

**Genetics Education and Underserved Populations: Summary of
the Literature**

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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 populations¹ 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

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.

1. Introduction

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. Genetic services include genetic testing of individuals (i.e. carrier testing, cancer susceptibility testing), population-based screening (i.e. newborn screening), genetic counseling, and follow-up care after diagnosis of a genetic condition. 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; that is, the services and counseling offered do not fully consider the individual's language, beliefs, values, and experiences based on their ethnic/racial background, country of origin and immigration history. As the gap widens between people who are able to access genetic services and those who are not, so may disparities in health status.

The GENE Project

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 strategies to improve access to culturally and linguistically appropriate genetics information, resources and services to assist underserved populations² in making informed choices about their health. Other partners in the project include two national organizations, Family Voices and the Genetic Alliance, as well as two community partners: Flint/Lansing, Michigan, and Washington Heights/Inwood, New York. The partners are developing and implementing culturally appropriate outreach and education strategies to help inform underserved populations about genetic resources and services, in order to narrow the gap in access to genetic services.

Approach to Literature Review

In support of the GENE Project, Abt compiled an annotated bibliography of the published literature between 1990 and 2003 on genetic education, counseling, and outreach strategies for underserved populations.

We searched several electronic databases covering the fields of medicine, public health, social work, psychology, education, sociology, and anthropology. We used the following key words to identify relevant publications:

- genetic counseling, genetic services/service delivery, genetic testing, genetic screening;
- consumer/patient education, communication, information services, outreach, educational materials related to genetics;
- beliefs, attitudes, knowledge, practice related to genetics;
- health services needs and demand, access to genetic services;
- minority, ethnicity/race/ethnocultural background, Hispanics/Latinos, African-Americans, Asians/Asian-Americans, Native Americans/American Indians, community, cultural competence.

² 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.

We limited our search to journal articles, abstracts, books/book chapters, or conference abstracts/proceedings. In order to limit the vast literature to the most relevant publications for the GENE project, we excluded publications if they focused exclusively on eugenics, distrust of genetic research, or differences in use of testing, unless there was a discussion of the implications for education, counseling, or outreach.

This search strategy yielded 56 publications. Most of the publications 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 tests. Few publications described outreach or educational strategies, and most of these were about the ethnocultural genetic demonstration projects funded by Special Projects of Regional and National Significance (SPRANS) grants from the Genetic Services Branch, HRSA during the 1990s.

We first created an annotated bibliography based on the abstracts and/or full text of the publications. Although the annotated bibliography included the publications we identified for several ethnic/racial groups that are traditionally underserved, this report summarizes findings only from the 19 articles on African-Americans and 17 articles 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 including Asian-Americans and Pacific-Islanders.

The published literature on genetic education/outreach/counseling for African-Americans and Latinos had several major gaps that may limit the applicability of the findings we summarize in this report. Most studies had small samples of African-Americans or Latinos, few studies included men, and most studies focused on genetic testing for women (breast cancer susceptibility testing for African-Americans and amniocentesis for Latinos). The findings described in these chapters reflect the publications identified in our literature review. Our conclusions about the results and recommendations are based solely on these publications.

Organization of Report

In Section 2 we outline the increasing importance of culturally appropriate genetic services as well as the multiple barriers to accessing services. Sections 3 and 4 describe the findings from studies for African-Americans and Latinos on health practices and beliefs that need to be considered for genetic education and counseling, knowledge and attitudes about genetic tests, and strategies for outreach, education and counseling. Section 5 discusses the limitations of the literature and summarizes the implications of these findings for those developing genetic education, outreach, counseling, and services. The Appendix provides a table of all studies, organized alphabetically by author last name, which summarizes methodology and results.

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

The literature discussed the general need for culturally appropriate genetic services, irrespective of race/ethnicity. This section describes the importance of culturally appropriate genetic services, and the growing need for these services among underserved populations. We summarize findings from the literature for African-Americans and Latinos specifically in the next sections.

Genetic services, including counseling and education, are ineffective unless they are culturally appropriate

An individual's decision to undergo genetic testing requires more education and counseling than other medical tests and procedures because:

- Understanding the benefits, limitations, and results of genetic tests require understanding complex concepts such as probabilities and test characteristics;
- Genetic tests have greater risks related to confidentiality, discrimination, and stigma for the individual or family;
- Genetic tests related to reproduction require an individual to consider the benefits and risks of testing in terms of their beliefs and values about when life begins, abortion, quality of life, and disability;
- Some genetic tests require an individual to weigh the benefits of knowing one's diagnosis or one's increased susceptibility to disease in the absence of acceptable or effective treatment options; and
- The decision should be autonomous, non-coerced, and accompanied by informed consent.

Thus, health care providers who counsel and educate individuals considering genetic testing play an important role in assisting people with complex decision-making processes.

Genetic education and counseling needs to consider the health-related aspects of the client's culture because the type of information discussed during genetic education and counseling, as well as the manner in which it is discussed, can influence an individual's testing decision:

- Definition of health;
- Beliefs about causes of disease;
- How symptoms are described and how illnesses are reacted to;
- How and when medical help is sought;
- Who is responsible for decision making; and
- Types of behaviors and preferred communication styles in physician/patient interactions.

Providers need to assess each individual patient's culture rather than make assumptions based on stereotypes. Culturally appropriate genetic counseling can help ensure that appropriate informed consent is provided prior to testing; that education and explanations are tailored to the individual's culture; and that questions are answered in a way that is sensitive to their beliefs and values. The influence of culture is important to consider when trying to understand the motivation behind an

individual's health decisions, but also to understand an individual's ability to manage a particular situation or express grief.

The Need for Genetic Education, Counseling, and Services Is Increasing for Ethnic/Racial Minorities

The increasingly diverse U.S. population includes ethnic/racial groups that have different and greater risk for certain genetic conditions:

- Sickle cell disease among African-Americans;
- Diabetes among Latinos;
- Thalassemia among some Asian-Pacific Islander groups and hemoglobin H disease among Laotians.

Ethnic/Racial Minorities Face More Barriers to Genetic Services

Barriers to medical care in general also affect access to genetic services:

- Financial barriers such as lack of health insurance;
- Transportation, lack of child care, and inability to take time off from work;
- Western biomedical models of definitions of illnesses, explanation of their causes and prevention and treatment;
- Condescending response to traditional health beliefs and practices;
- Inflexible and unfriendly service hours;
- Prejudice and social discrimination; and
- Language barriers when the patient speaks a language other than English.

Genetics is associated with negative historical treatment of ethnic/racial minorities:

- Unethical treatment of African-American and other minority human subjects in research (e.g. Tuskegee study);
- Discrimination against sickle cell anemia carriers related to sickle cell screening in the 1970s;
- Eugenics movements in U.S. and Nazi Germany; and
- Concern that underserved populations will not benefit from advances in genetics related to inequitable access to medical care.

The lack of ethnic/racial diversity among U.S. genetic service providers can result in genetic services that are not culturally appropriate:

- In 1998, only 1% of genetic counselors (members of the National Society of Genetic Counselors) were Latino, 4% were Asian, and 1% were African-American;
- Of the 4,810 U.S. members of the American Society of Human Genetics (both researchers and geneticists/clinicians), 13% are Asian, 1% are African-American, 0.7% are Latino, and 0.6% are Native American.
- Providers may not share their client's language or culture and thus may need to rely on interpreters, few of whom are trained in genetics concepts;
- Providers may not be well-versed in which disorders are more common among particular ethnic/racial groups or the accuracy of the test for particular groups; and
- Providers may not be aware of their own assumptions and beliefs that may not necessarily match their clients.'

Genetic counseling and education have been predominantly designed for Caucasians and thus may be less culturally appropriate for underserved populations:

- Counseling and education may not be responsive to the needs of other groups;
- The paradigm of genetic counseling may not apply to other cultures because it is based on a Western model involving:
 - Direct information, individual decision-making, and a future orientation;
 - Assuming control over the environment, which goes against some culture's beliefs that fate or the forces of nature cannot be tampered with or that life cannot be controlled without causing imbalance or illness.

The remainder of this report describes in more detail findings from the literature on the health beliefs and attitudes of African-Americans and Latinos related to genetics that can be ethnocultural barriers to culturally appropriate genetic services. In addition, the sections that follow describe strategies that attempt to reduce some of these barriers.

3. Findings from Literature on Genetics Outreach, Education, and Counseling for African-Americans

Types of Literature Identified

We identified 19 articles that fit the criteria of discussing African-Americans and genetic education, counseling, outreach, or services. We first present some information about the types of studies identified, and then summarize key findings.

Many of the publications in the literature caution readers to avoid developing stereotypes of groups but rather recognize that all groups have a diversity of experiences based on their life experiences, socioeconomic class, degree of assimilation into the U.S., cultural beliefs, etc. We summarize the findings noting that they are not generalizable to all people.

