

Epidemiologic Research in Hispanic Populations Opportunities, Barriers and Solutions

Working Group, July 31-August 1, 2003, Bethesda, MD

Summary and Recommendations

I. Objectives of the Work Group

The objectives of this work group were to identify research questions, barriers to research, and methodological solutions to research problems related to the study of cardiovascular, lung, blood and sleep disorders in Hispanics. The Hispanic population in the United States is increasing in size; is diverse in culture, backgrounds and countries of origin; is experiencing unique influences from social and behavioral acculturation to the U.S.; is reported nationally to have lower rates of heart disease; is reported to have increased prevalence of diabetes and asthma; and is generally poorer and less educated. Consequently, Hispanic populations provide a unique resource to study research questions not readily addressed by other populations in the U.S. The work group identified critical research questions in this growing segment of the U.S. population. Barriers to research in Hispanics were identified and solutions proposed.

II. Background on Hispanic Populations in the U.S.

The Hispanic population in the U.S. has grown considerably in recent years, and in 2000, persons of Hispanic origin comprised nearly 13% of the U.S. population. In 2003, the Hispanic population became the largest minority population in the U.S. There have been large increases in population from all of the primary countries of origin. In Mexican Americans, the population sizes in 1990 and 2000 were, respectively 13 and 21 million. There is a marked difference in the age distribution of those who were U.S. born vs those born outside of the U.S., with native born showing a much younger age distribution. Nearly 20% of the U.S. born Hispanics were less than 10 years of age, while about 2% of foreign born were in that group. Immigrants tend to be older and in the work force. By 2050, the Hispanic population is expected to triple, while the non-Hispanic white population is projected to increase by 8%.

The economic status of the Hispanic population is lower than that of non-Hispanic whites. For those age 65 or over, 21% of Hispanic men are in poverty as compared to 6% of non-Hispanic white men. For women age 65 or over, the percent in poverty is 26% for Hispanics and 12% for non-Hispanic whites. Measures of wealth accumulation show large average differences, with non-Hispanic white households (male or couple-headed) of over \$300,000 while those of Mexican origin show less than \$100,000. The percent of population (age 51-61) with no health insurance is less than 10% for non-Hispanic whites, but slightly more than 40% for those of Mexican origin.

This large population growth and economic disadvantage will have important implications for Hispanic health and for health care services. While emigrants who leave their country tend to be healthier than those who remain behind, it is critical to understand how this healthier status can be maintained, how new immigrants can adopt the healthy, rather than the unhealthy, behaviors of their new country, and how they can successfully negotiate the health care system and utilize the health care services available to them.

III. Hispanic Health in the U.S. and the Hispanic Paradox

National mortality rates imply that Hispanics have lower age-adjusted mortality rates than non-Hispanic whites or non-Hispanic blacks. Of the three major Hispanic groups, Puerto Ricans appear to have the highest age-adjusted mortality rates and Cuban Americans the lowest. The apparent Hispanic advantage in mortality holds for both genders and for all Hispanic subgroups including those who are age 65 years or more. Low mortality from cardiovascular diseases, and major cancers such as lung, colon, breast, and prostate has been reported. However, there are higher mortality rates from cancers of the stomach, liver, gallbladder, and cervix. There are also higher mortality rates from diabetes and liver diseases in many of the Hispanic groups. The population studies of Mexican Americans consistently find a high prevalence of type 2 diabetes. The highest prevalence of self-reported physician diagnosed diabetes is in the commonwealth of Puerto Rico when compared with the rest of the nation. Other national studies confirm the high prevalence of diabetes among Mexican Americans and Puerto Ricans living on the mainland. In contrast to the national mortality results, the San Antonio Heart Study did not find that Mexican Americans had less overall mortality or mortality from heart disease than did non-Hispanic whites.

Risk factors for heart disease, comparing Hispanics and non-Hispanics, are best compared using national surveys, although regional surveys often provide unique information. There are no major differences in cholesterol and blood pressure, but Hispanics

smoke fewer cigarettes per day than non-Hispanic whites. However, there are more Hispanic men currently smoking than observed in non-Hispanic white men. Type 2 diabetes, as mentioned above, is significantly higher in the Hispanic groups.

