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

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Project Approved by: University of Wisconsin-Milwaukee Institutional Review Board No. 11.089
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).
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

Black African Immigrant / Refugees Population-Based Survey: Country of Origin

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.
RESULTS/FINDINGS
Description of the sample
Age and Insurance Status

African Immigrants (n=211)

**Age**
- **Mean** = 38.91
- **SD** = 9.78

**18-61**
- 18-29: 18%
- 30-39: 30%
- 40-49: 32%
- 50-61: 16%

**Insurance Status**
- Government: 20%
- Private: 48%
- No Insurance: 32%

African Americans (n=209)

**Age**
- **Mean** = 42.40
- **SD** = 12.49

**19-75**
- 18-29: 18%
- 30-39: 30%
- 40-49: 29%
- 50-61: 16%

**Insurance Status**
- Government: 51%
- Private: 30%
- No Insurance: 17%
Description of the sample: African Immigrants

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

- <5 years: 30%
- 5-10 years: 26%
- 11-20 years: 30%
- >20 years: 14%

4 months - 40 years
Mean = 11.43 years  Std=9.03
Description of the sample (Education and Gender)

African Immigrants (n=211)

- Graduate degree: 20%
- College graduate: 32%
- Some college: 24%
- High school graduate: 15%
- Less than High School: 9%

Gender:
- Female: 55%
- Male: 45%

African Americans (n=209)

- Graduate degree: 7%
- College graduate: 15%
- High school graduate: 24%
- Less than High School: 14%
- High school: 40%

Gender:
- Female: 54%
- Male: 46%

Description of the Sample
(Income & Employment)

**African Immigrants** (n=211)
Median category $40,000-$49,999

- Missing 31%
- $50,000-$70,000+ 18%
- $30,000-$49,999 16%
- $10,000-$29,999 19%
- < $9,999 16%

**Employment**
- Full time 57%
- Part time 14%
- Unemployed 16%
- Not able to work/Student 7%

**African Americans** (n=209)
Median category $20,000-$29,999

- Missing 11%
- $50,000-$70,000+ 8%
- $30,000-$49,999 17%
- $10,000-$29,999 36%
- < $9,999 28%

**Employment**
- Full time 52%
- Part time 14%
- Unemployed 23%
- Not able to work/Student 7%

Knowledge of Medical Genetics: Percent Answering Correctly

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

**Proportion in agreement with statements on ethnic group mistrust of healthcare system:**

<table>
<thead>
<tr>
<th>Statement</th>
<th>African Americans</th>
<th>African Immigrants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our complaints aren't taken seriously</td>
<td>21%</td>
<td>34%</td>
</tr>
<tr>
<td>We are treated poorly or unkindly</td>
<td>18%</td>
<td>34%</td>
</tr>
<tr>
<td>Medical information can be used against us</td>
<td>13%</td>
<td>18%</td>
</tr>
<tr>
<td>People of my ethnic group have difficulties trusting our health care providers</td>
<td>13%</td>
<td>14%</td>
</tr>
<tr>
<td>Providers don't have the best interest in my people</td>
<td>31%</td>
<td>78%</td>
</tr>
<tr>
<td>We don't receive the same kind of care</td>
<td>48%</td>
<td>49%</td>
</tr>
<tr>
<td>Providers sometimes hide health information</td>
<td>22%</td>
<td>36%</td>
</tr>
<tr>
<td>Suspicious of modern medicine</td>
<td>28%</td>
<td>23%</td>
</tr>
<tr>
<td>Suspicious of information from health care provider</td>
<td>19%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Future Expectations/Anticipated Consequences of Medical Genetics Research

- Government will not be able to protect our genetic information: 26% (Immigrants), 42% (Americans)
- Disabled people will be less accepted: 26% (Immigrants), 37% (Americans)
- Society will split by "good" or "bad" genes: 33% (Immigrants), 41% (Americans)
- Insurance companies will use the information to charge more: 71% (Immigrants), 75% (Americans)
- Hiring based on genetics: 39% (Immigrants), 52% (Americans)
- Fewer disabled children will be born: 58% (Immigrants), 45% (Americans)