The literature used a wide range of methods to explore beliefs, attitudes, and use of genetic services, or education, counseling, and/or outreach strategies for African-Americans:

- Interviews (Beeson and Doksum, 2001; Culver et al., 2001; Hill 1994; Hughes et al., 1997; Kinney et al., 2001; Lerman et al., 1999);
- Focus groups (Baty et al., 2003; Matthews et al., 2000);
- Surveys (Cadori et al., 2003; Cohen et al., 1998; Donovan and Tucker, 2000; Durfy et al., 1999; Hipps et al., 2003; Honda 2003; Learman et al., 2003; Wertz 1998);
- Randomized study of two different education/counseling approaches (Durfy et al., 1999; Lerman et al., 1999);
- Community-based approach to outreach (Mittman 1998); and
- Literature review (Olopade et al., 2003; Telfair and Nash, 1996).

The literature has major gaps and limitations; therefore, the results are not generalizable to all African-Americans or to all genetic tests:

- Half of the studies discussed genetic testing for susceptibility to breast/ovarian cancer; the remainder focused on cancer, predictive testing for Alzheimer's disease, sickle cell disease, birth defects, or genetic tests in general;
- Most of the studies assessed knowledge and/or attitudes about testing rather than actual use of testing (and many studies of other populations have shown that actual use is much lower than interest as measured by an attitudinal study);
- Only one study used a community-based outreach strategy and only one focused on the development of more effective educational materials;
- Most of these studies involved small samples of African-Americans, ranging from 15 to 189 and few studies included African-American men; and
- Types of participants in each study differed in terms of region of the country, family history of cancer, age, etc.

Health Practices and Beliefs

Several articles described the health practices of some African-Americans that may affect knowledge, attitudes, access to, or use of genetic tests:

- Less frequent use of preventive care or tests until condition affects activity;
- Use of folk medicine (e.g. spiritual advisors, alternative remedies) in addition to traditional western medicine; and
- Use of informal networks such as family, folk healers, or an African-American church for sources of support.

Two small studies found examples of some African-Americans' beliefs about the causes of birth defects and genetic disorders that differ from medical or genetic explanations:

- Some believe that birth defects are caused by eating the wrong foods; worrying about a loved one; viewing a horror movie; looking at animals, the evil eye or a casted spell; punishment from God; having bad thoughts; and/or movements of cold wind/air; and
- Few realized that birth defects could be caused by drug and alcohol use.

Studies indicated that many African-Americans tend to highly value family and motherhood, which may influence their attitudes toward reproductive and other genetic tests:

- Preference for physician disclosure of an individual's test results to relatives at risk, without the individual's consent, rather than protecting the privacy of the tested individual;
- Importance of mother figures in decision-making; and
- Reluctance to abort wanted babies who may have a birth defect due to belief that God will provide for the child.

Thus, genetic outreach, education, and counseling strategies should incorporate clients' practices such use of folk medicine and informal sources of support, and health beliefs such as beliefs about the causes of birth defects.

Knowledge, Attitudes, and Practices Related to Genetic Tests and Genetic Counseling

Most of the studies summarized below compared knowledge and attitudes of African-Americans to Caucasians and other groups, including Ashkenazi Jews, Native Americans, and lesbians/bisexuals.

Several studies found that African-Americans have little awareness or knowledge about breast/ovarian cancer and genetic testing:

- Awareness/knowledge of the following is low among African-Americans: breast cancer and the genetic risk for breast cancer; genetic counseling; genetic testing for breast/ovarian cancer susceptibility; and
- Knowledge is lower among African-Americans compared to Caucasians and other groups, even among those with similar socioeconomic status and risk for cancer.

Low knowledge about breast/ovarian cancer can result in lower perceived risk and/or no follow-up:

- Compared to Caucasians, African-American women were less likely to believe they were candidates for genetic testing (among those with a family history); and rated their cancer risk lower than Caucasian women;
- Even in an extended family with an identified mutation for breast/ovarian cancer susceptibility, use of mammograms was low and few family members had discussed cancer causes, genetic testing, or risk factors with their health care providers.

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 and one study on colorectal cancer susceptibility testing found similar results:

- This finding was consistent across studies that included people from the general population (who may or may not have had a family history); women with a family history of breast/ovarian cancer; and members of an African-American family with an identified breast/ovarian cancer susceptibility mutation;
- African-American women had more positive attitudes about the benefits of breast/ovarian cancer susceptibility testing compared to Caucasians;
- Among extended family members of an African-American family with an identified breast/ovarian cancer mutation, interest in testing was higher among younger individuals, those with a personal history of breast/ovarian cancer, and those with one or more first-degree relatives (i.e. mother, sister) with breast/ovarian cancer;
- One study found that interest in breast/ovarian cancer susceptibility testing declined when participants had to pay for the test themselves;
- One study on colorectal cancer susceptibility testing found no significant differences between African-Americans and Caucasians on cancer screening behavior, attitudes about cancer screening, hypothetical interest in genetic testing, or perceived risk for colorectal cancer, although African-Americans had stronger expectations that genetic information would be used to discriminate against people of color.

Differences in socioeconomic status among studies' participants may explain the mixed results regarding whether African-Americans have fewer or more concerns about genetic testing for breast/ovarian cancer susceptibility:

- A few studies found that even though African-American women had more positive attitudes about the benefits of testing, they also had more concerns about the limitations and risks;
- One study found that African-American women at increased risk of cancer had fewer concerns about the limitations and risks of testing than similar Caucasian women;
- Several studies found that African-Americans of lower socioeconomic status were more concerned about limitations and risks of testing compared to those of higher socioeconomic status;
- Study results were mixed regarding whether African-Americans are more concerned about risk of employment or insurance discrimination due to test results.

One focus group study described the reasons why some African-American men and women would or would not have genetic testing for cancer susceptibility:

- Reasons to have genetic testing for cancer:

- concerns about the risk of cancer for their children or other family members and who else should be tested; and
- to plan for the future.
- Reasons to not have genetic testing for cancer:
 - Distrust of the medical community, fear of physicians and tests;
 - Uncertainty of test results;
 - Limited benefit of the test because some already assumed they had the mutation;
 - Insurance or costs of test;
 - Confidentiality and concerns about losing health insurance;
 - Perceptions of connection between stress (caused by testing) and getting the disease;
 - Emotional issues; and
 - The effect on their family.

One study on predictive testing for Alzheimer’s disease found that compared to Caucasians, African-American men and women were similarly supportive of testing and its benefits; however, African-Americans:

- Showed less interest in testing;
- Endorsed fewer reasons for pursuing testing; and
- Anticipated fewer negative consequences from a positive test result.

Two interview studies on testing for sickle cell disease and several on amniocentesis suggest that many African-Americans are not interested in genetic screening and selective reproduction:

- Several studies found that African-American women were less likely to undergo amniocentesis after a positive alpha-fetoprotein test result;
- Sickle cell disease screening programs were designed based on the assumption that once informed about the risks of having a child with serious disease, a person will engage in preventative health behaviors; however:
 - A small study of low-income women found that, despite knowing their trait status and their risk of having a child with sickle cell disease, women did not pursue options for avoiding having a child with sickle cell disease, such as not having children or by having the father tested for sickle cell trait due to economic barriers such as lack of good prenatal health care; and cultural barriers including lack of power to persuade potential fathers to be tested for sickle cell disease trait; unwillingness to forego motherhood due to strong cultural values placed on motherhood; and fatalistic attitudes about children getting sick; and
 - A study of 189 men and women with all levels of socioeconomic status found little interest in carrier testing or prenatal diagnosis for sickle cell disease due to religious beliefs, a value on ‘romantic love’ (not basing choice of partner on test results), and/or a positive experience with an affected family member.

In summary, studies in the literature suggest that knowledge about breast/ovarian cancer and genetic testing is low among African-Americans, which can result in lower perceived risk for cancer; and interest in testing is similar to Caucasians for breast/ovarian cancer susceptibility testing, but lower for reproductive tests.

Ethnocultural Barriers to Genetic Counseling and Services

Two studies had mixed findings on the use of genetic counseling by African-American women to discuss breast/ovarian cancer risk and testing:

- One small study of women from the general population (who did not necessarily have a family history of breast/ovarian cancer) found that about half of the women completed a genetic counseling session when offered, with no differences between African-Americans, Caucasians, Jews, and Native Americans with similar educational levels;
- A larger study of Caucasian and African-American women at increased risk for breast/ovarian cancer found that 49% of African-Americans completed genetic counseling, compared to 68% of Caucasians; and
- Other factors may determine use of genetic counseling, including higher education, higher perceived risk for breast cancer, and reducing barriers such as cost, transportation, and child care.

Some African-Americans have communication style preferences that may make them less interested in genetic counseling:

- Preference to take care of one's own problems and reluctance to discuss family problems with outsiders;
- Cancer is not typically discussed within some African-American families;
- Reluctance to discuss cancer with providers because of a perceived connection between stress and cancer;
- Preference for directive and paternalistic patient-provider communication that is opposite of the principles of genetic counseling; and
- Tendency for some to have a present rather than future orientation, resulting in not understanding the need for both pre- and post-test genetic counseling.