The "Hispanic paradox" states that based on the observation that some risk factors are elevated and that there is social and economic disadvantage, one would expect a higher mortality and morbidity in Hispanic populations. However, national mortality data suggest lower mortality for Hispanics, though some population-based studies do not support this finding. If there is health advantage, it is important to understand the source of the advantage, and to develop preventive efforts so that the health advantage is maintained, and not lost during the acculturation process. Conversely, if the apparent health advantage is spurious, it is obviously important to document this fact.

IV. Research Opportunities in Hispanic Populations

A. Acculturation and Immigration

One of the most unique features of Hispanic populations is the wide range of immigration and acculturation experiences. Since culture is a key determinant of health beliefs and behaviors, social and psychological resources, and health care utilization, the transition of Hispanic populations from one culture to another provides a natural experiment in describing and understanding the processes and consequences of cultural change. These consequences can be both beneficial and harmful to varying degrees. By understanding the components of cultural adaptation which influence health and disease, modifiable factors can be identified, populations at high risk can be targeted, and interventions can be tailored to fit the specific components affecting risk. While there are the more obvious components of acculturation such as changing diet and psychological consequences of living in a society with different norms, there are less evident components such as changing beliefs about disease and the ability or inability to negotiate the medical care system.

Current measurements of acculturation are generally non-specific with a major component the assessment of language use. There are, however, many other dimensions of acculturation that need to be incorporated into measurements and defined clearly within the specific cultural context. These include assessment of assimilation into the structure of the society (cliques, clubs and institutions or the functional integration into the broader society); the value placed on preserving the culture of origin as compared to the new culture; the attitude toward family structures, all of which could influence health in different ways. Appropriate measurements require knowledge of the culture of origin which is often lacking, as well as the culture actually experienced by the immigrant. Measurement techniques need to be developed to identify those components of acculturation which influence health. Also, the specific mediators between acculturation and health need to be identified and quantitated.

B. Psychosocial and Behavioral

The "Hispanic paradox" described earlier has led to speculation that there may be some protective behavioral or psychosocial component which makes the Hispanic populations more resilient against coronary heart disease. The psychological hypotheses have suggested that spirituality, adaptive coping behaviors and adoption of healthy behaviors may be protective, while "John Henryism" (the pressure to succeed at all costs) may have detrimental effects. Social hypotheses have proposed that family norms and strong social support systems may be particularly protective. There are also negative family forces and data show differences among Hispanic groups. The prevalence of unmarried mothers is 60% among Puerto Ricans, 42% among Central and South Americans, 40% among Mexican Americans, and 25% among Cuban Americans. Cultural hypotheses have postulated that positive community norms and values, health beliefs, healthy convictions, and traditionalism are beneficial to health. These components, however, have not been fully examined within the context of Hispanic health. The paradox itself needs to be examined since there are conflicting results on whether it exists. Nevertheless, the behavioral and psychological components listed above do provide a unique opportunity to study these influences on disease.

Ethnicity involves a sense of "belongingness" with a group of people that share a common historical origin. Both ethnic and minority identity have the common motive of banding together, for promoting a sense of connectedness to others for comfort and survival. Minority cultures may be described as relational cultures, because many members give significant attention to the nature and quality of relationship with significant others. Relational factors present unspoken and subtle, yet powerful messages that influence behavior. A cultural variable such as ethnic pride, level of acculturation, and traditionalism may operate as moderators or mediators of effect between an environmental condition and a health outcome.

Within the Hispanic context, it is essential to integrate cultural factors into classic health behavior models. How may the Latino cultural concepts of *familialism* (the high significance placed on the family unit), *collectivism* (the importance of friends and extended family in helping to make decisions in health), *simpatia* (the need for smooth interpersonal relationships in which criticism and confrontation are discouraged), *personalismo* (the preference for relationships with members of the in-group), and *respeto* (the need

to maintain one's personal integrity and allow for face-saving strategies) operate as additional components that may add predictive strength to any of the classical health behavior and motivation models established under mainstream American health psychology? Beyond simple acculturation, there are opportunities within Hispanic populations to study the relationship of cultural orientation and healthy lifestyle to CHD risk and outcome. What elements of traditional-agrarian lifestyle may protect against CHD? Does a modernist-urbanized lifestyle only confer risk, or does it offer protection? Does "John Henryism" as observed among African-Americans also apply to Hispanics as a risk condition for CHD and hypertension?

