. Higher trust in information provided by religious organizations (13.1%) is one of the main determinants in the racial gap in genetic testing awareness along with clinical trial awareness (13.1%), and lower educational attainment (11.5%).	Race and ethnicity are described as predictors for genetic test awareness. Attempts to measure the racial awareness gap provides indications that uniform policies and interventions may not as well for African American populations due to rank differences in the factors associated with genetic testing awareness. Trust in information from religious organizations is higher in the African American community. The discussion suggests these organizations be used for health communications, but other aspects of trust are not mentioned yet fatalistic beliefs are described as barrier without historical or cultural context.
(Krakow et al., 2017) HINTS 5, cycle 1 (2017)	To determine prevalence of genetic testing awareness and to assess uptake of genetic tests in the general population.	African American respondents (OR: 0.49, CI: .31, .78) were less likely be aware of genetic testing, compared to non-Hispanic white respondents. Individuals with household incomes over $75,000 were more likely to report awareness of genetic tests, compared to the lowest household income category (OR: 1.72, CI: 1.13, 2.60). The most commonly reported types of tests were ancestry tests (11.11%), paternity tests (8.97%), DNA fingerprinting (8.51%), and Cystic Fibrosis carrier tests (6.87%). Only 5.36% had undergone at least one cancer-related test: 4.88% reported BRCA testing, and even fewer (2.52%) had undergone testing for Lynch Syndrome.	Genetic testing awareness was determined by a yes to the following question, "Doctors use DNA tests to analyze someone's DNA for health reasons. Have you heard or read about this type of genetic test?" The question injects a bias because many may be aware of ancestry and paternity tests but may not refer to them as genetic tests or they may not be aware that doctors use genetic tests for health reasons. Only those who answered "yes" to genetic testing awareness were also asked about the types of genetic tests they had ever received.
(Kushalnagar et al., 2019) HINTS- ASL HINTS 5, cycle 1 (2017)	To comparatively investigate genetic testing awareness among Deaf and the Hearing women and their use of eHealth platforms.	Deaf women who had not heard of genetic testing were more likely to self-identify as African American. The racial disparity for awareness of genetic testing was significantly higher among Deaf women compared to their hearing peers ($\chi 2 = 20.90$, $p < 0.001$).	Racial disparities may be more challenging when individuals represent multiple disparity populations. This study showed an association between educational attainment and genetic testing awareness, which may indicate a need for ASL health education materials that are understood at a 6th grade level.

First Author, Study Year, HINTS Dataset	Objective	Key Findings	CRT Considerations
(Quillin, 2016) HINTS 4, cycle 3 (2013)	To explore lifestyle risk factors and uptake of genetic testing for BRCA or Lynch Syndrome.	About 80 % of respondents reported white race. Most (about 65 %) had at least some college education. There were no differences in race or education according to genetic testing status. Two leading lifestyle risk factors for cancer are obesity and smoking. Over half of the respondents reported having a BMI of equal to or greater than 25 kg/m^2 (58%), which indicates being overweight or obese and 24% identified themselves as current smokers. "Seeking genetic testing for cancer risk does not necessarily mean that the patient has also made lifestyle changes to address her or his cancer risk."	The analysis was stratified as white or Non-white. There is no discussion of disparities specific to African American populations. Also, the study demystifies the notion that genetic testing awareness equates with health behaviors and cancer risk reducing lifestyle factors.
(Roberts et al., 2018) HINTS 4, cycle 3 (2013)	To examine the association between receiving genetic information from trusted sources and genetic test uptake within a sample of US adults to determine if people trust their genetic testing information sources and is trust associated with uptake.	Overall, individuals with missing data for the dependent variable and primary independent variables had lower education and income and were African American, Hispanic, or female (data not shown). However, those receiving cancer-related genetic testing tended to be female and were more likely to have a personal history of cancer compared to those who did not receive testing. Respondents reported that they trusted information from health professionals the most but were less likely to hear about genetic testing from them. More often respondents heard about genetic testing from the television, which happened to be a less trusted source. Increased levels of trust for genetic information sources were associated with increased predicted probability of uptake, only if the respondent had a personal history of cancer.	When data is missing, African American women may not be adequately represented in the study population and results are conveyed without distinguishers for race and ethnicity. Backwards elimination was used and only independent variables that were significant were used in the final regression model.
(Roberts et al., 2019) HINTS 5, cycle 1 (2017)	To examine associations between worry, perceptions, attitudes, and sociodemographic characteristics and uptake of BRCA1, BRCA2, or Lynch syndrome testing using an adaptation of the Multiplex Genetic Testing Model.	Being aware that genetic testing can guide treatment decisions was related to uptake of BRCA1, BRCA2, or Lynch syndrome testing in both descriptive and multivariable models (adjusted risk ratio (aRR) = 2.57, $p < 0.01$; aRR = 3.23, $p < 0.04$, respectively). Among those who had heard of genetic tests, 40% know that genetic tests could be used to determine disease treatment or drug choice (40.7%, 95%CI = 0.37, 0.44 and 43.3%, 95%CI = 0.39, 0.47, respectively). This study did not find associations between psychosocial or attitudinal variables and receipt of cancer-related genetic testing.	People who avoid cancer information were equally as likely, as those who did not avoid, to report having cancer-related genetic testing. This finding suggests that those who had cancer-related genetic testing and were cancer information avoidant may display a paradox of choice, as their attitudes were in opposition to their testing behavior. Other information preferences related to knowing the likelihood of passing an inherited gene to one's children may take priority over one's own cancer risk information.