Several (but not all) studies found more negative attitudes about the medical community among African-Americans:

- Some studies (primarily the qualitative rather than quantitative studies) found a general mistrust of the medical community, perhaps due in part to the sickle cell disease program of the 1970s or the Tuskegee syphilis experiments;
- Other studies found that many men and women had favorable attitudes towards physicians or that women did not show more distrust of medical community but were concerned about confidentiality; and
- One study found that males were more likely to voice mistrust of the medical establishment, which may explain differences in study findings because most only included women.

Strategies need to address ethnocultural barriers to genetic services such as communication style preferences that conflict with genetic counseling and negative attitudes about the medical community.

Outreach and Counseling/Education Strategies to Increase Access to and Use of Genetic Services

Outreach and education strategies need to be developed to address barriers to genetic counseling and services mentioned above. Unfortunately, few studies in the published literature focused on outreach and educational strategies for African-Americans.

In one focus group study, African-American participants suggested the following outreach strategies for cancer genetic services:

- Engage African-American celebrity spokespersons who have cancer or a family history of cancer and have had genetic counseling;
- Create a toll-free or local telephone number for questions about genetic testing;
- Distribute educational materials and telephone numbers in high-traffic areas (churches, schools, local clinics, buses, parks, libraries, etc.);
- Match the content of messages to the audience in different settings; for example, materials in treatment settings should focus on helping people cope with a cancer diagnosis, rather than genetic services; and
- Develop public/private partnerships to provide information about cancer to local agencies serving African-Americans.

A three-year community-based project increased use of genetic services by 50% among African-Americans and Russian Jewish immigrants in Baltimore by using strategies that presented information at a local level and within the cultural context. The project:

- Gathered information about target populations to understand their needs;
- Created a Community Advisory Board with community leaders (clergy, neighborhood coalitions, advocates, public health professionals, etc.) to provide input to all aspects of the project;
- Hired an African-American genetic counselor and African-American home visitors;
- Organized community health fairs with local entertainment and food throughout the community built around seasonal cultural community themes; in addition to providing educational information about genetics and genetic services, they included topics like HIV, violence, child abuse, cancer screening, and family planning, as well as information on issues like fire safety; and provided free blood pressure checks and eye exams; and
- Conducted a total of 101 outreach activities over three years that reached more than 8,000 residents.

One study found that African-American women may be more motivated to pursue genetic testing for breast/ovarian cancer if they receive genetic counseling from an African-American:

- Study participants were African-American and Caucasian women at increased risk for breast/ovarian cancer, randomly assigned to standard education or education plus counseling;
- African-Americans, but not Caucasians, were more likely to submit a blood sample for genetic testing when they received more intensive education and counseling rather than just standard education;
- The authors hypothesize that there was a stronger rapport between client/educator due to greater perceived similarity in cultural backgrounds since previous studies have shown that trust is an important factor in use of medical services among African-Americans; and

- Expanded counseling, which includes familial issues about testing, may motivate African-American women to be tested for the sake of other family members, since family cohesiveness at times of crisis has been noted as a strength of the African-American community.

Lessons learned from strategies described in the literature include tailoring outreach and other strategies to each population by incorporating preferences such as using culturally appropriate themes, spokespeople, and/or counselors.

Implications of Findings from Literature for Genetic Education and Counseling for African-Americans

Many of the suggestions made in the literature for genetics education and counseling strategies follow principles for effective health education strategies in general.

Several studies recommended that education and counseling carefully balance the need to give adequate information for informed decisions and overburdening the individual:

- Do not overwhelm the client with too much information;
- Avoid requiring clients to go through multiple steps and procedures; and
- Tailor genetic education to the specific needs because underserved populations often face other pressing concerns.

The content of educational and counseling programs should address some of the ethnocultural issues discussed above:

- Encourage communication with family members about genetic testing;
- Include detailed informed consent procedures to ensure clients are aware of their rights and risks/benefits of testing including potential for insurance discrimination;
- Tailor content to attitudes, beliefs and educational level of persons and also to their care providers;
- Focus on providing genetic information to enhance understanding of causes of birth defects, rather than to try to disassemble cultural beliefs about genetics and health; and
- Empower individuals to make health care decisions by addressing inequalities of race, class and gender, as well as cultural values.

Several studies directly solicited feedback from African-Americans on how to develop better education/counseling materials on genetics. Suggestions included:

- Carefully develop educational/counseling materials since they may be the person's first contact with genetic services;
- Design printed materials in a clear and readable manner and at low literacy levels, to ensure that those with less education are better able to understand the relevance of genetics; specifically:
 - Use non-technical images to explain genetic concepts;
 - Personalize the information by making it relevant to the readers' lives and by using pictures and images;
 - Use colors, figures, and themes that are relevant to many African-Americans and avoid those with negative associations for African-Americans;

- Include a glossary, and references to other publications that describe both the pros and cons of genetic testing;
- Explain that the genetic test is a blood test involving no other medical procedures;
- Use case histories to show how testing can be beneficial;
- Explain costs and coverage of procedures;
- Discuss risks/concerns including confidentiality issues; and
- Emphasize the direct benefits of testing (e.g., improving the health of their families, early detection).

In summary, although the literature on African-Americans concentrated primarily on breast/ovarian cancer susceptibility testing, several concrete recommendations have been made to design more effective education and counseling strategies, including: ensure informed consent procedures address concerns African-Americans may have about genetic testing; incorporate rather than try to disassemble cultural beliefs; and empower individuals to make health care decisions.

4. Findings from Literature on Genetics Outreach, Education, and Counseling for Latinos

Types of Literature Identified

We identified 17 articles that fit the criteria of discussing Latinos and genetic education, counseling, outreach, or services. We first present some information about the types of studies identified, and then summarize key findings.

Many of the publications in the literature caution readers to avoid developing stereotypes of groups but rather 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 summarize the findings noting that they may be generalizable to some but not all Latinos.

The literature used a wide range of methods to explore beliefs, attitudes, and use of genetic services, or education, counseling, and/or outreach strategies for Latinos:

- Interviews (Aguilar, et al., 2001a; Browner et al., 1996; Browner and Prebran, 2000a; Browner and Preloran, 2000b; Browner et al., 2003);
- Case studies (Penchaszadeh and Puñales-Morejon, 1998);
- Pre/post observations and chart abstractions (Browner et al., 1999; Browner and Preloran, 2000b);
- Observation of on-site data (Bridge, et al., 1998; Browner et al., 1996; Mittman et al., 1998; Penchaszadeh and Puñales-Morejon, 1998);
- Surveys (Aguilar et al., 2001b; Browner et al., 1996; Browner et al., 1999; Cohen, et al., 1998; Honda 2003; Jaeger et al., 1997; Learman et al., 2003; Martinez et al., 2003; Mittman et al., 1998; Penchaszadeh and Puñales-Morejon, 1998); and
- Literature reviews (Lopez-Rangel, 1996; Penchaszadeh, 2001; Penchaszadeh and Puñales-Morejon, 1998).

However, the literature has major gaps and limitations; the results therefore, may not be generalizable to all Latinos or to all genetic tests:

- Almost all of the studies were about prenatal tests, specifically amniocentesis after a positive alpha-fetoprotein test result; the remainder focused on birth defects, pediatric genetic services, genetic testing for cancer susceptibility, genetic testing in general, and perinatal genetic services;
- Most of the studies assessed knowledge and/or attitudes about testing rather than actual use of testing (and many studies of other populations have shown that actual use is much lower than interest as measured by an attitudinal study);
- None of the studies used a community-based outreach strategy, although two assessed the use of bilingual/bicultural lay health workers;
- Most of these studies involved small samples of Latinos, mostly Mexican-Americans, ranging from 15 to 267 and few studies included Latino men; and
- Types of participants in each study differed in terms of country of origin (Mexico, Cuba, Puerto Rico), region of the country, family history of cancer, age, gender.

Health Practices and Beliefs

Some characteristics of Latino culture described by several articles may have direct impact on attitudes and use of genetic tests:

- Families are important and interdependence is valued over independence, affiliation over individualism, and cooperation over confrontation;
- Family members are loyal to extended family members, who play an important role in everyday life and particularly in reproductive decisions;
- Interpersonal trust is valued through warm and friendly relations, but Latinos also adhere to strict lines of authority and respect for others, especially elders;
- Religion can play an important role in the lives of Latinos; the majority of Latinos are Roman Catholics, but an increasing number of Latinos belong to Protestant denominations and evangelical sects;
- Adoption rarely occurs outside of the family, but could be mentioned as an option when discussing reproductive genetic technologies; and
- Definitions of disability vary among Latino groups (e.g, a child with mental retardation may be less welcome in a middle/upper class well-educated Latino family than the lower class families; disability may not be viewed as limiting if the person can work in the fields).

