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Cross-cultural Factors Influencing Perceived Disadvantages of Genetic Testing Among African **Americans and Black African Immigrants**

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Background

- The ability of genetic researchers to assess and advance the growth in genetic science is purported to be hindered by low participation rates of ethnic minority populations in health services research (Bates, Quinn, Killion, et al., 2011; Schmotzer, 2012).
- Empirically-based information on how to successfully recruit from ethnically diverse populations for participation in genetic studies including biobanking is limited (Withall, et al., 2011)
- Major factors reported in the literature on participation of ethnic minorities in genetic studies are: knowledge, attitudes and beliefs about research, community involvement, incentives and cultural adaptations (Yancey, Ortega, & Kumanyika, 2006)

Background: Knowledge Medical Mistrust and Perceived Disadvantages Genetic Testing

- The public's knowledge of perspectives on, and expectations for genetics research are fluid because of rapid scientific discoveries (Henneman, et al., 2004).
- Researchers have indicated that the relationship between knowledge and attitudes may not be clear cut in relation to participating in genetic initiatives (Jallinoja & Aro, 2000; Evans & Durant, 1995).
- Published research assessing genetic knowledge, medical mistrust, and perceived disadvantages of participation in genetic studies among Black African immigrants in comparison to African Americans is sparse.
- Although both groups are "black," research on the personal and group-based factors surrounding Black African immigrants compared to African Americans decision to participate in genetic testing is poorly understood.
- The lack of available studies on the knowledge, attitudes, and expectations of Black African immigrants compared to African American perspectives of genetic studies underscores the importance of exploring and examining these factors in both subpopulation.

Purpose and Aims of the Project

- The purpose of this research was to conduct a cross-sectional comparative investigation describing and examining selected factors of group-based medical mistrust (GBMM) that would potentially influence urban African Americans versus Black African immigrants' knowledge, concerns and perceived disadvantages of availing themselves to genetic testing and/or participating in genetic research.
- Research questions investigated were:
 - What is the level of knowledge of medical genetics among Black African immigrants compared to African Americans?
 - What is the extent of medical mistrust among Black African immigrants versus African Americans?
 - What are the future expectations/anticipated consequences of medical genetics and perceived disadvantages of genetic testing among Black African immigrants versus African Americans?
 - What is the influence of knowledge of medical genetics, future expectations/anticipated consequences, and medical mistrust on perceived disadvantages of genetic testing among Black African immigrants versus African Americans?

Methods and Procedures

Design and Study Sample

- Cross-sectional exploratory design
- Participants recruited through a community-based organization
- Non-probability sample of Blacks (n=420) -African immigrants (n = 211) and African Americans (n = 209) age ≥18 years
- Signed informed consent obtained
- Survey administered by trained field interviewers

Survey Measures

- Socio-demographic characteristics
 - (age, gender, length of time residing in US, education, employment, etc.)
- Independent Variables
 - Knowledge level of medical genetics
 - Group-based medical mistrust scale
 - Future expectations/anticipated consequences
- Dependent Variable
 - Perceived disadvantages of genetic testing

Country of Origin of Participants in Study

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Data Analysis

- Data analyzed using the Statistical Package for the Social Sciences version 24 (IBM SPSS®).
- Descriptive statistics of frequencies, means, standard deviations obtained to describe the sample.
- Pearson product-moment correlations were computed to determine bivariate relationships of variables in the study.
- Multivariate hierarchical linear regression analysis performed identifying the influence of variables on perceived disadvantages of genetic testing.

Graduate School

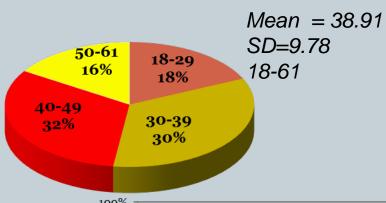
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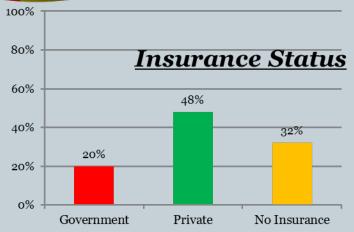
RESULTS/FINDINGS

Description of the sample Age and Insurance Status

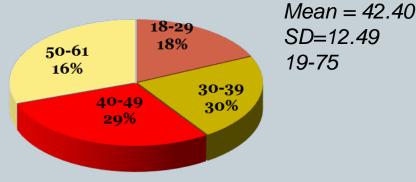
African Immigrants(n=211)