C. Nutrition

One of the more obvious changes that can occur in the transition of residence to a new culture is the change in diet. Though evidence is limited, there is some information which suggests that Puerto Rican diets become healthier as they acculturate to the mainland, while Mexican American diets become less healthy in the U.S. as compared to their diets in Mexico. There are significant differences in the types of foods eaten by Puerto Ricans, Mexican Americans and Cubans. From the Hispanic HANES (1982-1984) population over age 64, tortillas are eaten by Mexican Americans but rarely consumed by the other groups. Rice is more often eaten by Puerto Ricans and Cubans but much less often by Mexican Americans. There are also differences among these groups in the consumption of beef, pork, beans, and eggs.

The changes in food consumption in the acculturation process can be substantial, and provide a natural experiment to quantify the change and to assess the impact on health and disease. While it is difficult to obtain dietary information prior to immigration, comparisons can be made among recent and long term immigrants, those who have evidence of extensive acculturation as compared to those who remain more traditional. The diets of the various Hispanic groups can be quite different, and there is an opportunity to quantify these differences and estimate the differential impact on health in the different groups. In addition to the standard hypotheses regarding dietary fat and atherosclerosis, and dietary salt and hypertension, other dietary hypotheses can be addressed. These include hypotheses regarding glycemic load and diabetes, antioxidant vitamins/phytochemicals and heart disease, B vitamins and heart disease, and the interaction between genes and physiologic responses to diet.

The greatest challenge in addressing nutrient hypotheses is to overcome the substantial difficulties in dietary assessment. The usual problems in assessment are compounded by the added diversity of Hispanic foods, and the variation among the Hispanic groups and the varied manner in which food dishes are prepared and named. While a 24-hour dietary recall can capture the specific foods eaten during that period, multiple recalls are necessary for each person to minimize the day-to-day variation in food intake. Food frequency recalls are cost-efficient but it is essential that they are constructed carefully to include the full range of foods, preparation techniques, recipes and portion sizes. Utilization of food frequency questions designed for U.S. populations are inadequate for this purpose without extensive modification and additions, and validation. The assessment can be improved by a combination of instruments, for example, to use at least 3 repeated 24-hour recalls along with a food frequency recall.

D. Obesity and Physical Activity

Obesity in Hispanic populations, as in all other ethnic groups in the U.S., is increasing and worsening as a significant health problem. In 2002, the age-adjusted prevalence of obesity among adults age 20 or more in men was 26% for Mexican Americans and 24% for non-Hispanic whites. For women the comparable percentages were 26% and 21%. In children from NHANES III, Mexican American boys had a higher prevalence of obesity than either non-Hispanic whites or non-Hispanic blacks. In girls, the prevalence of obesity in Hispanics was higher than that in non-Hispanic whites, but less than that in non-Hispanic blacks. The highest prevalence rates in all these groups was among Hispanic boys, age 6-11 years old, with 17.4% in the obese classification.

The controllable influences of obesity involve the balance in energy from dietary intake and the expenditure from physical activity. Measurement of energy expenditure in Hispanic populations is complicated by the observation that levels of work activity, which are often not measured, may be high relative to leisure time activity. Additionally, leisure activity needs to be viewed in a different cultural context (e.g., may be discouraged) when considering populations with high levels of work activity. However, as levels of work activity change in response to acculturation and improved education, the consequences to obesity may be significant. The percent of the population which does not partake in leisure-time activity is highest for Mexican Americans as compared to non-Hispanic whites at all levels of income. In Hispanics, the percent with no leisure activity is highest for those at the lowest levels of income, decreases at levels of middle income, but increases again for those of highest income. Among Mexican Americans, the percent with no leisure-time activity is highest among the least acculturated (Spanish speaking) and lowest among the most acculturated (English speaking). Research in Hispanic populations will need to carefully assess leisure and work activity among adults, and evaluate the activity and sedentary patterns of children.