Most articles describe how many Latinos blend Western and folk medicine:

- Latinos of lower socioeconomic class and who are less acculturated are more likely to use folk healers;
- Latinos tend to use non-prescribed over-the counter and homemade medications more than any other ethnic group; and
- Medications are usually prescribed by traditional healers who combine them with therapeutic methods and spiritual practices, magical rituals and prayer.

Recent Latino immigrants are often unfamiliar with the U.S. health care system, including theories of disease causation and healing processes:

- They may have little knowledge of scientific concepts of illness or basic anatomy and genetics;
- They tend to view disease/illness in a metaphysical rather than scientific framework; and
- Fully-informed decisions about reproductive technologies may be difficult because the technologies may be so foreign to them.

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:

- Latinos tend to tolerate adversity rather than exert control of their environment;
- Unfavorable events may be viewed as inevitable “if God wants”;
- Some women carry fetuses to term despite poor prognosis because they do not want to interfere with an act of God;
- While some Latinos may say “It’s God’s will”, at the same time they may have a rational understanding of their disease, risk, or birth defect.

Several factors may lower Latinos’ perceptions about risk:

- Some Latinos are not future-oriented, or tend to be optimistic about future outcomes;

- Immigrants might be unimpressed by risk figures which may be lower than risks associated with hardships endured in their country of origin, difficult living conditions in the U.S. (poverty, drugs), or deportation; and
- Folk or religious beliefs provide reassurance, which lowers perception of risk.

Studies differ in their conclusions about the roles of Latino men and women in making decisions in general and health care decisions:

- Some Latino families are patriarchal in nature so it is not unusual for men to make decisions; however, a substantial portion of single mothers are heads of Latino households in the U.S., which means the role of women as decision makers has increased;
- While the father tends to make decisions in general, medical decisions are typically made among the family, not alone; and
- One study of amniocentesis decisions found that men had a supporting rather than controlling role in the woman's reproductive behavior; women or the men and women jointly made the decision among most of the couples studied.

Several small studies describe examples of Latinos' beliefs about the causes of birth defects that differ from medical and genetic explanations:

- Beliefs about causes of birth defects: natural or supernatural forces (e.g., evil eye/curse, witchcraft); God's will; punishment for previous life; hot/cold imbalance; strong emotions or disturbance in physical or psychological well-being; flattering comments about the baby (but can be done away with if one holds the baby afterwards);
- Compared to Caucasians, Latinos were less likely to believe the following caused birth defects or genetic disorders: drug and alcohol use; chromosomes; medication; and
- One study found that folk healers as well as patients listed the following as causes of genetic disorders: natural forces such as eclipses of the sun and moon; emotions such as fright or stress; unacceptable or censored behavior; and outside forces such as evil doing and witchcraft.

In one study, most Latinas said they did not know why they had a positive alpha fetoprotein test result. However, in informal conversations, the women provided a wide range of explanations:

- Weakness ("debilidad"), was the most common reason cited, due to malnutrition, poor diet, vomiting, blood loss from testing;
- Stress, anxiety, depression from job conditions, emotional problems, financial problems, and terrifying experiences like being mugged;
- Diagnostic error, limits of technology;
- Misdated pregnancy;
- Age;
- Drug use – prescription or illicit;
- Supernatural explanations (curse);
- God's intervention;
- Heredity (but did not view them as unalterable – they believed that prayer and resting more might counteract this);
- Diabetes;
- Conspiracy (economic or eugenic motives to control high birth rates among Latinos); and
- Environmental – living too close to power lines, etc.

Thus, genetic outreach, education, and counseling strategies should incorporate clients' practices such as blending of folk and Western medicine, especially among immigrants who are often unfamiliar with the U.S. health care system, and health beliefs such as beliefs about birth defects and abnormal test results.

Knowledge, Attitudes, and Practices Related to Genetic Tests and Genetic Counseling

Two studies of Latino immigrants found low levels of awareness and knowledge of prenatal tests including:

- Awareness of the availability of prenatal diagnosis and chromosomes and chromosomal abnormalities;
- The association between mother's health during pregnancy and chromosomal abnormalities;
- The ability of amniocentesis to detect sex and chromosomal abnormalities, but not detect all genetic diseases, mental retardation, or their child's future health; and
- Possible complications of amniocentesis.

One study found some misunderstandings of prenatal technologies and birth defects among Latinas:

- Some exaggerated the risks of amniocentesis; and
- Some exaggerated the risks of birth defects.

A national telephone survey that included Latinos found that the majority had positive attitudes towards genetic tests:

- Most Latino respondents approved of genetic tests that could tell them whether they or their children would be likely to have a serious disease and three-fourths indicated they would personally take such a test;
- Over three-fourths thought that it was a "good thing" for a healthy person to find out how likely they were to get a serious health condition;
- The concerns among the few respondents with negative opinions included worry, negative self-perception, or having to alter plans; and
- Over three-fourths said they would undergo a genetic test for cancer if they had a family history of cancer, and one third would be tested if they had no special risk factor for cancer.

One survey of 110 first and second-degree female relatives of patients with breast/ovarian cancer found high levels of interest in breast/ovarian cancer susceptibility testing:

- Interest was higher for women who perceived more benefits compared to risks of testing and these women wanted to get testing sooner; and
- Interest was lower for women with higher incomes and those who had longer exposure to U.S. culture.

Several studies found that use of amniocentesis after a positive alpha-fetoprotein (AFP) test result is lower for Latinas compared to Caucasians. Possible reasons for not using amniocentesis included:

- Association of amniocentesis with abortion, which is not an option for many Catholic Latinas;
- View of amniocentesis as unnecessary because they would follow God's will;
- Fear of miscarriage;

- Fear of pain and high levels of anxiety regarding pain of the procedure and the chance of an abnormal result;
- Lack of familiarity with Western obstetric care and interventions and view of them as intrusive;
- Burden and anxiety created by choices; and
- Hopeful approach to childbearing and tendency to emphasize optimism in future outcomes.

Reasons cited by Latinas’ surveyed about why they would decide to have an amniocentesis are:

- Influence from obstetrician;
- Reassurance from a normal test result; and
- Option to interrupt an abnormal pregnancy.

The findings were mixed on the influence of sociodemographic characteristics on decisions to use amniocentesis:

- Two studies found no sociodemographic differences between Latinas who accepted amniocentesis and those who declined, and found similar results among their male partners;
- Women (but not men) born in Mexico were more likely to refuse amniocentesis, especially among those less acculturated;
- Length of time in the U.S. and level of acculturation did not significantly influence those who refused amniocentesis; and
- Although most studies found that acceptance rates of amniocentesis differ between Caucasians and Latinos, studies of low-income women of Mexican origin suggest that they tend to make prenatal diagnostic testing choices that are similar to those made by middle-class Caucasian women, but for different reasons, perhaps due to different contexts within which the choice is made.

One in-depth examination found that Latinas’ had complex decision-making processes regarding amniocentesis after a positive alpha-fetoprotein test result that went beyond the usual explanation of fatalism:

- Latinas who underwent amniocentesis were more likely to believe that:
 - Physician recommendations were important;
 - The AFP test result “meant something could be wrong with pregnancy”,
 - A positive amniocentesis result would give physicians information that could help the baby; and
 - A negative amniocentesis result would resolve uncertainty and provide reassurance.
- Latinas who declined amniocentesis:
 - Had much more complex explanations beyond biomedical explanations for why they had a positive AFP test result, which they ‘critically evaluated’ with family and friends rather than easily accepting;
 - Were more likely to express skepticism about the accuracy and value of scientific information and believe that the fetus was okay despite positive AFP results;
 - Were more likely to believe the test was risky, have more discomfort with technology, machines, and needles; and
 - Sought practical action to address the problem such as using traditional or alternative medicine to try to restore pregnancy to a healthy state and keep hope alive.

A few studies have reported mixed effects of genetic counseling on Latinas and recent immigrants:

- Among women of advanced maternal age, knowledge was increased after genetic counseling, even for recent immigrants with low education levels;
- Latina study participants had very positive reactions (high satisfaction ratings) to genetic counseling they had received; and
- One interview study found that decisions to pursue amniocentesis were affected by overuse of medical jargon, nondirective counseling, translation issues, lack of trust, and failure of counselors to address important educational issues due to fears of cultural insensitivity.

In summary, studies in the literature suggest that awareness and knowledge of prenatal tests among Latinos is low, especially among recent immigrants; interest in genetic tests in general is high, but actual use of amniocentesis after a positive alpha-fetoprotein test result is low which can be explained by complex decision-making processes that incorporate cultural beliefs and practices.

Ethnocultural Barriers to Genetic Counseling and Services

A few studies suggest that some Latinos may have fears or concerns about medical institutions and/or genetic counseling:

- One-third of Latinos are recent immigrants, and many come from countries affected by war and repression, which can result in fear and distrust of social institutions in their host country;
- Latinos may be hesitant to discuss inherited disorders with strangers, including disclosing a family disability or carrier status; and
- Most Latinos referred for genetic counseling fear that there is something terribly wrong, either with the future offspring or with an already born child.

