

The Development of a Relevant and Comprehensive Research Agenda to Improve Hispanic Health

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Synopsis

The development of an appropriate research agenda for Hispanics requires progress in three

THE DEVELOPMENT of a relevant and comprehensive behavioral and biomedical research agenda for Hispanics involves the joint actions of individual people, institutions, and government agencies. At the most basic level is the need to plan, develop, and implement programs that train, equip, and support both Hispanic and non-Hispanic researchers.

A research agenda must address existing needs in at least three areas: (a) research infrastructure, that is, issues central to the design, implementation, and support of research programs, such as funding, training of Latino personnel, and information dissemination; (b) appropriate research instrumentation that provides valid and reliable information about Hispanics; and (c) definition of research priority areas based on the prevalence or high incidence of health-related problems among Hispanics.

It is important to note that the successful development and implementation of a Latino research agenda depends on the following factors: areas: (a) developing an appropriate research infrastructure, (b) increasing the availability of appropriate research instrumentation, and (c) identifying and assigning priority areas.

In addition, a Latino health research agenda must identify mechanisms for increasing the number of trained Hispanic researchers and the number of Latino professional staff members at the Department of Health and Human Services.

It is recommended that an Office of Hispanic Health be established within the Office of Minority Health at the Department to oversee the implementation of the recommendations made as part of the Surgeon General's National Hispanic Health Initiative.

• the availability of improved data collection methods and research instruments,

• the participation of Hispanic researchers, and • increased Latino professional staff representation at policy and program levels within the Department of Health and Human Services (HHS).

Likewise, the development of an appropriate research agenda relevant to Hispanics must include an analysis of the realities and needs of all Latinos, including residents of Puerto Rico who are affected by the policies and initiatives of HHS and other agencies.

Understanding the Problem

Deterrents to the development of a valid and comprehensive research agenda for Hispanics are the lack of an appropriate research infrastructure, the dearth of appropriate data and research instrumentation, and difficulties in identifying and assigning priority areas. Lack of research infrastructure. More than 6 years ago, the Office of the Surgeon General at HHS determined that there was an alarming lack of data about the health status of Hispanics and of other ethnic or racial minorities; yet the intervening years have not produced a measurable increase in the knowledge base. The funding level for HHS-sponsored Latino health research is disproportionately low. Less than 2 percent of HHS research funding is spent on Hispanic health issues and in support of Latino researchers (1).

Some institutions, such as the National Cancer Institute, have made isolated efforts to develop initiatives targeting Hispanics. These efforts, however, are often insufficiently funded and inadequately staffed. Other institutions, such as the National Institute on Alcohol Abuse and Alcoholism, have sought requests for research funding specifically targeting ethnic or racial minorities. These efforts, too, have had limited funding and have been sporadic in nature. Lack of sufficient and consistent funding seems to be a major deterrent to the development of a research agenda for Hispanics.

A problem directly related to the lack of adequate funding is the lack of appropriate representation of Latinos in the groups that establish funding priorities or make funding decisions. Few Hispanics occupy positions of influence within Public Health Service (PHS) agencies or hold jobs at the various levels of national advisory councils. Unofficial data provided by PHS officials show that in 1992 only 83 of the 2.342 members (3.5 percent) of Initial Review Groups (IRGs) that screen proposals for research funding are Latino. This lack of representation of Hispanics among review group members implies that, in general, IRGs cannot properly judge the cultural appropriateness (2), sensitivity, or competence of proposals. Similarly, there is inadequate representation of Latinos within HHS itself, where Hispanics constitute less than 2 percent of professionals with doctoral degrees.

Only a very small number of researchers (Hispanic and non-Hispanic) are trained properly to carry out culturally appropriate health-related research among Latinos. Hispanics are chronically underrepresented in the health professions (3), and the small number of Latinos currently in graduate or professional schools will do little to ameliorate this problem. This difficulty in developing a core base of trained Latino professionals is especially salient because the number of doctoral degrees awarded to Hispanics in the life sciences continues to be small (241 in 1990), according to a private

communication from the American Council of Education on July 17, 1992.