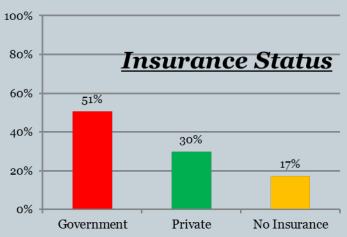
<u>Age</u>





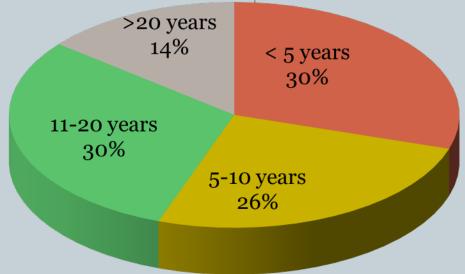
<u>African Americans (n=209)</u> <u>Age</u>





Description of the sample: African Immigrants

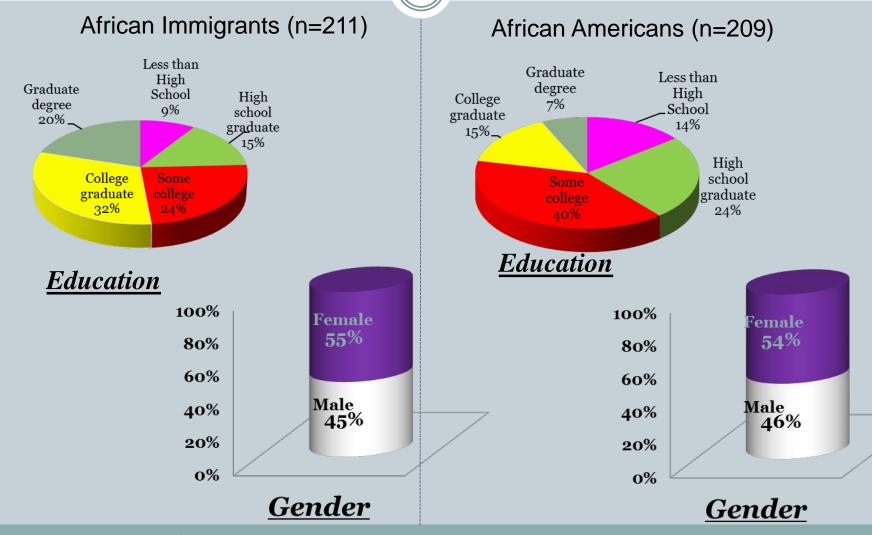
Length of time living in U.S. (N=211)



4 months - 40 years

Mean= 11.43 years Std=9.03

Description of the sample (Education and Gender)



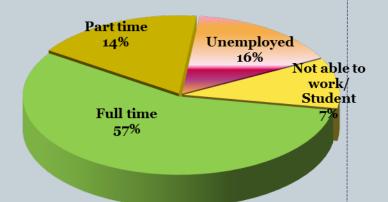
Description of the Sample (Income & Employment)



Median category \$40,000- \$49,999



Employment

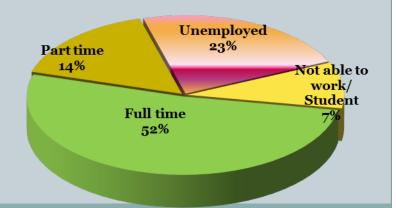


African Americans (n=209)

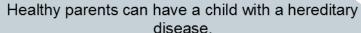
Median category \$20,000- \$29,999



Employment



Knowledge of Medical Genetics: Percent Answering Correctly



High maternal age increases the risk of having a child with Down Syndrome.

Parents that are related have an increased risk of having a child with a genetic disorder.

Some of the heritable disorders express themselves later in adult life .

A disease is only heritable if more than one family member is affected.

If a person has a genetic risk for disease, the person will certainly get the disease.

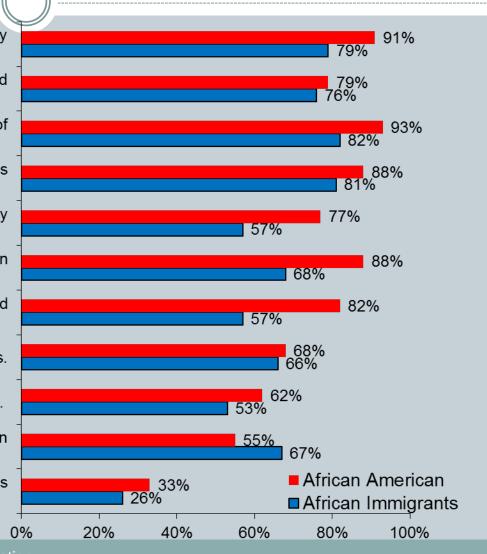
If nothing is found in a test during pregnancy the child will be healthy.

Newborns are tested for genetic diseases.