Several studies and reviews suggest that the model of genetic counseling which includes concepts of informed consent and nondirective counseling may not be well-understood nor desired by Latinos who want more guidance:

- Latinos may view health professionals as authority figures, with the expectation that they would provide advice, guidance, and recommendations about medical matters, using a more prescriptive approach. If this expectation is not met, they may seek advice from less knowledgeable sources such as family members, community figures, or folk healers;
- Some new immigrants (of any ethnicity) may want and expect more directive counseling, and some may feel that the genetic counselor is less than competent for ignoring their needs;
- Latinos surveyed indicated that when their physician discusses the pros and cons of genetic testing, they would like him/her to “tell me his/her opinion, but emphasize that I have to make my own choice”, rather than “emphasize that I have to make my own choice without telling me his/her own opinion”;
- Some Latinas considering amniocentesis after a positive AFP test result said they would have liked the counselor to be more directive; and
- Latinas may have submissive attitudes towards men, which may present challenges to male providers who attempt to provide nondirective genetic counseling.

Strategies need to address ethnocultural barriers to genetic services such as distrust of social institutions among immigrants, hesitancy to discuss inherited disorders with strangers, and expectations for more directive counseling.

Outreach and Counseling/Education Strategies to Increase Access to and Use of Genetic Services

One outreach project for Latinos increased access to genetic services using the following strategies. The project:

- Established a collaboration between the state health department, Healthy Start, and a university genetics program;
- Trained lay health workers in genetics in order to increase their ability to make referrals for genetics services;
- Increased the cultural sensitivity of other genetic services providers by providing cultural and Spanish language training; and
- Established pediatric genetics outreach clinics in the communities in conjunction with Healthy Start sites, county health department offices, and community health centers.

One project increased knowledge and use of reproductive genetic services through the provision of linguistically and culturally appropriate genetic counseling to South and Central American and Asian-Pacific immigrants. Strategies used included:

- Established hospital-based prenatal diagnosis services and provided genetic counseling, amniocentesis, or hemoglobin testing regardless of ability to pay; and
- Hired and trained two bilingual, bicultural counseling aides from Nicaragua and Hong Kong to co-counsel with genetic counselors and provide expertise in the clients' culture and language who:
 - Used large flipcharts, pamphlets in Spanish and Chinese, and a slide show to describe amniocentesis;
 - Helped reduce ethnocultural barriers by eliciting more information on cultural beliefs related to health than the genetic counselors were able to elicit; and
 - Served as client advocates in educating clients about Western medical practices such as informed consent; logistics of securing medical appointments, applying for medical coverage, and exploring resources available for low-income families.

Several studies have demonstrated that videos may be as effective as more traditional forms of patient education in increasing short-term knowledge, and generally more effective than written materials alone :

- Women who received an informational AFP booklet and viewed a video remembered more than those who were given the booklet only;
- Videos are particularly helpful in making pregnant women carefully think through the decision to undergo prenatal testing; and
- Videos may help patients hear some of the messages multiple times (in addition to pamphlets and classes).

Regardless of educational strategy used (pamphlet alone or pamphlet and video), women are able to remember more about the procedural aspects of prenatal testing, and less about genetic information such as the definitions of neural tube defects and the purpose of AFP testing:

- Knowledge was lowest among Mexican immigrants and women with less education compared to Caucasian and Mexican-American women;
- Women who had AFP testing were no more knowledgeable about the test than those who refused.

Strategies described in the literature include training Latino lay health workers in genetics, increasing the cultural sensitivity of genetic service providers, and supplementing written educational materials with videos.

Implications of Findings from Literature for Genetic Education and Counseling for Latinos

In developing culturally appropriate genetic educational materials, reading level and preferred learning styles should be considered:

- Mexican-Americans may prefer to learn in small groups of 4-5 people with videotapes and demonstrations (according to one small study);
- The least preferred ways to learn was through large groups of 10 or more, written materials and by teaching done by other parents (for privacy reasons); and
- Focus on providing genetic information to enhance understanding of causes of birth defects, rather than to try to disassemble cultural beliefs about genetics and health.

Genetic counselors and counseling aides suggested that counseling include a recognition of the following cultural issues of Latinos (or clients of any culture):

- Risk perception;
- Religious beliefs regarding medical interventions;
- Preventive health practices;
- Reaction to nondirective counseling;
- Perception of disability and disease burden; and
- Understanding of genetic transmission of disease.

Consider aspects of Latino culture in the counseling session:

- Expecting clients to remain calm in the face of bad news may be considered culturally inappropriate;
- Latinos tend not to ask questions to avoid confrontation, so clients need to be encouraged that questions are expected;
- Clients may downplay supernatural explanations when speaking with a counselor;
- The client should always be allowed time to consult with families before making decisions; involve families/partners perhaps with a follow-up session after counseling the woman, or a telephone follow-up to address others' questions/concerns (although involvement of family members may vary);
- Recognize that some women's male partners may be more or less involved in decision-making:
 - Partners may hold divergent views about the same condition;
 - Value on courtesy means that a couple will tend not to openly disagree so allow time for them to talk in private; and
- Since many Latinos may use both folk and Western medicine, ask client what other treatments they have used, and what they think caused the problem.

Recommendations for more directive counseling style:

- Empower the client to make a difficult decision in an environment of empathy and support, but do not shy away from giving some empathic non-coercive advice if needed; and
- Carefully navigate the line between power guidance and making a decision for the client.

Additional recommendations for prenatal genetic counseling:

- Genetic service providers should be trained and encouraged to create a nonjudgmental environment in which their clients feel they can express their fears about pregnancy and their own views about why they screened positive (AFP testing);
- Counselors should encourage clients to repeat what they understand about the nature of pregnancy risk, including options regarding fetal diagnosis and treatments if an anomaly is detected, and ambiguities and limitations of human genetic information.

Ideally, clients should be counseled in their native language by providers that, in addition to being knowledgeable and empathic, also share the same cultural background, or:

- Counselors that regularly see Latino clients should learn Spanish and be conversant with Latino culture;
- Use Spanish-speaking interpreters from the same culture (preferably with a medical background), who have been shown to minimize cultural and language barriers to genetic services, but do not use:
 - A family member (due to confidentiality and level of comfort);
 - A child or a stranger from a waiting room (due to privacy);
- Train a culturally native person as a genetic assistant to serve as interpreter; and
- Do not assume that an English-speaking Latino can read or write in English or is well-versed in medical terms and concepts.

If genetic counselor is not of same culture as client:

- Give special attention to possible conflicts between provider and client resulting from potential for cultural insensitivity;
- Avoid stereotypes of any cultures and recognize the individuality of the client;
- Avoid the temptation of paternalism when facing the gap between the provider and client; and
- Try to keep the same genetic counselor rather than rotate staff because of the value of relationships to some Latinos.

Finally, provide information and referrals to resources in the Latino community:

- Be knowledgeable about and share with client resources;
- Psychological counseling may not be accepted but community networks may be helpful; and
- Resources can help clients deal with a child with disabilities, perinatal loss, and risk of developing a genetic condition later in life.

In summary, although the literature on Latinos concentrated primarily on prenatal testing, several concrete recommendations have been made to design more effective education and counseling strategies, including: tailor the mode of learning (small versus large groups, video, demonstration, etc.) as well as who provides the education to the preferences and culture of the clients; and recognize cultural issues such as the importance of family in decision-making and communication style preferences.

5. Limitations and Summary

Limitations of Literature Review

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

- **Few publications met our criteria:** Although we identified 56 publications on various underserved populations and genetics outreach, education, and/or counseling, for each ethnic/racial group we found only 17 to 19 publications that met our criteria;
- **Most studies included small numbers of participants from specific underserved ethnic/racial groups:** study sample sizes ranged from 15 to 189 African-Americans and from 15 to 257 Latinos;
- **Within each ethnic/racial group, most studies focused on one type of genetic test:** most studies of African-Americans focused on breast/ovarian cancer susceptibility testing while most studies of Latinos focused on prenatal diagnosis through amniocentesis;
- **Most studies focused on women so little is known about the views of African-American and Latino men;**
- **Few studies evaluated specific education, counseling, or outreach strategies,** but rather discussed knowledge gaps, attitudes, and barriers, and made suggestions based on lessons learned in clinical practice or literature reviews;
- **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 the non-published literature, which may provide additional information,** such as the final reports of the former HRSA SPRANS grantees that addressed ethnocultural barriers to accessing genetic services (these projects, however, are currently being synthesized in a separate report).

To address some of these limitations, further studies are needed that should:

- Include larger samples of specific ethnic/racial groups as well as include subgroups;
- Include men;
- 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.

Summary of Findings for Both African-Americans and Latinos

Despite the limitations mentioned above, this literature review provides a preliminary exploration and identification of the issues that may arise for those designing 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. In addition, the publications caution readers to avoid stereotyping by recognizing the heterogeneity of each racial/ethnic group (e.g., different incomes, education, levels of acculturation, beliefs, etc.). 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.