E. Diabetes

Type 2 diabetes is consistently recognized as being highly prevalent in Hispanic populations. There is regional and "country of

origin" variation, with some of the highest prevalence rates in the lower Rio Grande Valley of Texas. Prevalence rates can reach up to 50% of the population above age 45 years. The causes of these high rates are not well understood, but genetic admixture with Native American population groups is likely to play a role. In these populations, there are incorrect assumptions that diabetics are not compliant with medical advice and thus cannot lower their blood glucose or Hb A1c. Experience has shown that with concerted effort to communicate with the community to establish trust and confidence, and to understand and use culturally appropriate methods, diabetes control can be significantly improved. The lesson for epidemiologic research is that successful entry into a community requires extensive effort to learn and apply methods appropriate to the cultural norms, and to extend effort and resources, in advance of the study, to gain the community's trust and confidence.

The high prevalence of type 2 diabetes provides opportunities for research. The higher prevalence means that required sample sizes are more likely to be met. Known factors associated with diabetes can be studied, again because of their higher prevalence (e.g., obesity). The differing genetic admixtures of the various Hispanic groups can provide opportunities to investigate genetic influences and gene by environment interactions. The variation in diet among Hispanic groups and individuals can be used to assess dietary influences in diabetics. Studies in Hispanic children can investigate the increasing onset of type 2 diabetes in children and identify factors related to childhood onset.

F. Asthma

Data on the prevalence of asthma in Hispanics is sparse, and often dependent upon a medical history (which can be biased by availability and use of medical care services) and by mortality (which only accounts for the most severe fatal cases). A more carefully constructed survey of asthma in North Brooklyn shows striking difference in asthma prevalence between Puerto Ricans and Dominicans who live in the same areas. The prevalence of asthma in Puerto Ricans was 13.2% but only 5.3% in Dominicans. These differences were not explained by education, household size, household location, use of home remedies, or country where education was completed. The excess asthma in Puerto Ricans is also seen in mortality statistics for asthma. The death rate from asthma for Puerto Ricans in the Northeastern U.S. is double that for Cubans and other Hispanics in the Northeast. The medical history data from NHANES suggests that asthma in Hispanic groups other than Puerto Ricans is similar to that in non-Hispanic whites. The hypothesized risk factors for asthma include genetic susceptibility, gestational age, lower respiratory tract illnesses, environmental factors, nutrition factors, obesity and physical activity. There is a need to understand the differing asthma rates among the Hispanic subgroups which may lead to a further understanding of the role that risk factors play in the development of this disease.

G. Genetics

While it is quite clear that single gene effects are very unlikely to play a major role in the cause of heart, lung, blood, and sleep disorders, it is equally clear that susceptibility to many of these diseases, with responses to environmental factors, are genetically mediated. There may be genetic contributions to disease susceptibility that are specific to Hispanics and that require specific therapies. There may also be genes that are important in all populations but that are easier to detect in Hispanics. At the present time, the answers to the above hypotheses are unknown but need investigation.

Much of the genetic research in Hispanics has concentrated on Mexican Americans and on genetic influences on diabetes and obesity. In the San Antonio Family Heart Study, diabetes is 2 to 3 times higher in Mexican Americans than in non-Hispanic whites and 25-35% are severely overweight. The family study approach is most efficient with large pedigrees, and utilizing genome scans of known markers (usually 400 or more), localization of potential "risk factor genes" on the chromosomes can be done through linkage analysis. Narrowing the chromosomal regions implicated by linkage studies is daunting and recourse is often made to studying positional candidate genes in the linked regions, identifying all common single nucleotide polymorphisms (SNPs) in a candidate gene, and analyzing all of the SNPs simultaneously to identify the SNP or SNPs most likely to be influencing the trait. In addition, the effects of genes are evaluated as to whether their effects are influenced by other factors or by other genes.

Since family studies are most efficient with large pedigrees which to some extent conflicts with the primary goals of population epidemiology studies, it is most advisable to develop family studies after the core epidemiology population has been identified. In the primary epidemiology study, information about pedigrees should be obtained, and DNA collected and stored. Because the various Hispanic populations have varying admixtures from indigenous populations, and because Hispanic populations have varying cultural, behavioral, and environmental influences, opportunities exist to discover susceptibility genes and identify environmental interactions.

