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Views of Black Nurses Toward Genetic Research and Testing

Yolanda M. Powell-Young, PhD, PCNS-BC[1] and **Ida J. Spruill, PhD, LISW, FAAN**[2]

[1]*Gamma*, Visiting Professor, The University of Iowa, Iowa City, IA and Associate Professor, Dillard University, New Orleans, LA, USA

[2]*Gamma Omicron*, Assistant Professor, Medical University South Carolina, College of Nursing, Charleston, SC, USA

Abstract

Purpose—To describe views and beliefs that Black nurses hold regarding several conceptual areas of genetic research and testing.

Design—Data were generated using a descriptive, cross-sectional design. The sample consisted of 384 Black nurses attending the 2009 annual conference of the National Black Nurses Association in Las Vegas, Nevada.

Methods—The chi-squared test was used to evaluate group differences by education level, functional area, age, and gender.

Findings—One half of the Black nurses surveyed believed the potential for the discriminative misuse of genetic information against minority populations exists. However, 84% of these nurses believed the possibility of information misuse should not be used as a barrier to participation in genetic research and testing by the Black populace.

Conclusions—Black nurses expressed concerns about the potential for discriminatory use of genetic information gleaned from research and testing. Yet, Black nurses recognize the importance of racial-ethnic minority participation in genetic research and testing.

Clinical Relevance—Participation in genetic research and testing by diverse populations will provide opportunities to improve the healthcare delivery system and aid the eradication of health disparities. More research is needed to clarify factors that contribute to the bifurcation of importance for participation, reluctance to participate, and what interventions might reduce reluctance.

Keywords

Genetic research; Blacks; nurses

In April 2003, researchers announced the completion of the Human Genome Project (HGP). Directed by the National Institutes of Health and the U.S. Department of Energy, the HGP was the first publicly funded international research collaborative credited with the successful sequencing of the entire human genome. Even in its infancy, the implications of the HGP for forwarding biomedical science and improving the population's health were well publicized. Improved diagnosis of disease; early detection of genetic predisposition to disease; and customized drug therapies to meet the health needs of diverse ancestral groups throughout

Correspondence: Dr. Yolanda M. Powell-Young, Dillard University, 2601 Gentilly Blvd., Stern 100-B, New Orleans, LA 70122. ypyoung@dillard.edu.

the world were a few of the espoused benefits of successfully decoding and uncovering the human genome sequence.

Most scholars agree that the field of medical genetics has almost unlimited potential to revolutionize medicine. Examples of current applications include the use of a family health history to facilitate the identification of disease susceptibility to common health conditions such as diabetes, cancer, and heart disease so that a management plan can be developed to reduce modifiable risk. Reproductive genetic testing is being used to inform potential parents about the possible outcomes of current and future pregnancies. Knowing this information can help prospective parents with decision making regarding family planning and reproductive health matters. Newborn screenings enable the early diagnosis of gene-based disorders such as phenylketonuria that could have long-term health implications. Pharmacogenomics explores genetic variations related to drug response with implications for individualized pharmaceutical treatment options.

Genetic research and testing will continue to play a major role in risk assessment, disease detection, and treatment in the future. To fully understand the biological meaning of the information gleaned from genetic research and testing at the population level, it must follow that the effects of genetic diversity must be critically considered. This is of particular significance among high-risk populations such as Blacks living in the United States, as well as around the world, who continue to be disparately impacted by myriad chronic diseases to an extent that is unobserved in other ancestral subgroups (Hall et al., 2011; Liao et al., 2011; Ogden, 2009).

The term Black is a broad descriptive, often used interchangeably with African American, indicating African descent groups (Agyemang, Bhopal, & Bruijnzeels, 2005). In practice, this term generally suggests African ancestry and may also connote other non-White minority groups. The phrase Black American expands and clarifies this definition by signifying residence within the Americas and its territories. For the purpose of this article, we are using the terms Black and Black Americans and the phrase Blacks in America to denote those of African ancestral origin who reside in the Americas or its territories.