Although some non-Hispanic researchers working in collaboration with Hispanics understand the issues involved in cross-cultural research, many researchers are currently collecting data on Latinos without paying attention to such methodological issues as the development of culturally appropriate research instrumentation, appropriate sampling procedures, and the identification of variables that moderate data interpretation (4).

Another problem is the lack of comprehensive health care data repositories and data bases on Hispanics. Although some findings about Latinos have been published by major health care journals, a significant amount of information is available only through program reports and government documents that are usually not abstracted by the major data bases. This problem of information dissemination makes it difficult for researchers to identify baseline information and to build on the work of others. Additionally, the sampling of Latino subgroups in major national health data systems is inadequate, thus rendering these systems ineffective in adequately documenting the health status of Hispanics.

Dearth of research instrumentation. The availability of culturally appropriate research instruments (4) is essential to the development of a research agenda. A large number of research projects that include Latinos are currently being carried out without adequate attention to the culture of the respondents; their group-specific attitudes, perceptions, expectations, norms and values; or the requirements of appropriate linguistic adaptation. Overall, the lack of appropriate research instrumentation limits the availability of valid and reliable data and deters the development of further research.

Priority areas of needed research. Although various individuals and institutions have proposed priority areas for research on Hispanics (1, 5-8), few efforts have been made to develop a comprehensive research agenda. Research is needed to explore the role of certain group-specific characteristics of Latinos and how these characteristics affect health status. There are few studies that focus on the role of acculturation on Hispanic health (9-12) and on the possible effects of poverty on health-related behaviors. The identification of culture-specific beliefs and practices has been limited to areas such as cigarette smoking or cancer.

Although the development and evaluation of culturally appropriate interventions are of paramount importance (2), little effort has been directed in this area. Further research is needed to identify the most effective characteristics of behavior change interveners and of the optimal channels and sources for dissemination of an intervention. Likewise, it is essential to study the possible role of national origin or background on the health status of Hispanics (13) and to identify reasons for observed differences between and among the various Latino subgroups. The effects that socioeconomic backgrounds and the degree of acculturation have on health practices-as well as on the prevalence of certain conditions or illnesses-also need to be explored.

The second aspect to be considered in developing priority areas for research is an examination of those conditions that Hispanics seem to be overafflicted by or at particular risk of. Latinos tend to be overrepresented in certain work environments that carry specific health risks, such as migrant agricultural work, high-output assembly factories, and textile industries, that may in turn interact with the institutional characteristics of the health care of Hispanics (3).

Although the literature is sparse and incomplete, recent findings suggest that particular attention must be given to studying issues such as prenatal and perinatal care, diabetes, HIV infection, cancer, substance abuse including the use of ethanol and tobacco, violence and accidents, heart disease, and depression (3,5,7,8,10,12,14-18). In all these cases, Hispanics are either at great risk for the condition or show prevalence rates that are higher than one would expect in terms of their demographic characteristics or the size of the population, or both.

Summary of Recommendations

The literature on Hispanic health and most integrative reports (3,5,7,9,10) have consistently mentioned the need to develop a research agenda to guide research programs and help shape funding priorities at the Federal and State levels. The literature has also consistently cited the need to solve the research infrastructure problems mentioned previously and to promote a better understanding of situational circumstances—such as acculturation, national background, or socioeconomic status—that affect the health status of Hispanics. As might be expected, there are differences in the specific topics emphasized in various reports, but a common theme is the need for group-specific programs of research that receive adequate funding and that are carried out in a culturally competent fashion.

The following suggested strategies, to be carried out by private and public agencies at the local, State, and Federal levels are based on the information summarized previously. These strategies are presented in no particular order because they are all considered essential in achieving the goals of Healthy People 2000, the national health objectives.

Improve the research infrastructure.

Increase Hispanic representation in health-related research.

• Provide orientation to PHS program staff members on Latino health and related methodological issues.

• Instruct members of IRGs on the procedures required for culturally competent research that targets Hispanics and on the evaluation of proposals that include specific points assigned for appropriate sampling, instrumentation, methodology, and cultural sensitivity in the development of research protocols.

• To prepare IRGs to be competent in the evaluation of Latino research, provide appropriate training and guidelines to reviewers. This initiative is consistent with the recent National Institutes of Health guidelines for including women and minorities in study populations.

