Genetics Education and Underserved Populations: Summary of the Literature

Evaluation and Technical Assistance for the GENE Project

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Final Report
Executive Summary

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Executive Summary

Advances in the science of genetics offer the potential to improve health through new genetic tests or therapies. Unfortunately, the disparity in access to health care that currently exists in the U.S. for ethnic/racial minorities is even greater for genetic services. Even if ethnic/racial minorities are able to access genetic services, the quality of these services may be poor because they often are not culturally or linguistically appropriate.

To help address this problem, the Health Resources and Services Administration (HRSA) funded a 5-year cooperative agreement with the March of Dimes, called the Genetics Education Needs Evaluation (GENE) Project. The central mission of the GENE Project is to develop community-based, participatory outreach and education strategies to improve access to culturally and linguistically appropriate genetics information, resources and services to assist underserved populations\(^1\) in making informed choices about their health.

In support of the GENE Project, Abt compiled an annotated bibliography of the published literature between 1990 and 2003 on genetic outreach, education, and counseling strategies for underserved populations. We identified 56 publications, most of which reported on knowledge and attitudes toward specific genetic tests, comparing Caucasians to ethnic/racial minorities. The most common genetic tests studied were breast cancer susceptibility testing and prenatal testing. Few publications described outreach or educational strategies. This report summarizes findings only from the 19 publications on African-Americans and 17 publications on Latinos, the two groups that are the focus of the community GENE Projects. A publishable manuscript (forthcoming) will also include findings for other underserved populations such as Asian-Americans and Pacific-Islanders.

The Importance of Culturally Appropriate Genetic Services for Ethnic/Racial Minorities

The literature discussed the increasing need for genetic education, counseling, and services for ethnic/racial minorities as well as the barriers to services that are culturally appropriate. Genetic services, including counseling and education, are ineffective unless they are culturally appropriate because the type of information providers discuss during genetic education and counseling, as well as the manner in which they discuss the information with their client, can influence an individual’s testing decision. Ethnic/racial minorities face many barriers to accessing medical care, which also affect access to genetic services. In addition, U.S. genetic service providers are not ethnically/racially diverse and genetic counseling and education have been predominantly designed for Caucasians.

Summary of Findings for Both African-Americans and Latinos

Many of the publications in the literature caution readers to avoid developing stereotypes of groups and recognize that all groups are heterogeneous and have a diversity of experiences based on their life experiences, socioeconomic class, degree of assimilation into the U.S., cultural beliefs, etc. We provide a preliminary exploration and identification of the issues that may arise for those designing

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\(^1\) The term ‘underserved populations’ can include many groups, but this project is focusing on people who face ethnocultural and other barriers to care, including ethnic/racial minorities, recent immigrants, and refugees.
and implementing genetics outreach, education, and counseling strategies for underserved populations. However, some of the findings may not be generalizable beyond populations with characteristics similar to the small study populations. We focus on the general recommendations that were consistently mentioned across a number of publications and/or were similar for both African-Americans and Latinos.

**Genetics outreach, education, and counseling strategies should consider the following health beliefs and practices of clients:**

- Beliefs about health, risk, the meaning of disability, the causes of illness such as birth defects, and the value of motherhood; and
- Practices related to use of and/or blending folk medicine and Western medicine; preferred patient-provider communication style, especially regarding level of directiveness in genetic counseling; the importance of family, gender roles, and information sharing and decision-making within families; religious beliefs; and approach to life.

**Barriers to genetic services that were identified for both African-Americans and Latinos:**

- General barriers to medical care, including financial, transportation, prejudice and social discrimination, language, and mistrust or lack of familiarity with Western biomedical system etc.;
- Reluctance to discuss health/family issues with outsiders; and
- Preference for directive communication style rather than nondirective genetic counseling.

**Outreach and education strategies suggested by literature to address these barriers:**

- Work with communities and their leaders to determine appropriate strategies and programs;
- Tailor programs to the target population (specific recommendations vary by population);
- Learn about the population in general and about their understanding of genetic disorders and technologies;
- Train providers who share the same cultural background with the client in order to increase rapport and communication; and
- Provide information to enhance understanding of genetics rather than trying to disassemble cultural beliefs.

Due to the limited types of genetic tests included in the studies, not enough is known about the level of awareness/knowledge or interest of African-Americans and Latinos in genetic testing.