It is well documented that among Black Americans the perception of exploitation by and subsequent mistrust of the research establishment appears to negatively influence willingness to participate in genetic research and testing. Findings from several studies show that mistrust of the medical community acts as a primary barrier to Black American participation in all domains of biomedical research (Byrd et al., 2011; Griffith, Passmore, Smith, & Wenzel, 2012; Suther & Kiros, 2009). Other researchers such as Halverson and Ross (2012) also found that participation among Black Americans in biomedical research advanced by means of genetic research databases such as biobanks was also influenced by their degree of trust versus mistrust toward the research community.

Based on perceptions of discrimination and mistrust, other ethnic-ancestral minority groups in the United States, such as Latinas, Hispanics, Native Americans, and Asians, have also indicated less willingness to participate in genetic research and testing (Nwulia et al., 2011; Sung, 1999; Thompson, Valdimarsdottir, Jandorf, & Redd, 2003). Global trends appear to be similar to U.S. trends. Indigenous peoples of Mexico, Australia, Canada, the United Kingdom, and elsewhere have also shown a higher propensity to decline DNA sampling for research studies (Hussain-Gambles et al., 2004; Jacobs et al., 2010; Meisel, Shankar, Kivimaki, & Wardle, 2012).

In addition to the historical issues of trust associated with medical research, there are biological-specific challenges to investigator trust that may influence participation in genetic research and testing. One such issue among members of the Black population is the

perceived misuse of generated information for discriminative practices (Armstrong et al., 2012). In a 2003 genetics ethics report, the World Health Organization concluded that:

> All adults have a right, if they so choose, to know their genetic makeup and implications for the health of their potential offspring, to be educated about their own genetics, and to have the services available to act upon their knowledge. (p. 6)

However, documented instances of discrimination on the basis of genetic information can be found in the extant literature. Among these works is a discrimination paper published by the Council for Responsible Genetics (2001). This document highlights several researcher-supported genetic-based discrimination cases. For example, some genetic traits such as sickle cell anemia are found more often in the most vulnerable ancestral subgroups such as Black Americans (Nussbaum, McInnes, & Willard, 2007). For this reason, many believe that the misuse of genetic information from research and testing could disproportionately impact these populations.

Community-based approaches to communicating the value of genetic research and testing have been identified as strategies to successfully overcome culturally and socially influenced challenges among vulnerable populations (Johnson, Powell-Young, Torres, & Spruill, 2011; Johnson et al., 2009). One strategy that has received noteworthy attention in the literature for recruitment and education purposes is the use of researchers and providers who are ancestrally similar to the prospective genetic research and testing participants. Systematic analysis of the relevant genetics literature revealed that research participation rates among Black Americans increased by as much as 75% when the prospective participants and research team were of like ancestry.

Diaz, Mainous, McCall, and Geesey (2008) found that Black Americans were more likely to provide DNA for genetic testing if the investigator was a Black American. The probability of participation in a genetics-related project was also found to increase if the investigator's supporting institution had a legacy of engagement in and fair treatment toward the Black community. Based on these data, ethnic and minority nurse associations that advocate for the health improvement of underrepresented groups are in a prime position to facilitate recruitment efforts and to disseminate knowledge about the importance of participation in genetics-based protocols and testing in the communities they serve.

One such organization, the National Black Nurses Association (NBNA) is a professional association with chapters in all 50 states, the District of Columbia, and many U.S. territories. The NBNA membership represents approximately 150,000 active and retired registered nurses and licensed vocational-practical nurses of African heritage. A primary goal of the NBNA is to facilitate collective actions that address the healthcare needs of Black Americans within their communities.

In recent years the NBNA has been proactively engaged in promoting genetic awareness among its membership. This has occurred by broadly publicizing genetic information from both general and legislative perspectives. However, to meaningfully advance an understanding of the value of the genetic enterprise throughout the Black community, it is critical to recognize and appreciate the views held by Black nurse stakeholders with respect to participation in genetic research and genetic testing.

Researchers suggest that in many instances Black healthcare professionals share the same opinions of ancestrally driven healthcare and research inequalities as the general Black populace (Johansson, Jones, Watkins, Haisfield-Wolfe, & Gaston-Johansson, 2011). These positions could be additionally problematic when striving to meaningfully integrate the concept and value of genetic research and testing at the community level. Currently,

however, there is a lack of information about the views that Black nurses hold toward their own and other Black Americans' participation in genetic research and testing.