Health beliefs and practices are culturally based and can affect the way individuals approach decisions about genetic tests. For example:

- A client who believes that disease is a punishment may view their condition as shameful and not wish to discuss it with outsiders and/or may omit some relevant genetic -related or medical history; and
- Medical interventions may be viewed as interfering with destiny.

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

Beliefs:

- About health: some groups define health as the absence of disease, so may not seek preventive care or understand presymptomatic genetic testing;
- About risk and about the meaning of disability;
- About the causes of illness such as birth defects: studies provided evidence that many non-biomedical explanations exist among both African-Americans and Latinos; and
- About the value of motherhood may outweigh risks of having child with birth defects;

Practices related to:

- Use of and/or blending folk medicine and Western medicine;
- Preferred patient-provider communication style, especially nondirective genetic counseling, which may be confusing if client expects authority figure to have all the answers;
- The importance of family, including family hierarchy, gender roles, and communication, information sharing, decision-making, including who needs to get the information, how the information is processed, and who is involved in decision-making;
- Religious beliefs, especially regarding adverse events such as birth defects; and
- Approach to life; fatalistic versus being open proactive about using medical technology to change the future.

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, since “establishing trust and rapport” may mean very different things depending on the client’s background and group, practices and beliefs, culture; 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 attitudinal 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.

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.

6. References

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Appendix: Table of Publication Summaries