Increase the number of Latino researchers.

Develop specific support programs within PHS for pre- and post-doctoral training of Hispanics in behavioral and biomedical research to eliminate their underrepresentation in health-related research.
Develop programs directed at Hispanic researchers to allow them to become better equipped and to improve methodological expertise in health-related research.

• Target and intensify efforts to recruit Latinos into existing research and training programs of PHS.

• Develop and fund distinguished research career programs within PHS to allow Hispanic researchers to concentrate on research, writing, and mentoring and to free them from the multiple requirements and expectations commonly faced by minority academicians.

• Conduct grantsmanship workshops like those developed by the Hispanic Cancer Control Program at the National Cancer Institute, in which Hispanic researchers have the opportunity to learn proposal-writing strategies and have their preproposals reviewed by an ad hoc IRG. These programs must be made available in the National Institutes of Health, the Centers for Disease Control and Prevention, and other Federal agencies concerned with health issues.

• Expand and evaluate specific initiatives within the Department of Education and the National Science Foundation to ensure that Latino middle and high school students take courses essential for entering science careers.

• Assess results of programs such as Minority Biomedical Research Supplements, Minority Access to Research Careers, and the Minority High School Apprenticeship Program with respect to Latino students.

• Encourage professional associations to stimulate the involvement of Hispanic students in research careers.

Develop special initiatives to fund grants submitted by new and established Latino investigators.
Increase and enhance the institutional capacity for Hispanic health research through establishment of Latino health research centers and through support of individual Hispanic investigators.

Improve the training and cross-cultural competence of non-Hispanic researchers.

• Establish requirements by regional and professional accreditation agencies that Hispanic health research issues be incorporated into curriculums.

• Develop and institute courses, seminars, and conferences by educational, institutional, and professional associations and PHS on methods for conducting research in Latino populations.

Increase the number of Hispanics participating in the funding process.

• Survey the national agencies concerned with Latino health issues, researchers, universities, and research institutes every year to identify qualified people who may be willing to serve in this capacity. Results of those surveys should be published in a directory, updated yearly, and made available to Federal and State agencies funding health-related research.

• Include Latino representation on IRGs within technical evaluation groups, national advisory councils, and scientific advisory boards.

• Expand short-term service initiatives that allow Hispanic researchers and academicians to serve

within PHS without severing ties with their home institutions.

• Implement special efforts to recruit, retain, and promote Latinos at all levels of the scientific and program staff of PHS.

Improve communication and interaction among Hispanic scientists.

• Centralize and expand the existing PHS databank on Latino researchers and on non-Hispanics conducting research on Hispanic populations.

• Encourage professional associations to facilitate networking among Latino researchers.

Improve the dissemination and availability of data and culturally appropriate materials.

• Develop Federal programs to fund research to test the usefulness of current instruments and to develop new culturally appropriate instruments that meet applicable standards of validity and reliability.

• Provide funding through PHS for a repository of Hispanic health-related instruments. This repository must be managed by Latino institutions or researchers who can properly serve as the caretakers of these files and report on the issues dealing with Hispanics.

Study the applicability of existing constructs and theories to Hispanic populations.

• Provide funding through PHS for research to develop new behavioral models and theories and to test the validity of existing ones.

Define a specific research agenda. The Office of Minority Health in HHS must commission a number of research efforts that critically analyze the literature on Hispanic health in each of the areas identified by previous reports as deserving attention, such as child and adolescent health, women's health, diabetes, HIV, cancer, substance abuse, depression, violence, accidents, and unintentional injury. These reports will present a review of the current knowledge base on each of the areas covered by Healthy People 2000, clarify objectives, and identify research needs.

A high-level committee with appropriate Hispanic health expert involvement must be appointed by the Office of Minority Health to review the outcome of the activities of the Surgeon General's Hispanic Health Initiative and the information obtained from the state-of-art reviews described previously. This panel must be charged with developing an outline of priorities for research with Latinos.