The primary aim of this study was to determine the views that Black nurses have about their current genetic knowledge: their beliefs regarding genetics as explanatory models for disease prevalence, the potential for health information discrimination, population- versus self-participation in research and testing, and support for an awareness platform. A secondary aim was to determine if these viewpoints diverged as an effect of the nurses' education level, functional area, age, and gender.

Methods

Sample and Setting

Data were collected from a convenience sample of 384 Black nurses attending the 2009 annual conference of the NBNA in Las Vegas, Nevada. Based on the total conference attendance of 916, the sample response rate was 41.9%. Given an α of 0.05 and an effect size of 0.30, power for the analyses conducted in this study with the current sample size was > 0.80.

The study volunteers ranged in age from 21 through 80 years (mean age = 56 ± 10 years). Females accounted for 96% of the study participants. Nurses prepared at the baccalaureate (31%) and master's (35%) levels comprised the largest proportion of attendees. Clinicians comprised 38% of the study participants. Researchers accounted for the smallest proportion (3%) of study volunteers. Residence of the sample respondents by NBNA region were Southeast (34%), Northeast (28%), Southwest (20%), and Midwest (19%). Approximately 60% of respondents denied ever having taken any kind of formal course in genetics. Table 1 provides an overview of the sample demographics.

Human Subjects Protections

Prior to the implementation of recruitment procedures, written approvals to conduct the study were obtained from Cedars-Sinai Medical Center Institutional Review Board and the NBNA Executive Board. Willingness to complete the survey was the sole criterion for inclusion. Written consent was waived. Completing and returning the study questionnaire implied consent to participate.

Data Source

A study-specific self-administered questionnaire was developed to capture data on the knowledge and beliefs of nurses of African ancestry regarding genetic research and genetic testing. The first component of the questionnaire gathered information on the demographic characteristics of the study volunteers (e.g., age, gender, education level). The second component included the use of five single-item questions that independently evaluated the nurses' (a) perceptions of their current genetic knowledge; (b) belief that genetic research and testing can be used to explain variation in disease prevalence among ancestrally diverse groups; (c) belief that genetic information can be used to discriminate against minorities; (d) belief that Black Americans should participate in genetic research and testing; (e) likelihood of self-participation in genetic research and testing; and (f) support for an NBNA-guided genetics awareness initiative.

Item generation—The questionnaire items were developed based on a comprehensive review of the existing findings on nurses' attitudes, perceptions, and knowledge about genetic testing. The psychological and behavioral literature on genetic testing was also utilized. Items were generated and categorized into the content areas of knowledge, beliefs,

interests, and practice. Face and content validity were addressed using graduate student nurses and experts in instrument development. Further verification of the instrument's potential viability was established with pilot data collected at the 2006 NBNA annual conference ($N = 77$; Spruill, Coleman, & Collins-McNeil, 2009). Common factor analysis estimated single-item reliability with the current sample (Ginns & Barrie, 2004). According to Harmon, as reported by Wanous and Hudy 2001, "the reliable variance for an item is the sum of its communality and its specificity" (p. 363). Thus, communality can be considered a conservative estimate of single-item reliability. Reliability indices (r) with the current sample ranged from 0.82 to 0.87. Table 2 provides the questionnaire items and reliability scores.

Response options—Categorical response options varied according to the research question. For current genetics knowledge, the options were *poor, fair, good*, and *excellent*. For questions related to nurses' beliefs, the options were *strongly disagree, disagree, undecided, agree*, and *strongly agree*. The response options for self-participation and initiative volunteerism attributes were *yes, undecided*, and *no*.

Procedures

During the opening conference plenary, the principal investigator presented a standardized introduction to the study. In addition, a written communication, as a part of each survey, provided information about the goal and aims of the study, the researchers' contact information, and affirmation that participation was strictly voluntary. As part of the conference registration process and packet, all conference attendees were provided both the study questionnaire and written introduction to the study. Because we did not request any identifying information, data generated from the surveys could not be linked to an individual. There were random and deliberate recruitment reminders delivered throughout the 5-day conference. Completed questionnaires were collected from drop boxes, located in designated areas throughout the conference area, by the study investigators or designees several times throughout each day.