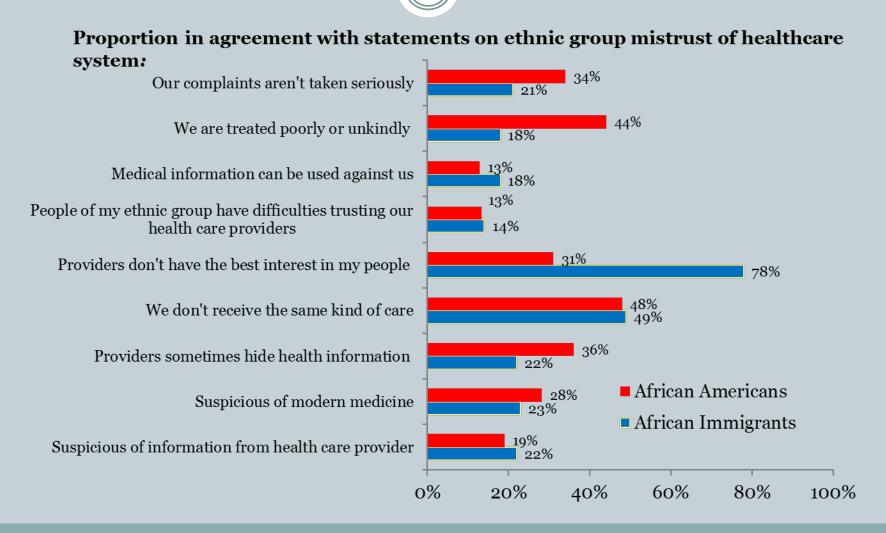
Genetic diseases mostly skip a generation.

The use of Folic acid tablet by pregnant women reduces risk of child with spina bifida

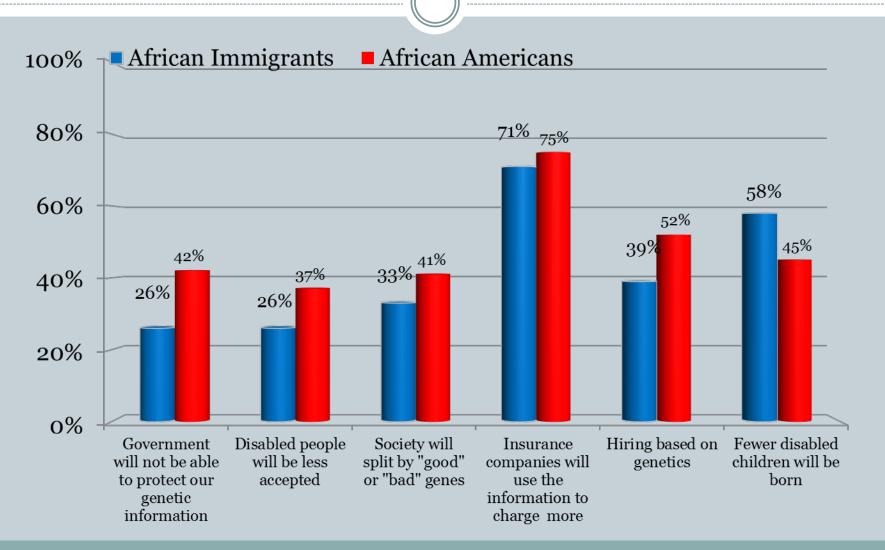
People are genetically more related to their parents than to their brothers and sisters



Group-based Medical Mistrust: Extent to Which Participants Distrust the Health Care System