Anticipated Concerns of Medical Genetic Research

I am concerned that genetic testing/research will:

- Cause certain group to be treated unfairly: 28% African Americans, 34% Afrian Immigrants
- Allow health care providers and scientist to "play God": 15% African Americans, 30% Afrian Immigrants
- Show that my ethnic group is not as good as others: 22% African Americans, 31% Afrian Immigrants
- Interfere with the way God intended people to be: 26% African Americans, 34% Afrian Immigrants
- Interfere with the natural order of life: 28% African Americans, 34% Afrian Immigrants

Perceived Disadvantages of Genetic Testing

- I'm feeling good now, genetic testing is not important
  - African American: 10%
  - African Immigrants: 25%

- Results won't stay confidential
  - African American: 58%
  - African Immigrants: 54%

- Effects of testing on my family
  - African American: 48%
  - African Immigrants: 52%

- Testing for a gene will make me feel singled out
  - African American: 9%
  - African Immigrants: 25%

- Carrying a gene for a condition will make me ashamed
  - African American: 8%
  - African Immigrants: 29%

- I won't be able to handle results emotionally
  - African American: 22%
  - African Immigrants: 34%

- No time to get genetic tests
  - African American: f
  - African Immigrants: 21%

- Carrying a gene would cause others to view me negatively
  - African American: 13%
  - African Immigrants: 36%

<table>
<thead>
<tr>
<th></th>
<th>African Immigrants (n=211)</th>
<th>African Americans (n=209)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.101</td>
<td>-0.051</td>
</tr>
<tr>
<td>Education</td>
<td>-0.130</td>
<td>-0.169*</td>
</tr>
<tr>
<td>Marital Status</td>
<td>0.081</td>
<td>0.0147*</td>
</tr>
<tr>
<td>Expectations/anticipated consequences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance of genetic information</td>
<td>0.028</td>
<td>-0.072</td>
</tr>
<tr>
<td>Use of genetic information</td>
<td>0.131</td>
<td>0.039*</td>
</tr>
<tr>
<td>Negative impact of genetics</td>
<td>0.320**</td>
<td>0.045*</td>
</tr>
<tr>
<td>Group-Based Medical mistrust (total score)</td>
<td>0.303**</td>
<td>0.260**</td>
</tr>
<tr>
<td>Knowledge of genetics</td>
<td>-0.278**</td>
<td>-0.142*</td>
</tr>
</tbody>
</table>

* p<0.05  ** p<0.01
# Factors Influencing Perceived Disadvantages about Genetic Testing among Black African Immigrants vs African Americans

<table>
<thead>
<tr>
<th></th>
<th>African Immigrant (n=211)</th>
<th>African American (n=209)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β</td>
<td>β</td>
</tr>
<tr>
<td>Age</td>
<td>-0.076</td>
<td>-0.098</td>
</tr>
<tr>
<td>Education</td>
<td>-0.035</td>
<td>-0.033</td>
</tr>
<tr>
<td>Marital Status</td>
<td>0.075</td>
<td>0.186**</td>
</tr>
<tr>
<td>Expectations/anticipated consequences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance of genetic information</td>
<td>-0.085*</td>
<td>-0.081*</td>
</tr>
<tr>
<td>Use of genetic information</td>
<td>0.099</td>
<td>0.021</td>
</tr>
<tr>
<td>Negative impact of genetics</td>
<td>0.232**</td>
<td>0.351**</td>
</tr>
<tr>
<td>Group-Based Medical mistrust (Total Score)</td>
<td>0.274**</td>
<td>0.165*</td>
</tr>
<tr>
<td>Knowledge of genetics</td>
<td>-0.300**</td>
<td>-0.128*</td>
</tr>
</tbody>
</table>

F(8,197)=10.17, p<.001  
R² =29%  
F(8,196)=8.61, p<.001  
R² = 26%

* p<0.05  ** p<0.01
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!!!

QUESTIONS AND DISCUSSION