Data Analysis

All data were entered into a computerized database. Coded data were analyzed using the Statistical Package for the Social Sciences (SPSS Inc., Chicago, IL, USA). Prior to analyses, all variables were edited separately for accuracy, completion, credible values, and violation of statistical assumptions. Item nonresponse was < 5% for each of the given measures; therefore, all questionnaires were used as part of the final analyses. Sample-wide medians were substituted for the missing values.

We summarized demographic characteristics and sample responses using counts (percentages) and central tendency measurement. The chi-squared (χ^2) test was used to test group differences by education level. Fisher's exact test was used when expected frequencies were < 1 in any cell or < 5 in more than 20% of the cells. Statistical significance was analyzed using the post hoc Sidak-Bonferroni method to correct for multiple comparisons.

For the purposes of the analyses presented here, the five-option categories regarding nurses' beliefs were collapsed into three categories: disagree (*strongly disagree* + *disagree*), undecided, and agree (*strongly agree* + *agree*). Several considerations guided the category adjustments. These included the study's primary aims, the preservation of the substantive meaning implied by the consolidated response categories, and the reflection of self-report differences while maintaining interpretation integrity. Education levels were defined as vocational, technical (associate and diploma), professional (baccalaureate), and graduate

(master's, doctorate). These options would allow for the capture and differentiation of data along the training continuum.

Results

General Perceptions and Beliefs

Current genetic knowledge—Approximately 4% of respondents considered themselves as having an excellent knowledge of genetics. Most (78%) believed they had a fair to good understanding of genetics. Eighteen percent of the participants indicated a poor knowledge of genetics. Study variables are characterized in Table 2.

Explaining genetic variation—The largest proportion of nurse respondents (80%) agreed that genetics could be used to explain the prevalence variation in common diseases such as diabetes and hypertension among ancestrally diverse subgroups. The percentage of nurses who disagreed or who were undecided was comparable at 9% and 10%, respectively.

Genetic discrimination—Approximately 51% of the sample believed that information from genetic research and testing could be misused for discriminatory purposes. Of the remaining respondents, 36% remained undecided about the potential for discrimination based on genetic information. A relatively small percentage (13%) of nurses sampled felt that genetic information could not be used to discriminate against individuals from minority subgroups.

Participation in genetic research and testing—Black nurses overwhelming agreed (84%) that Black Americans should participate in genetic research. Only 6% of the sample remained undecided regarding participation in genetic research and testing by the Black American populace. A small proportion of NBNA nurses (< 10%) did not believe Black Americans should participate in genetic research and testing.

Sixty-six percent (66%) of the Black nurses in this study would themselves participate in a genetic study. Approximately one fourth (25%) of the sample remained undecided about self-participation. Nine percent (9%) of these nurses would decline to participate in genetic research and testing for themselves.

Support of genetic awareness—Eighty-three percent of the nurse respondents would actively promote an NBNA genetics awareness initiative within their community; of the remaining 17% of nurses, 14% were undecided and 3% would not support an awareness platform.

Differences by Education, Functional Area, Age, and Gender

Our study found that education level and nurses' beliefs regarding the use of information from genetic research and testing for discriminative practices were found to be significantly related (χ^2 [6, N = 384] = 14.78, p = .02). Pairwise comparisons found significant differences between nurses educated at the vocational level and those educated at the professional (p = .02) and graduate levels (p = .005). Nurses prepared at the professional and graduate levels were, respectively, 2.3 and 4.7 times more likely than vocationally prepared nurses to accept that genetic information could be used for purposes of discrimination. There were no statistically significant differences in Black nurses' views regarding genetic research and testing according to functional area, age, or gender (see Table 2).

Discussion

Black American participation in genetic research and testing is critical to seeing the enormous potential of the genetics revolution. Nursing organizations that represent diverse populations are in a position to launch and influence platforms in their communities that raise the importance of participation in genetic research and testing to the health and well-being of the nation. Little is known about the perceptions that Black nurses hold regarding participation of Black Americans in genetic research and testing. To our knowledge, this study is one of the first to examine the perceptions and beliefs of Black nurses regarding perceived knowledge, participation, discriminative, and awareness dimensions of genetic research and testing.