**Awareness/knowledge:**

- Among African-Americans, several studies reported that knowledge about breast cancer susceptibility testing was low compared to Caucasians, even when socioeconomic status and risk of cancer were similar;
- Among Latino immigrants, level of awareness and knowledge related to prenatal diagnosis was low;

**Interest/use:**

- Interest in genetic testing for breast/ovarian cancer susceptibility among African-Americans as assessed through attitudes surveys was high and similar to general population; but low for actual use of carrier testing for sickle cell disease;
- Among Latinos, interest (as measured by a survey) was high for genetic tests in general and for cancer susceptibility tests; but studies of actual use of prenatal tests showed lower interest compared to Caucasians; and
• Studies varied in their findings of whether race/ethnicity plays a role in explaining differences in attitudes toward and use of genetic services; some studies found that differences were by socioeconomic status, not by race/ethnicity.

Findings from Publications on African-Americans

• Several studies found that African-Americans have little awareness or knowledge about breast/ovarian cancer and genetic testing, which can result in lower perceived risk and/or no follow-up;
• Several studies found that African-Americans have a high level of interest, similar to the general population, in genetic testing for breast/ovarian cancer susceptibility;
• Studies had mixed results regarding whether African-Americans had fewer or more concerns about genetic testing for breast/ovarian cancer susceptibility, which may be due to differences in socioeconomic status among the studies’ participants;
• Two interview studies on sickle cell disease and several on amniocentesis suggest that genetic screening and selective reproduction might not be of interest to some African-American women, particularly low income African-American women who may lack the power and inclination to avoid having a child with a disease;
• In addition to the common barriers to accessing medical care, African-Americans may have additional barriers to genetic counseling such as reluctance to discuss cancer and mistrust of medical system;
• Several studies tested and/or suggested specific outreach and educational strategies such as empowering individuals to make health care decisions by addressing inequalities of race, class and gender, as well as cultural values, and including detailed informed consent procedures to ensure clients are aware of their rights and risks/benefits of testing including insurance discrimination.

Findings from Publications on Latinos

• Recent Latino immigrants are often unfamiliar with the U.S. health care system, including theories of disease causation and healing processes;
• Some Latinos have a fatalistic approach to life, which may mean they will be less open to genetic testing that might enable them to change their situation;
• Studies differ in their conclusions of the roles of Latino men and women in making health care decisions;
• Two studies of Latino immigrants found low levels of awareness and knowledge of prenatal tests;
• A national telephone survey that included Latinos found that the majority had positive attitudes towards genetic tests, although several studies found that actual use of amniocentesis after a positive alpha-fetoprotein (AFP) test result is lower for Latinas compared to Caucasians;
• A few studies have found that genetic counseling has positive effects on Latinas and recent immigrants, although Latinos face additional ethnocultural barriers to accessing genetic counseling such as fear of medical institutions, reluctance to discuss inherited disorders with strangers, and a preference for more directive counseling;
• Several studies tested and/or suggested specific outreach and educational strategies such as training lay health workers to help genetic counselors provide linguistically and culturally
appropriate genetic counseling to immigrants and using videos in addition to traditional written educational materials.

Limitations

We consider this review and summary of the literature exploratory due to the following limitations:

- Only 17-19 publications for each ethnic/racial group addressed genetics education, counseling, and/or outreach and most studies included small numbers of participants, primarily women;
- Within each ethnic/racial group, most studies focused on one type of genetic test (breast/ovarian cancer susceptibility testing for African-Americans and prenatal diagnosis for Latinos);
- Few studies evaluated specific education, counseling, or outreach strategies and many of the studies measured level of interest in genetic testing using surveys of attitudes, which usually overestimate actual use of genetic tests; and
- Our review does not include non-published literature, which may provide additional useful information.

To address some of these limitations, further studies are needed that include larger samples of both men and women; expand the focus to other genetic tests; evaluate the effectiveness of different genetics education, counseling, and/or outreach strategies; and measure outcomes such as actual use of genetic services rather than hypothetical interest in a genetic test.

Finally, since there is a vast literature of culturally appropriate outreach, education, and counseling strategies for other types of health services (such as HIV/AIDS counseling, mental health, etc.), this literature should be reviewed for relevance to genetic services.

Suggested Uses of Literature Review Findings for HRSA

The findings from this literature review should be used to help guide current and future HRSA projects like the GENE Project that seek to develop culturally and linguistically appropriate outreach, education, and counseling strategies for African-Americans or Latinos. HRSA projects should build on what these previous authors have learned, as well as what previous SPRANS grantees have learned (when that summary becomes available). HRSA can use the gaps we identified in the literature to develop funding opportunities that will fill these gaps through additional projects as well as an emphasis on more formal evaluation of strategies as well as widespread dissemination of project findings through the published literature.