V. Recommendations

Population Identification and Selection for Study

- Because of the diversity of culture, countries of origin, genetics and acculturation, research should be conducted on Mexican Americans, Puerto Ricans, Cuban Americans, and Central/South Americans in sufficient sample sizes for each group.
- Because of regional and local influences on behavior, social and economic factors, changing population composition, and external exposures, multicenter studies should be done, with populations selected in diverse regions of the country, including rural and urban settings, border and non-border settings, and communities of varying population densities of Hispanic origin.
- Because of significant influences of immigration and acculturation, populations should include those with varying lengths of residence in the U.S. The impact of movement within the U.S. and return to country of origin needs to be studied.
- Because little is known about the health outcomes, risk factors, and behaviors in the countries of origin, studies should be done within these countries.

Population Recruitment

- Strong community support and input is required for high participant recruitment.
- Prior to study implementation, adequate time and commitment must be given to develop knowledge of the community, to establish liaisons with the community, and to gain a relationship of trust with the community.
- Participant recruitment varies by community, neighborhood, and social and economic status. Resources and labor will vary and commitment is needed to support an effective level of effort.
- Participants residing in barrios generally need additional recruitment effort and may be influenced by safety, poorer health of individuals, and difficulty in finding time to participate. Repeated attempts and incentives are needed.

Resources, Materials and Methodology for Hispanic Research

- Data collection procedures and questionnaires are only minimally developed for use in Hispanic populations. In addition to language, the appropriate cultural and community context needs to be considered in development of these instruments. Resources need to be expended to develop new methods and to expand use of existing methods appropriate to the various Hispanic population groups.
- A repository of available culturally appropriate research instruments and protocols applicable to Hispanic populations should be developed and maintained.
- Research on questionnaire development relevant to Hispanic populations is needed in the following areas:
 - Physical activity.
 - Health and cultural beliefs with particular attention to incorrect stereotypes and misconceptions.
 - Acculturation and traditional beliefs with attention to development and validation of measures not solely dependent upon language.
 - Diet
- Personnel resources should include professionals involved in intervention research so that the study design and content can provide relevant data for future intervention studies.
- To better understand Hispanic health and risk in the nation, maximal use of national surveys and data needs to be implemented. Comparative analysis of U.S. surveys (NHANES) should be conducted in conjunction with national surveys in other countries (e.g., Mexico). Morbidity and mortality follow-up of Hispanic HANES and NHANES III should be funded and conducted to provide national estimates of disease and death rates among Hispanic populations. Inaccurate classification of Hispanic status on death certificates leads to downward bias in death rates, and improving this ascertainment and classification process is a priority.
- Research in Hispanic populations should include the training of professionals of Hispanic origin. Both Hispanic and non-Hispanic researchers need to be trained in cultural issues and norms relevant to the populations being studied.

Community Support

- Community support is critical for any successful recruitment and retention.
- Studies in Hispanic populations must provide a contribution back to the community. The contribution can include study results, community newsletters, a presence at community functions, and information about how the research can benefit their health as well as that of their children. Both the study and community can benefit from using community workers in the conduct of the study.
- Studies will need to address, in advance, how to communicate study information back to participants, and how to handle health problems discovered in participants who do not have access to health care services.

Needed Research (in priority order)