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Aguilar et al. (2001a)	23 Mexican-American clients, 25 providers, 20 folk healers in 5 South TX cities	To identify barriers to genetic services and to develop a culturally sensitive information/ training manual for providers	Genetic services	Interviews	Barriers: language and communication, cultural differences, poverty, and system issues. Beliefs about causes of genetic disorders: natural forces, emotions, behavior, and outside forces such as witchcraft.	Need to develop and implement culturally sensitive training manuals for providers; need to address socioeconomic barriers.
Aguilar et al. (2001b)	27 Mexican-American families in South TX selected on basis of clinic attendance rate of 80% and poor compliance with medical recommendations.	To assess Spanish/ English health literacy, values/attitudes, and preferred learning methods		Test of Functional Health Literacy in Adults (TOFHLA), Family Learning Preferences (FLP) tool, Health Beliefs Questionnaire-Revised (HBQ-R)	31% had inadequate to marginal TOFHLA scores and 69% had adequate functional health literacy level. Preferred to learn via small groups of 4-5 people, videotapes, demonstration; least preferred ways included large groups (10+), written materials, teaching by parents. HBQ-R: positive correlations between acculturation and education, and literacy and education; negative correlation between folk beliefs and education.	Development of culturally/ linguistically genetic educational materials should pay attention to reading level and preferred learning methods.
Baty et al. (2003)	36 female and male family members of an African-American kindred with a BRCA1 mutation in Louisiana and Utah	To develop educational materials to facilitate culturally sensitive genetics education and communication	Genetic testing for breast/ ovarian cancer susceptibility	Materials were revised and tested using feedback from 4 focus groups	Participants indicated that genetic educators needed to establish trust with African Americans due to a negative history with the medical community; materials need to be more relevant to African-American lifestyles, include less technical information and more colorful images, and emphasize faith and family.	Input from focus group was very useful in the ongoing study to provide additional feedback about the effectiveness of the culturally tailored genetic education and counseling materials.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Beeson and Doksum (2001)	180 Caucasian and 189 African-American men and women with family history of cystic fibrosis or sickle cell anemia	To explore nonbiomedical stories about decision-making regarding carrier testing	Carrier testing for cystic fibrosis or sickle cell disease	In-depth interviews	Few participants had pursued carrier testing primarily because of religious values or the values of 'romantic love'. African-Americans who had been tested rejected the relevance of testing in choosing a partner and failed to mention carrier status. Some participants cited resistance to testing due to the positive experience of the affected child's life.	The decision-making process for genetic testing is complex and results in individuals relying on values that can conflict with biomedical views. Low use of carrier testing may reflect some of these alternative values rather than ignorance or irresponsibility.
Bridge et al. (1998)	Hispanic communities in Arizona	To train community lay health workers about genetics, increase cultural competency of genetic services providers, and provide local access	Genetic services	Training curriculum developed for community lay health workers; Pediatric genetics outreach clinics established in 8 communities	Community lay health workers eagerly incorporated genetic information; providers enthusiastically accepted cultural competence training.	Cultural competence training of genetic service providers is enthusiastically accepted and utilized in the provision of locally accessible genetics clinics.
Browner and Preloran (2000a)	379 women of Mexican origin from 6 southern California state-approved prenatal diagnosis centers who screened AFP positive.	To understand how women of Mexican origin who have screened alpha-fetoprotein positive make decisions about amniocentesis	Amniocentesis after a positive AFP screen	Patient charts and in-person interviews with 147 women and 120 male partners after the women had made their amniocentesis decision, some of whom are still awaiting results	Explanations for a positive AFP test result included stress, weakness, curse, drug use, and conspiracy. Some actions taken by women who declined an amniocentesis after a positive AFP test result included praying, cleansing with water, resting, altering diet, etc.	Genetic service providers should be trained and encouraged to create a nonjudgmental environment in which their clients feel they can express their fears about pregnancy and their own views on why they screened positive. Counselors should encourage clients to repeat what they understand about the nature of pregnancy risk fetal diagnosis options, and ambiguities and limitations of human genetic information.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Browner and Preloran (2000b)	147 low-income and working class women of Mexican backgrounds in southern California.	To present the decision-making process of a Latina who accepted amniocentesis after learning that she had a positive AFP screen	Amniocentesis after a positive AFP screen	Interviews; supplemental and follow-up information was obtained by telephone.	All women agreed to the Level 2 sonogram, 60% accepted the amniocentesis and 40% declined.	Factors that influence the Latinas' experiences include: Latin culture (being cursed, filial loyalty, the church), family, friends, neighbors, local lay experts, and public perceptions of health risks. These steer women in a particular direction on how to solve medical problems.
Browner et al. (1999)	379 women of Mexican origin from 6 southern California state-approved prenatal diagnosis centers who screened AFP positive.	To understand how women of Mexican origin who have screened alpha-fetoprotein positive make decisions about amniocentesis	Amniocentesis after a positive AFP screen	Patient charts and in-person interviews with 147 women and 120 male partners after the women had made their amniocentesis decision, some of whom are still awaiting results	40% of women in interview sample declined amniocentesis. Women born in Mexico were more likely to refuse amniocentesis than U.S. born women. Catholicism was not found to be a determinant of declining amniocentesis. Those who refused were more likely to question the accuracy and value of scientific information and were more uncomfortable with technology, and needles.	Most important factors in a woman's decision for amniocentesis are her understanding of the birth defects, faith in medicine, and the relationship with her physician.
Browner et al. (1996)	130 low-risk pregnant European-American, Mexican-American, and Mexican immigrant middle and lower class women from 5 branches of an HMO in southern California	To study the role that health care providers and instructional materials play in the decision of pregnant women from diverse ethnic and social class backgrounds to take an alpha-fetoprotein (AFP) test	Amniocentesis after a positive AFP screen	Interviews within 3 months of receiving an 8-page education booklet at the time they were offered AFP screening. Approximately half the women also viewed an educational video.	Women who received the booklet and viewed a video remembered more than those who were given the booklet only, although neither group remembered much about the purpose of the screening. Women with higher educational backgrounds and European-American or Mexican-American women were more likely to retain accurate information about prenatal testing.	Videotaped instruction can enhance the retention of factual information about a program of prenatal screening for certain groups.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Browner et al. (2003)	156 pregnant women of Mexican origin who screened positive on AFP test	To examine the effects of miscommunication between genetic counselors and Mexican origin women regarding amniocentesis	Amniocentesis	Interviews	Decisions to pursue testing were affected by overuse of medical jargon, nondirective counseling, translation issues, lack of trust, and failure of counselors to address important educational issues due to fears of cultural insensitivity.	Health professionals and educators must not misplace cultural sensitivity by failing to address misinformation among certain populations. However, trust must be established through language efforts and patience with clients in order to facilitate this proper communication.
Codori et al. (2003)	41 Caucasian and 41 African-American men and women with a first degree relatives with colorectal cancer	To assess attitudes of African-Americans toward genetic testing for colorectal cancer	Genetic testing for colorectal cancer susceptibility	Mail survey of cancer screening behavior, attitudes about cancer and cancer screening, attitudes about genetic testing, and perceived risk for colorectal cancer	There were no significant group differences on cancer screening behavior, attitudes about cancer screening, attitudes about genetic testing, or perceived risk. In both groups, about 90% were likely to take a genetic test for colorectal cancer. African-Americans perceived themselves as more likely to get colorectal cancer compared to Caucasians and had stronger expectations that genetic information would be used to discriminate against people of color.	Hypothetical willingness to undertake genetic testing for colorectal cancer is virtually identical among Caucasian- and African-Americans, when controlling for age, sex, and education. Because African-Americans are more likely to expect that genetic information will be used against people of color, actual uptake of testing may be lower than among Caucasians.
Cohen et al. (1998)	93 Caucasian, White Hispanic, African-American, and other women who were either: 1) pregnant with no family history of birth defects, or 2) have a child with a birth defect or genetic disorder	To analyze the current status of health beliefs as a cause of birth defects and to compare beliefs between cultural groups	Birth defects, genetic disorders	Self-administered questionnaires asked about demographics, pregnancy history, and family history of birth defects and genetic disorders.	Statistical differences between groups of respondents were found with respect to known medical causes.	Counselors can familiarize themselves with beliefs held by individuals from various cultural groups to guide, facilitate, and optimize counseling sessions with these individuals.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Culver et al. (2001)	97 women in the greater Seattle who were European American, African American, Native American, or Ashkenazi Jewish	To determine if sociodemographic variables correlate with use of genetic counseling services, and to determine whether removal of financial barriers and the need for physician referral increases uptake of genetic counseling among minority groups	Breast cancer genetic counseling	2-hour interview followed by offer of genetic counseling	Half of the women completed genetic counseling session; women who accepted counseling had higher education and perceived risk for breast cancer, and were more likely to expect positive results. Half perceived risk of cancer as higher than average, particularly those with family history. Interest in testing and ethnicity was not predictive of whether women accepted counseling. Higher perception of risk was a predictor of acceptance of genetic counseling.	If barriers to minority groups are removed, similar levels of interest and acceptance of genetic counseling between minorities and non-minorities can be attained.
Donovan and Tucker (2000)	108 African American and 112 Caucasian women at one of three clinics at the University of Alabama School of Medicine	To investigate the education and counseling needs for genetic testing of breast-ovarian cancer susceptibility among a sociodemographically diverse group of women	Breast-ovarian cancer susceptibility testing	Three instruments/ scales to assess knowledge about breast cancer, genetic risk for breast cancer, and perception of the benefits, limitations, and risks of genetic testing	Knowledge was higher among women with higher income, more education, and Caucasians, but not for those with a positive family history. Caucasian women were more likely than African American women to perceive themselves at greater risk than average for developing breast cancer. Women with less income and less education tended to rate the limitations and risks of genetic testing as more important.	Counseling and education efforts should highlight individual knowledge deficits.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Durfy et al. (1999)	White, African American, lesbian/bisexual, and Ashkenazi Jewish women from Western Washington State with a family of breast cancer	To examine the knowledge, opinions, and predictors of interest in genetic testing for breast cancer risk in 4 diverse groups	Breast/ovarian cancer susceptibility testing	Women were randomized into individual or group counseling to ascertain their knowledge and opinions of genetic testing for breast cancer risk	Each of the four groups had 3.7-4.5 fold higher perceived risk for breast cancer than actual risk. The majority of women across groups had not read or heard much about genetic testing for breast cancer risk, especially African Americans. Between 70-94% (depending on their group) indicated they would want to know if they had a gene mutation that put them at greater risk for breast cancer.	These results should be considered when providing genetic counseling and population testing for susceptibility to breast and ovarian cancer.
Hill (1994)	29 low-income African-American mothers of children with sickle cell disease	To examine why African American women decided to give birth with knowledge of their sickle cell trait/disease status.	Sickle cell screening	In depth interviews were conducted	Mothers indicated that they chose to have children knowing of their own sickle cell trait/disease status due to inadequate knowledge about the disease, lack of options, and their value of motherhood.	The study suggests that the reproductive behaviors of low-income African American women with sickle cell disease are not affected by knowledge and education about their disease status.
Hipps et al. (2003)	278 Caucasian and 174 African-American men and women	To determine differences between Caucasians and African-Americans in attitudes about predictive genetic testing for Alzheimer's disease	Predictive genetic testing for Alzheimer's disease	Survey that assessed attitudes, beliefs, and knowledge of predictive testing and Alzheimer's disease	While each group noted broad interest in predictive testing for Alzheimer's disease, African-Americans did show less interest in testing. On average, Caucasians endorsed more of the suggested reasons for seeking testing than African-Americans. The majority of all respondents indicated they would be able to cope with the test result. Most respondents regardless of race believed that predictive testing should be offered with few restrictions.	The differences between Caucasians and African-Americans have implications for genetic services such as how genetic testing for Alzheimer's disease is implemented.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Honda (2003)	31,886 U.S. residents	To identify factors associated with awareness of genetic testing for cancer risk	Genetic testing for cancer susceptibility	Survey	14% of foreign-born respondents had heard of genetic testing for cancer risk compared to 86% of US-born respondents. After controlling for immigration status and other demographic characteristics, Caucasians were 2 times as likely as Latinos and 1.5 times as likely as African-Americans to have heard of genetic testing for cancer risk.	The lack of genetic testing information among racial and ethnic minorities and immigrants suggests more research is needed, as well as targeted health and genetics education and interventions.
Hughes et al. (1997)	407 African-American and Caucasian women aged 18-75 with at least one first degree relative with breast and/or ovarian cancer	To clarify levels of knowledge about BRCA 1 testing and inheritance of breast cancer among women with a family history of breast or ovarian cancer; to investigate differences by race; and to determine the relationship between knowledge and attitudes about testing, with a woman's testing history.	Breast-ovarian cancer susceptibility testing	Baseline interview on family history, genetic testing exposure, and knowledge about breast cancer genetics followed by random assignment to one of two educational interventions	Knowledge about breast cancer was greater among women who were married, Caucasians, or those with income greater than \$50,000. Previously tested women had greater knowledge about BRCA 1 testing and the inheritance of breast cancer. African-Americans and women with low education showed higher scores reflecting attitudes of the benefits of genetic testing. Attitudes about the limitations and risks of genetic testing were higher among women who were unmarried, with lower incomes, and without health insurance. Women at increased risk (particularly African-Americans) demonstrated positive attitudes about testing for breast/ovarian cancer.	There is some knowledge about BRCA 1 testing and the inheritance of breast cancer among women with a family history of breast and ovarian cancer, however more knowledge is needed. There are ethnic differences between African-American and Caucasian women regarding knowledge of and attitudes towards breast cancer testing and inheritance.
Jaeger et al. (1997)	1039 U.S. residents, including 52 Hispanics	To determine U.S. Hispanics' attitudes towards genetic testing	Genetic Testing	Nationwide telephone survey via random digit dialing	90% of Hispanic respondents approved of having genetic tests available that could tell them whether they or their children would be likely to have a serious or fatal disease. 71% would personally take such a test, 21% would not and 8%	Genetic testing for research purposes or in a clinical setting requires cultural sensitivity and competency among genetics professionals.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
					<p>were unsure.</p> <p>83% of respondents thought that it was a good thing for a healthy person to be able to find out how likely they were to get a serious health condition in the future, and 51% of those in favor cited prevention of the condition as their reason for this opinion.</p> <p>79% of Hispanic respondents said that they would be tested for cancer if they had a family history and 38% wanted to be tested even if they had no special risk factor for cancer. Hispanic respondents were less approving of “identifying persons” who would develop disease than non-Hispanics. 85% of Hispanic respondents indicated that they would like their physician to give their opinion on the pros and cons of genetic testing.</p>	
Kinney et al. (2001)	95 adult men and women in an African-American kindred with a BRCA1 mutation	To assess counseling and testing needs, including knowledge, attitudes, beliefs, psychological distress	Breast-ovarian cancer susceptibility testing	Interviews	Knowledge about genetics of breast/ovarian cancer was limited. 82% would seek testing if BRCA1 test available. Interest associated with younger age, prior history of breast or ovarian cancer, and having one or more 1 st -degree relative with breast/ovarian cancer	Genetic services should be tailored to attitudes, beliefs, educational level
Learman et al. (2003)	999 pregnant women including 98 African-Americans and 115 Latinas	To examine the attitudes of racially and ethnically diverse pregnant women about prenatal genetic testing for Down syndrome	Prenatal genetic testing for Down syndrome	Surveys	African-American and Latina women were more likely to report acceptance of a Down syndrome child in their community. All women indicated a preference for a child born without Down Syndrome. Few women	Despite some differences, race/ethnicity explained less than 15% of the variance in the measures. Great heterogeneity was demonstrated within racial and ethnic groups as well. Genetic educators and