When compared with the few studies that have evaluated clinician perceptions between participation in genetic research and genetic discrimination, findings from our study reveal both similarities and differences. A recent systematic review conducted by Godino and Skirton (2012) indicated that nurses residing in various parts of the world generally report that their knowledge of genetics is poor. Yet, our data differ from previously published findings.

One explanation for the greater perception of knowledge among Black nurses in our study may be related to the genetic-based education offerings available to the NBNA membership during the annual conferences for the past 7 years. Institutes have included presentations on the societal implications of genomics, the biomedical significance of genetic variation in African Americans, increasing minority participation in human genetic research, and the integration of genetic concepts into clinical practice. Topic experts included Dr. Georgia Dunston, Founding Director of the Howard University National Human Genome Center; Dr. Jean F. Jenkins, Senior Clinical Advisor to the Director of the National Human Genome Research Institute (NHGRI); and Mr. Vence L. Bonham, Jr., Senior Advisor to the NHGRI Director.

In addition, interactive workshops on the use of family health histories in understanding genetics-genomics have been directed by representatives from the Centers for Disease Control and Prevention's Office of Public Health Genomics. The National Coalition of Ethnic Minority Nurses Association, of which the NBNA is a part, has also been actively involved in identifying factors that impact genetics and genomics in nursing practice. As a result, exposure to genetics-genomics education via this alliance may also provide some rationale for the greater perceptions of knowledge found within this sample.

The federal Genetic Information Nondiscrimination Act (GINA) was enacted to provide protection against the use of one's genetic information in employment or health coverage determinations. GINA is intended to safeguard information whether obtained through research or genetic testing that could be beneficial to one's health. Yet, we found that by and large Black nurses believe that genetic information gleaned from research and testing can be used to effect unfair treatment among minority groups.

Our findings are similar to those reported by several studies. One such study conducted by Lowstuter and colleagues (2008) indicated that 96% of 1,181 multi-ethnic nurses and physicians viewed genetic testing as beneficial. However, findings from this and other perception studies also indicated concerns among healthcare professionals about genetic testing relative to employment and insurance discrimination (Freedman et al., 2003; Laskey et al., 2003; Nedelcu et al., 2004).

Regardless of the perceived potential for genetic discrimination, more than three fourths of the Black nurses in our study supported participation in genetic research and genetic testing

among members of the Black population. In a somewhat similar study, Burnett et al. (2001) surveyed a diverse group of nurses employed at a National Cancer Institute–designated comprehensive cancer center. Ninety-six percent of those surveyed, of which 8% self-identified as African American, agreed that participation in clinical cancer research was essential. Comparable with our findings, a proportion of these nurses (> 50%) would themselves decline to participate in a clinical trial.

Level of education appeared to negatively influence Black nurses' perceptions of discrimination risk potential using genetic information. Higher education levels resulted in greater perceptions of information misuse potential. The paucity of literature on this topic in the general healthcare literature restrains our ability to contrast results within or across groups. These differences may be the result of nursing's growing interest in the genetic influences on health (Spruill et al., 2009). This includes the incorporation of genetics education into professional nursing curricula.

Strengths and Limitations

A few limitations should be discussed regarding these study findings. The nonprobability recruitment and convenience sampling make it difficult to generalize the results beyond this sample. We acknowledge that the NBNA annual conference attendees are more likely to be educated at or above the baccalaureate level. Sample representativeness may not be ideally characteristic of Black American nurses in the United States. However, the extent of possible bias is unknown. Data from this study are cross-sectional in nature, which precludes causal inference. Furthermore, individuals who participated in this research project were self-selected. Future studies would likely benefit from a larger, more representative sample of Black nurses.

These limitations notwithstanding, results from this study contribute to advancing the body of genetic research participation among vulnerable populations. At present, knowledge about Black nurses' attitudes regarding participation in genetic research and testing, particularly by Black Americans, is sparse. Although more research is needed, these findings provide much-needed insight into individual and group dynamics that could potentially affect how nurses support recruitment.