First Author, Study Year, HINTS Dataset	Objective	Key Findings	CRT Considerations
(Ross et al., 2018) HINTS 2007	To evaluate the relationships between three self-reported, perceived low numeracy items and cancer-related knowledge, beliefs, and affect.	The three perceived numeracy measures were associated with many of the demographic characteristics. Respondents with low numeracy understanding were more likely to be of ethnic/racial minority status (X2 = 18.3, P < .001), report lower household income (X2 = 18.3, P < .001), have lower educational attainment (X2 = 58.3, P < .001), and be more likely to prefer Spanish (X2 = 9.9, P = .002). Respondents with low numeracy comfort were more likely to be female (X2 = 10.0, P = .002), be of ethnic/racial minority status (X2 = 11.1, P = .010), report lower household income (X2 = 49.4, P < .001), have lower educational attainment (X2 = 49.4, P < .001), and be more likely to prefer Spanish (X2 = 9.3, P = .002). After controlling for most demographics, low numeracy comfort remained significantly associated with fatalism (OR 1.63, 95% CI 1.23±2.14, P < .001), information overload (OR 2.37, 95% CI 1.79±3.13, P < .001), low prevention knowledge (OR 1.79, 95% CI 1.32±2.42, P <.001), and high frequency of worry (OR 1.68, 95% CI 1.14±2.49, P = 0.01). Respondents with low numeracy use were more likely to report lower household income (X2 = 10.4, P = .030), and have lower educational attainment (X2 = 10.2, P = .020).	The results underscore the relationships between race, education, income, and perceived numeracy. Although many Americans (30%) score below the lowest numeracy proficiency level 1, numeracy among racial and ethnic minority and low-income populations show an even greater disparity. Also, the discomfort with numeracy is aligned with increased fatalism, overload and worry. To fully understand the essence of attitudinal factors, one must view them within the broadest historical and sociocultural context to accurately measure impact.
(Salloum et al., 2018) HINTS 4, cycles 1-4 (2011-2014)	To examine the overall awareness of genetic testing services by rural residents of the US compared with urban residents, and stratified across racial and ethnic groups, using multiple cycles of HINTS data.	Predicted awareness marginals of direct to consumer (DTC) genetic testing services was 34.4% among rural vs. 45.4% among urban non-Hispanic whites; 26.7% among rural vs. 36.7% among urban Hispanics, 28.3% among rural vs. 36.7% among urban non-Hispanic African Americans; and 27.2% among rural vs. 37.3% among urban non-Hispanics of other races. After controlling for demographic characteristics and confounders, awareness of direct-to-consumer (DTC) genetic testing was lower among rural residents and racial/ethnic minorities compared with urban residents and non-Hispanic whites, respectively. Furthermore, the prevalence of awareness of genetic testing services among rural non-Hispanic whites was comparable to awareness among urban minorities.	Although rural Americans have substantial mortality disadvantages, African American rural residents are at an even greater disadvantage and have worse overall health than rural white populations. Disparities may be better described when researchers recognize individuals may represent intersecting disparity populations.

First Author, Study Year, HINTS Dataset	Objective	Key Findings	CRT Considerations
(Taber et al., 2015) HINTS 4, cycle 3 (2013)	To examine how individuals share genetic test results, benefit from state-of-the-art counseling and behavioral recommendations, and with whom do they share genetic testing results (family members or physicians) that often accompany receipt of test results.	Out of 77 respondents who reported having had genetic testing for BRCA 1, BRCA 2, or Lynch syndrome, 15 identified as African American. Among these Black respondents who had genetic testing 10 shared results with a health professional and 11 shared the results with a family. No sociodemographic or medical factors were significantly associated with sharing results with health professionals. Several psychological factors were significantly associated with greater likelihood of sharing results with health professionals: being higher in optimism, reporting greater self-efficacy for health management, and reporting greater trust in health information from doctors.	Because the number of Black respondents was low, the researchers calculated the statistical difference as non-Hispanic white versus all other racial or ethnic categories. The researchers note in the discussion that the analyses should be considered exploratory and it would be premature to conclude that disparities in awareness will not be present in uptake.

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