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
					indicated that the influence of family or faith affected their decisions to engage in prenatal testing. Very similar attitudes about the importance of motherhood were reported between different racial and ethnic groups.	counselors must refrain from over-generalizing based on race and ethnicity.
Lerman et al. (1999)	228 Caucasian women and 70 African-American women with a family history of breast or ovarian cancer	To determine racial differences in response to two education strategies regarding BRCA1 genetic testing: a standard education model and education with counseling model.	BRCA1	Baseline telephone interview, which provided information about sociodemographic characteristics, numbers of relatives affected with cancer, and race. Outcome variables included changes from baseline to a 1 month follow-up in cancer-related distress and genetic testing intentions, as well as provision of a blood sample after the education session.	The effects of the interventions on testing intentions and willingness to provide a blood sample differed between African-American and Caucasian women. Among African-American women, education plus counseling yielded greater increases in intentions to be tested and provision of a blood sample than education only. This finding was independent of socioeconomic status and referral mechanisms. Caucasian women did not demonstrate differential effects. Both groups of women showed reductions in cancer-specific distress, with the smallest reduction shown among African-American women who received education plus counseling.	Pretest education and counseling may provide motivation for BRCA1 testing among low to moderate risk African American women. Additional research is needed to determine the methods, which lead alternate education strategies to influence testing behavior.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Martinez et al. (2003)	110 Latina women with a first-degree relative with breast cancer	To examine perceptions about BRCA1/2 genetic testing and effects of perceived risks and benefits on decision-making	Breast/ovarian cancer susceptibility testing	Questionnaires to assess acculturation, family history, perceived cancer risk, interest in and cons of testing	93% reported interest in undergoing genetic testing, 62% wanted to pursue testing as soon as possible. The more benefits perceived in finding out carrier status, the more likely they were to show interest in being tested for genetic susceptibility and the sooner they wanted to get tested.	The proportion of women interested in testing was significantly higher among those who considered themselves to be at higher risk for developing these diseases than among those who underestimated their lifetime risk. Higher levels of acculturation resulted in fewer perceived benefits. Longer exposure to U.S. culture and higher income levels resulted in significantly less interest in testing.
Matthews (2000)	21 African - American men and women in the Chicago area	To determine the factors that contribute to lower participation rates in genetic testing for cancer among African Americans compared to Caucasians.	Cancer susceptibility testing	Three two-hour focus groups of 5 to 8 people; prior to the focus groups, participants completed a study questionnaire, providing basic demographic information and information about factors influencing participation in genetic testing.	Quantitative data demonstrates factors that influence participation in genetic testing for cancer include: concerns about cancer risk for children or other family members, the effects of test results on other family members or themselves, the desire to know whether other family should be tested, and the need to plan for the future. Qualitative data shows that participation in genetic testing for cancer is affected by factors including the desire to prepare for children's future by "getting things in order", to help relatives and contribute to finding a cure for cancer, and to pursue appropriate preventive measures to "get rid of it". Reasons for not participating in genetic testing for cancer included: uncertainty of test results, the test being unnecessary, cultural mistrust, concerns about insurance, confidentiality, limited benefits	In an effort to improve access to and use of genetic testing among African Americans, increased education about screening guidelines and cancer control strategies are needed through outreach to the African American community. Additionally, the mistrust of medical research by many African Americans needs to be addressed. Educational and income levels can be an important determinants of attitudes, beliefs, and behaviors related to genetic testing behavior among African Americans.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Matthews (2000) (cont'd)					of participation (exploitation), emotional issues, unfamiliarity, fear of physicians and tests, expense of the test, and perceived connection between stress and the disease. Men and lower income participants were more likely to distrust the medical establishment and research.	
Mittman (1998)	African-American, and Russian Jewish immigrant communities of Baltimore	To provide genetic education to underserved communities and give attention to the community's extensive health care needs	Genetic services	Staff gathered relevant information about the communities, created a community advisory board in order to establish trust between the populations and health care providers, and held community fairs	101 outreach activities and 30 career education sessions took place over a 3-year period. More than 8,000 community residents participated in the activities. The number of African- Americans seen for genetic services increased by 50 percent. 75 Russian women and their partners elected to have Tay Sachs screening as compared to 4 prior to the initiation of the project.	Information about genetic services is better received, retained and used when the information is presented in a culturally sensitive and appropriate way that addresses the concerns and needs of communities. Providers must help empower diverse groups to participate in genetic services in order to improve understanding of the interventions and decrease feelings of alienation.
Mittman (1998)	Patients seen at San Francisco's county hospital who were primarily recent immigrants from the Asian Pacific (China, Hong Kong, Pacific Islands [the Philippines, Samoa, Tonga] and Southeast Asia) and from Central and South America.	To determine the effectiveness of cross-cultural reproductive genetic counseling to Asian Pacific and Latin American immigrants and make observations about cultural beliefs that related to perinatal genetic counseling.	Perinatal genetic services	Free perinatal genetic services were provided to 1,921 clients and 509 significant others over six years. Bilingual, bicultural counseling aides provided genetic counseling along with genetic counselors. Counselors and aides used large flipcharts, pamphlets written in Spanish and	The amniocentesis acceptance rate for all clients during the three-year project rose from 8% to 62%. Southeast Asian women had the lowest acceptance rate (41%) and Chinese women and the highest (61%). Post-counseling scores were significantly higher than pre counseling scores, which were low. Counseling aides helped reduce ethno cultural barriers to care such as eliciting more information on cultural beliefs related to health than the genetic counselors were able to elicit. Genetic counselors and aides made	Some cultural groups may not view prenatal diagnosis favorably, as it gives individuals more control over their circumstances, which can be viewed as intervening with nature. Therefore, decision-making about amniocentesis was heavily influenced by cultural beliefs. Some cultures may want more guidance in genetic counseling. Recent immigrants with low education levels showed increased knowledge after counseling, however all

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Mittman (1998) (cont'd)				Chinese, and a slide with show with simultaneous interpretation. Women who were pregnant and referred for counseling because of advanced maternal age were recruited to complete a 15 item pre and post counseling questionnaire to assess the effectiveness of cross cultural counseling.	observations regarding issues that counselors need to recognize such as: health beliefs; beliefs about blood and what causes illness in babies; lack of knowledge and views on Western obstetric care and interventions; risk perception; religious beliefs; use of traditional medical practices; norms regarding expression of emotion when hearing bad news; roles of males in medical decision making; reaction to nondirective counseling; perception of disability and disease burden, and understanding genetic transmission of disease.	recent immigrants may not be able to make fully informed decisions because reproductive genetic technologies may be entirely foreign to them. Whenever possible, genetic counselors should use bilingual and bicultural aides to work with recent immigrants of various backgrounds.
Olopade et al. (2003)	African-Americans	To provide an overview of the state of genetic testing for BRCA1 and BRCA2 among African-American women	Breast/ovarian cancer susceptibility testing	Literature review	The psychosocial implications of genetic testing for African Americans have not been well studied, so that high-risk African Americans may underestimate their risks of breast and ovarian cancer.	Access to genetic counseling and testing in a culturally sensitive research setting must remain a high priority before genetic testing can be disseminated in the community.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Penchaszadeh (2001)	Latinos	To examine demographics, social, economic, and cultural characteristics of Latinos as well as identify their primary health issues and barriers to access of health care.	Genetic services	Literature review	Some themes in the genetic counseling of Latinos: clients may fear that something is wrong with their future offspring or already born child, may expect genetic counselors to be directive rather than nondirective, may lack of desire particularly for prenatal diagnosis due to a naturally hopeful approach to childbearing, may lack prospective views on genetic risks due to a present orientation or difficult living conditions that may make their genetic risk seem lower or insignificant.	Genetic counselors need to be aware of the importance of both the nuclear and extended family in every day living and decision-making. Recommendations for improving genetic counseling of Latinos includes: use of an interpreter when unable to speak Spanish, or learning to speak Spanish, willingness to undertake a flexible nondirective approach that gives non coercive informed advice but also empowers patient decision making.
Penchaszadeh and Puñales - Morejon (1998)	Latinos	To describe the demographics and health profile of the U.S. Latino population		Case studies are presented to represent the great diversity among Latino Americans.	Latinos are a diverse group of people from various cultural, socioeconomic, and traditional backgrounds.	There are some common traditions and health beliefs that are helpful to understand in order to interact with the Latino population within the context of genetic services and the broader health care system.

Authors	Population	Study Objectives	Genetic Test/ Technology	Methods	Results	Conclusions
Wertz (1998)	988 U.S. members of general public, including 111 African-Americans	To compare survey results of African-American members of the general public with all other respondents about ethical beliefs related to genetics	Various	15 minute door-to-door survey	Response rate of 99% for the general public. Half of the responses given to the 50 survey questions were significantly different among African-Americans than all other responses. Generally, African-Americans expressed more concern about privacy issues related to their blood relatives and partners but less concern about privacy issues related to individuals. African-Americans were more likely to desire directive counseling from physicians. Questions related to using new or controversial reproductive technologies were more likely to be responded to with "I don't know" by African Americans. Compared to other participants, African American responses were less oriented towards autonomy. African Americans were less likely than other respondents to indicate they would abort a child for 5 of 6 congenital conditions.	African-Americans may have more family oriented as opposed to individualistic views and views that are more paternalistic than egalitarian. No differences were demonstrated in responses related to confidentiality vs. public safety, reports of employment and/insurance discrimination, genetic testing of children, preconception sex selection, premarital vs. prenatal diagnosis, workplace testing, and abortion after prenatal diagnosis.