- **The "Hispanic Paradox" needs to be evaluated in all Hispanic groups.** Though the data are not consistent, evidence from national studies describe lower mortality from many causes, including CHD, in Hispanics compared to non-Hispanics even though Hispanics have increased prevalence of type 2 diabetes, poorer economic profiles, and less access to health care. These existing estimates may be biased due to methodological problems. In particular, there is evidence that Hispanic deaths are undercounted, in part due to ethnic misclassification, in national mortality statistics, including the National Death Index. A high priority should be attached to efforts to correct these deficiencies. Valid estimates of incident morbidity and mortality rates are urgently needed for the Hispanic population groups to confirm or reject the "Hispanic paradox" and whether difference exist among subgroups. Longitudinal cohort studies of sufficient sample size among Hispanics are needed to definitively answer this question. Clearly, health policy with respect to Hispanics is unlikely to be optimal if it is widely believed that their mortality, both all-cause and cause-specific, is lower than in the general population when, in fact, it is higher! Follow-up of HHANES and NHANES III, as recommended above, could contribute substantially to clarifying the true mortality experience of Hispanics.
- **Studies in Hispanic children should be undertaken to identify risk factors for diabetes, asthma and obesity, to identify trends over time in these diseases, and to identify prevention efforts.** Preliminary evidence suggests that diabetes, asthma, and obesity are significant health problems for Hispanic children. Inclusion of children can enhance recruitment and retention.
- **Research should be undertaken to determine the genetic, environmental and other factors, including fetal exposure, that may contribute to differences in asthma among Hispanic groups.** Data show that asthma is significantly higher among Puerto Ricans as compared to other Hispanic groups.
- **Research needs to be undertaken to better define and measure obesity in Hispanics (fat mass vs. muscle mass), to seek genes and identify gene-environmental interactions of particular importance for obesity in Hispanic populations, and to better understand the interrelationship of obesity, diabetes (which is so highly prevalent in the Hispanic populations), and other CVD risk factors, including sleep disorders.**
- **Research is needed to identify the mechanisms that link acculturation**
 - to physical health, including obesity, diabetes, asthma, cardiovascular disease/risk factors and sleep disorders;
 - to mental health, particularly depression;
 - to social behaviors (including social interaction within families and the larger society),
 - to health behaviors (such as those relating to utilization of health care resources, nutrition and smoking); and
 - to communication of disease risk.

Hispanic populations encompass a full range of immigrant populations, from very recent immigrants to persons whose families have lived in the U.S. for generations. Consequently, Hispanic populations provide unique research opportunities to study the links between acculturation and health outcomes. Acculturation processes need to be identified and mechanisms for the role that acculturation plays in both improving and harming health need to be studied.

- **Research is needed on the impact that community and neighborhood have on individual health among Hispanics, including factors such as density and proximity to the U.S. border, which may be supportive and/or harmful for healthy behaviors.** Communities provide unique environments for immigrant populations, providing familiar language, markets, religious activities, and social support. What are the resources for integration into the larger society with respect to health care access, education, and employment? Are there unique stress factors for immigrant populations related to the type of community or neighborhood in which they live?

- **Epidemiology studies in Hispanics should capture information and materials relevant to genetic research including full family pedigree information and histories, and DNA.** Genetic research involving recruitment and examination of large pedigrees, though needed, are not essential for initial efforts in developing epidemiology studies. Since the Hispanic populations are from many different countries, there are differences in genetic admixture with the indigenous populations which will be relevant to genetic research. When identified by other studies, analyses of candidate genes and gene-environmental interactions will provide an important contribution.

VI. Members of the Working Group

Co-chairs of the working group

Amelie Ramirez, Dr. P.H., Baylor College of Medicine, Houston, TX

Michael Stern, M.D., University of Texas Health Science Center, San Antonio, TX

Members

Ronald J. Angel, Ph.D., University of Texas at Austin, TX

Sharon Brown, RN, Ph.D., University of Texas at Austin, TX

Felipe Gonzalez Castro, Ph.D., Arizona State University, Tucson, AZ

David B. Coultas, M.D., University of Florida, Jacksonville, FL

Carlos Crespo, Dr. P.H., State University of New York, Buffalo, NY

Helen Hazuda, Ph.D., University of Texas Health Science Center, San Antonio, TX

Jean MacCluer, Ph.D., Southwest Foundation for Biomedical Research, San Antonio, TX

Kyriakos Markides, Ph.D., University of Texas Medical Branch, Galveston, TX

Lucina Suarez, Ph.D., Texas Department of Health, Austin, TX

Greg Talavera, M.D., MPH, San Diego State University, San Diego, CA

Katherine Tucker, Ph.D., Tufts University, Boston, MA

VII. NHLBI Planning Group

Division of Epidemiology and Clinical Applications

Paul Sorlie, Cay Loria, Cheryl Jennings, Ana Gonzalez, Paula Einhorn

Division of Heart and Vascular Diseases

Winnie Barouch

Division of Lung Diseases

Hector Ortega, Sri Ram

Division of Blood Diseases and Resources

Duane Bonds

Office of Prevention, Education and Control

Matilde Alvarado

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