

Beliefs about Genetically Targeted Care in African Americans

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Abstract: We examined beliefs about genetically targeted care (GTC) among African American men and women in a hospital-based sample and identified sociodemographic, cultural, and clinical factors having significant independent associations with these beliefs. Specifically, beliefs about GTC were evaluated after respondents were randomly primed with a racial or non-racial cue about race and genetics. Despite priming with a racial or non-racial cue, many respondents had positive beliefs about GTC. But, 49% believed that GTC would limit access to medical treatment, 46% believed that people will not trust GTC, and 20% believed that people like them would not benefit from GTC. Racial and non-racial priming did not have significant associations with negative beliefs about GTC. However, cultural beliefs related to temporal orientation were associated significantly with believing that genetically targeted care will limit access to medical treatment. Greater levels of future temporal orientation were associated with a reduced likelihood of endorsing this belief (OR = 0.70, 95% CI = 0.49, 1.01, $p = 0.05$). Respondents who had a chronic medical condition had an almost three-fold greater likelihood of believing that they would not benefit from GTC (OR = 2.90, 95% CI = 1.00, 8.37, $p = 0.05$). Greater exposure to information about genetic testing for chronic conditions was also associated with a reduced likelihood of believing that they would not benefit from GTC (OR = 0.40, 95% CI = 0.64, 0.91, $p = 0.02$). African Americans have diverse beliefs about GTC that should be considered as genetic and genomic services are offered.

Keywords: African American ■ Beliefs ■ Genetically targeted ■ Medical care

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INTRODUCTION

Since the completion of the Human Genome Project, efforts have been directed towards developing strategies to translate and integrate genomic information into clinical practice and population health.¹ One of the best examples of this is genetic counseling and testing for BRCA1 and BRCA2 (BRCA1/2) mutations, which are associated with breast cancer. It is now possible

for women to learn if they have a deleterious BRCA1/2 mutation and to use this information to make informed decisions about risk reduction and management strategies.^{2–7} To date, many women have had genetic counseling and testing for BRCA1/2 mutations and these services are now the standard of care for women who have a personal or family history of breast cancer that is suggestive of hereditary disease. However, many unanswered questions remain about genetic factors involving other chronic diseases and research is being conducted to understand the contribution of these factors to conditions such as cardiovascular disease, diabetes, and obesity.^{8–10}

It is anticipated that these discoveries will be translated into clinical practices and be used to develop personalized approaches for treatment and management of disease.¹¹ Reducing racial and ethnic disparities in morbidity and mortality from chronic diseases is an expected outcome of personalized approaches for disease treatment and management. However, racial and ethnic minorities may have concerns about personalized approaches; less than one-third of African American women at increased risk for hereditary breast cancer received BRCA1/2 test results.³

Attempts to develop a better understanding of barriers and facilitators to utilization of personalized approaches to medical care and disease prevention among African Americans have explored beliefs and attitudes about race-based medicine. For instance, African Americans were concerned that use of genetic technologies in medical care would result in racial discrimination and a permanent genetic underclass that would further exacerbate unequal access to medical care.¹² In another study, Bevan and colleagues found that African Americans were significantly more concerned about race-based prescription drugs in comparison to whites, and African Americans also expressed concerns that race-based medicine is akin to racial profiling, which may increase medical distrust.¹³ But, beliefs and attitudes about genetically targeted care may differ from those about race-based medicine. Studies have shown that African Americans have favorable attitudes about genetic testing for inherited breast cancer risk^{14,15} and qualitative research has shown that some African Americans believe that individualized genetic testing will result in the best quality of care.¹³ However, quantitative data are not available on how these beliefs

might differ among African Americans and whether or not beliefs vary as a function of an individual's cultural values, health care experiences, and socioeconomic background. Attitudes about race-based medicine, and potential predictors of these beliefs, have been explored primarily in qualitative studies that were interested in racial differences between African Americans and whites.^{12,13}

To extend these studies, we completed a hospital-based survey with adult African American men and women to evaluate their beliefs about genetically targeted medical care. In this report, we describe the extent to which African Americans believed that genetically targeted care would result in positive (e.g., improved medical care) and negative (e.g., distrust, limited access) outcomes. Since prior reports have shown that African Americans and whites differ in their belief about race-based medicine,^{12,13} we sought to determine if beliefs about genetically targeted care differed based on whether respondents were primed with a racial or non-racial cue about race and genetics and examined the relationship between these beliefs and cultural values, clinical factors, and sociodemographic characteristics to identify factors that have a significant independent association with beliefs about genetically targeted care. Since qualitative studies have shown that individuals use religious frameworks to understand disease and these frameworks are important to beliefs about the roles that genetics play in health outcomes,^{16,17} we were particularly interested in the relationship between religious and spiritual values and beliefs about genetically targeted care. We predicted that individuals with greater religious values would be most likely to expect negative outcomes of genetically targeted medical care. We also evaluated the relationship between future temporal orientation and beliefs about genetically targeted care. Temporal orientation, or preferences to focus on past, present, and future implications and consequences, is one of the primary contexts through which individuals understand and give meaning to their experiences. Previous research has shown that future temporal orientation is positively associated with acceptance of genetic counseling for inherited cancer risk¹⁸; we hypothesized that future temporal orientation would be associated significantly with positive expectations about genetically targeted care.

MATERIALS AND METHODS

Sample characteristics

The study was approved by the Institutional Review Boards at the University of Pennsylvania and the Medical University of South Carolina. Respondents were African American men and women who had seen a primary care provider at the University of Pennsylvania. We identified a

random sample of 2062 patients from a billing database managed by the Office of Research and of these, 298 were screened for eligibility. Of the 298 who were screened, 206 (69%) were eligible and completed the survey. To be included in the study, individuals had to be at least age 18 years and be able to speak English. We excluded individuals who were currently participating in a research study. Respondents who were missing data on beliefs about genetically targeted care were also excluded from the analysis; thus the final sample included 152 respondents.

Procedures

Patients were invited to participate in the study using a mailed invitation that described the purpose of the study and the procedures involved in participation. A self-addressed reply card was included in the invitation letter for individuals to return if they did not want to be contacted. Individuals who did not opt out at this point were contacted to complete a 40-min structured telephone survey. Following provision of verbal consent, a screening interview was completed and those who were eligible completed the telephone survey to obtain sociodemographic information and clinical experiences and to evaluate exposure to information about genetics, cultural factors, and beliefs about genetically targeted care. Patients who completed the survey were mailed a \$20 gift certificate.

MEASURES

Sociodemographic factors

We obtained race, gender, marital status, education level, employment status, and income level by self-report during the interview. Respondents were also asked to indicate their usual source of health care (e.g., doctor's office or some other type of place).

Clinical factors

We obtained personal history of cancer and family history of disease using items from our previous research.¹⁹ Specifically, respondents were asked if they had ever been diagnosed with cancer (yes or no). We used a similar item to determine if respondents had a first-degree relative who had been diagnosed with cancer. Lastly, respondents were asked if they had ever been diagnosed with diabetes, hypertension, heart problems, or arthritis. Those who reported yes to any of these conditions were categorized as having a chronic condition and those who reported no for all of these conditions were categorized as not having a chronic condition.

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