Suggestions for Future Research

Further inquiry into factors that impact nurses' views of research discrimination with respect to genetics and the use of genetic information is needed. Further inquiry into facilitators toward feelings of research discrimination with respect to genetics and the use of genetic information is needed. For example, in-depth interviews with Black nurses to learn more about why they hold these beliefs, what influences these beliefs, and if the work of the NBNA has increased awareness and shifted any of their beliefs should be pursued. Studies are also needed that investigate possible predictor variables of their attitudes to genetic research and testing as well as their involvement in the genetic research and testing enterprise as participants.

Implications for Nursing

The results of this study have broad implications for underserved and underrepresented ethnic minority populations across the globe. Because nurses constitute the single largest group of healthcare providers in the world, opportunities to substantially advance our knowledge and understanding of the social and environmental paradigms that potentially affect the health of diverse people around the world are unlimited. Nurse researchers and clinicians involved in genetic research may find that collaborating with local chapters of minority-oriented nursing organizations could facilitate the recruitment of ethnic minority

groups into studies incorporating genetics. Nurse educators in academic and healthcare settings may find that nurses from diverse backgrounds are a unique, untapped resource to assist in bridging the gap between the nature of genetic research and testing, clinician comprehension, population-based awareness, and optimal health outcomes. The growth of biorepositories at academic institutions in the United States and abroad is extensive. Clinicians employed at these institutions may be called upon to explain the benefits of biobank participation to the future of science and health.

Conclusions

Our findings suggest that Black nurses appreciate that the potential for genetic discrimination is a reality for Black Americans. But then again, these nurses also comprehend that participation in genetic research and testing by Black Americans is important to the applicability of findings across populations. Specialty nursing organizations around the globe are in a distinctive position to foster genetics awareness to its constituents and the communities they serve.

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Clinical Resources

- National Coalition of Ethnic Minority Nurses Association Survey of Issues in Genetics and Genomics in Nursing Practice: http://www.nbna.org/index.php?option=com_content&view=article&id=324&Itemid=178
- Genetic Non-Discrimination Legislation: http://www.genome.gov/10002077

Table 1
Characteristics of Study Participants (*N* = 384)

Variable	%	Mean	Standard deviation	Frequency (*n*)
Region of residence				
Southeast	34.1			131
Northeast	27.5			106
Southwest	19.5			74
Midwest	18.9			73
Age (years)		55.7	10.4	
20–29	3.4			13
30–29	4.2			16
40–49	14.6			56
50–59	41.1			158
60+	36.7			141
Gender				
Female	96.4			372
Male	3.1			12
Education level				
Graduate	46.1			177
Doctorate	10.4			
Master's	35.7			
Professional	31.2			120
Technical	18.3			70
Associate	12.8			
Diploma	5.5			
Vocational	4.4			17
Functional area				
Clinical	38.5			148
Administration	23.7			91
Education	18.9			72
Other	16.0			61
Research	3.0			12

Table 2

Survey Items, Reliability Correlation, Descriptive Values, and Chi-Square Test of Association Education Categories and Nurses' Views for Sample Respondents (*N* = 384)

	Percent (%)	Frequency (n)	χ^2	*p*
How would you rate your knowledge of genetics? (*r* = 0.84)				
Poor	18.2	70	6.98	.639
Fair	53.1	204		
Good	24.7	95		
Excellent	3.9	15		
Do you believe that genetic research and testing can be used to explain variation in disease prevalence (e.g., diabetes, hypertension) among racial and ethnic groups? (*r* = 0.82)				
Disagree	9.2	35	5.89	.436
Undecided	10.2	39		
Agree	80.7	310		
Do you believe that information generated from genetic research or testing can be used to discriminate against minorities? (*r* = 0.84)				
Disagree	13.6	52	14.78	.025
Undecided	27.6	106		
Agree	58.8	226		
Do you believe that Black Americans should participate in clinical trials or genetic research? (*r* = 0.87)				
Disagree	9.9	38	7.28	.295
Undecided	6.0	23		
Agree	84.1	323		
Would you participate in a genetic research study for Black women/men? (*r* = 0.80)				
Yes	66.4	255	10.04	.123
No	8.3	32		
Undecided	25.3	97		
Would you support a genetic-genomic awareness initiative sponsored by your local NBNA chapter? (*r* = 0.86)				
Yes	82.8	318	3.28	.350
No	3.1	12		
Undecided	14.1	54		

Note. *r* = reliability estimate; NBNA = National Black Nurses Association.