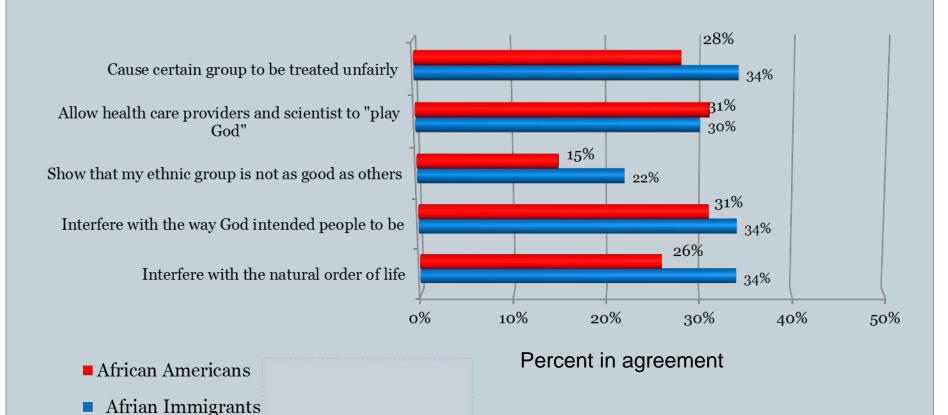


Future Expectations/Anticipated Consequences of Medical Genetics Research

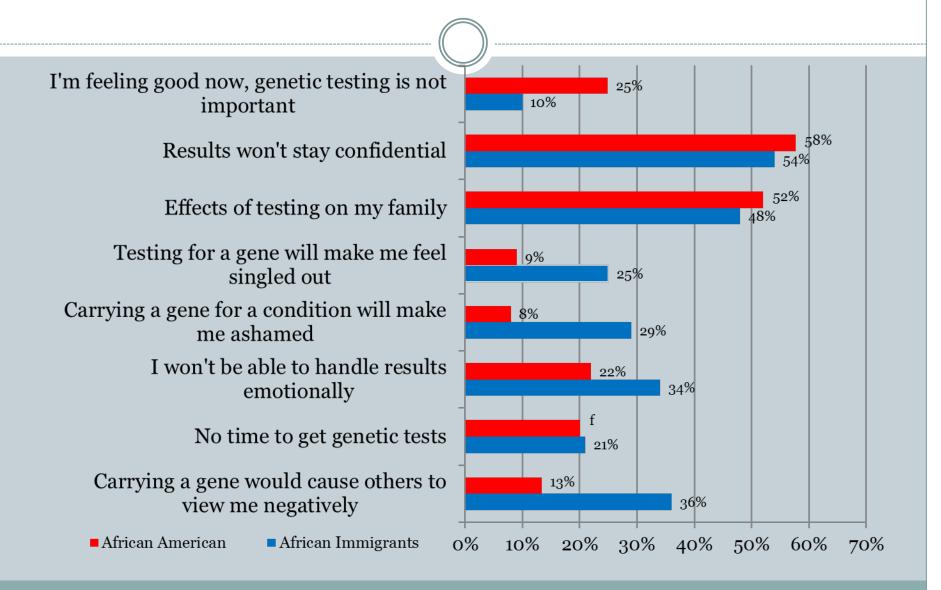


Anticipated Concerns of Medical Genetic Research

I am concerned that genetic testing/research will:



Perceived Disadvantages of Genetic Testing



Correlations of Knowledge, Group-based Medical Mistrust, Future Expectations & Perceived Disadvantages of Medical Genetic Testing with Negatives Attitudes Toward Genetic Testing

	African Immigrants (n=211)	African Americans (n=209)
Age	-0.101	-0.051
Education	-0.130	-0.169*
Marital Status	0.081	0.0147*
Expectations/anticipated consequences		
Importance of genetic information	0.028	-0.072
Use of genetic information	0.131	0.039*
Negative impact of genetics	0.320**	0.045*
Group-Based Medical mistrust (total score)	0.303**	0.260**
Knowledge of genetics	-0.278**	142*

* p<0.05

** p<0.01

Factors Influencing Perceived Disadvantages about Genetic Testing among Black African Immigrants vs African Americans

	African Immigrant (n=211)	African American (n=209)
	β	β
Age	-0.076	-0.098
Education	-0.035	-0.033
Marital Status	0.075	0.186**
Expectations/anticipated consequences		
Importance of genetic information	-0.085*	-0.081*
Use of genetic information	0.099	0.021
Negative impact of genetics	0.232**	0.351**
Group-Based Medical mistrust (Total Score)	0.274**	0.165*
Knowledge of genetics	-0.300**	-0.128*
	F(8,197)=10.17, p<.001 R ² =29%	F(8,196)=8.61, p<.001 R ² = 26%

Study Limitations

- Participants in the study are based on a non-probability sample recruited from a confined Midwest metropolitan setting.
- The current study uses a cross-sectional survey design and is limited to Black African immigrants from sub-Saharan Africa and urban African Americans
- The majority of the African immigrant participants in this study were highly educated.
- In the US, a person's ethnicity may have an effect on his/her perception of health including genetic science.

Implications and Conclusion

- Current understanding of the knowledge, beliefs, and attitudes of Black African immigrants and urban African Americans participating in genetic initiatives is limited.
- Our study provide additional evidence that the group-based medical mistrust found among participants is an important factor to consider when recruiting ethnic minorities to participate in genetics initiatives.
- Future expectations about medical genetics and the use of genetic information are important domains to consider when developing genetics studies with ethnic minority groups.
- It is imperative for healthcare providers and geneticists to become knowledgeable about the perspectives, fears, and concerns of immigrant populations participating in genetic studies in order to work with them to become informed consumers in genetics-based healthcare.
- Addressing these concerns and increasing Black African immigrants' and African Americans' knowledge of genetic sciences are prerequisites to assisting them in making informed decisions on whether to participate in genetic initiatives.

Thank You!!!

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QUESTIONS AND DISCUSSION