Special funding programs or initiatives must be developed by the Federal Government to fund research on the role of factors such as acculturation, national origin or background, socioeconomic status, and migrational history on the health status of Hispanics. Large-scale, cross-sectional, and longitudinal research with Latinos, funded by Federal and State initiatives, must be required to include these factors as possible moderators of the findings. PHS should fund research specifically targeted at providing baseline data to enable formulation of Latino-specific objectives for Healthy People 2000.

Special funding programs or initiatives must be developed by the Federal Government to analyze the health status of Hispanics working in high-risk environments such as agriculture, assembly plants (including border *maquiladoras*), service professions, and other industrial environments.

Health services research must be conducted to identify the characteristics of health care delivery, including personnel that facilitate access, utilization, and effectiveness of health services among Hispanics. At least 25 percent of the evaluation set-aside funds at the Substance Abuse and Mental Health Services Administration and the Health Resources and Services Administration of the PHS should be targeted for services research to investigate questions pertaining to Latinos. The PHS Office of Health Planning and Evaluation should also direct funds for research on health services utilization by Hispanics.

An Office of Hispanic Health should be created within the Office of Minority Health to coordinate Latino health-related initiatives and to oversee their implementation within the Federal Government. This office must be properly funded and must include an Advisory Board on Hispanic Health Research to review its activities on a quarterly basis. In addition, the Office of Minority Health should issue a biannual report to Congress detailing progress on the Hispanic health agenda and the progress within PHS in meeting the mandates in the Disadvantaged Minority Health Act as they relate to Hispanics.

References.....

1. National Hispanic Health Policy Summit: Summary of discussions and recommendations in assessing Hispanic

health needs. National Hispanic Family Against Drug Abuse, Washington, DC, 1992.

- Marin, G.: Defining culturally appropriate community intervention: Hispanics as a case in point. J Community Psychol 21: 149-161 (1993).
- 3. The state of Hispanic health. National Coalition of Hispanic Health and Human Services Organizations, Washington, DC, 1992.
- Marin, G., and Marin, B. A.: Research with Hispanic populations. Sage Publications Inc., Newbury Park, CA, 1991.
- 5. Lewin, I. C. F.: Health care for Hispanic individuals. Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration, Rockville, MD, May 1991.
- U.S. General Accounting Office: Hispanic access to health care: significant gaps exist. GAO/PEMD Publication 92-6. U.S. Government Printing Office, Washington, DC, 1992.
- 7. Healthy People 2000: an ounce of prevention. National Coalition of Hispanic Health and Human Services Organizations, Washington, DC, 1992.
- 8. The state of Hispanic America 1991: an overview. National Council of La Raza, Washington, DC, 1992.
- Solis, J. M., Marks, G., Garcia, M., and Shelton, D.: Acculturation, access to care, and use of preventive services by Hispanics: findings from HHANES, 1982-84. Am J Public Health 80 (supp.): 11-19, December 1990.
- Marks, G., Garcia, M., and Solis, J. M.: Health risk behaviors of Hispanics in the United States: findings from HHANES, 1982-84. Am J Public Health 80 (supp.): 20-26, December 1990.
- 11. Council on Scientific Affairs: Hispanic health in the United States. JAMA 265: 248-252, Jan. 9, 1991.
- 12. Amaro, H., Whitaker, R., Coffman, G., and Heiren, T.: Acculturation and marijuana and cocaine use: findings from HHANES, 1982-84. Am J Public Health 80 (supp.): 54-60, December 1990.
- 13. Novello, A. C., Wise, P. H., and Kleinman, D. V.: Hispanic health: time for data, time for action [editorial]. JAMA 265: 253-255, Jan. 9, 1991.
- 14. Guendelman, S., Gould, J. B., Hudes, M., and Eskenazi, B.: Generational differences in perinatal health among the Mexican American population: findings from HHANES, 1982-84. Am J Public Health 80 (supp.): 61-65, December 1990.
- 15. Stroup-Benham, C. A., Treviño, F. M., and Treviño, D. B.: Alcohol consumption patterns among Mexican American mothers and among children from single and dual-headed households: findings from HHANES, 1982-84. Am J Public Health 80 (supp.): 36-41, December 1990.
- 16. Markides, K. S., Ray, L. A., Stroup-Benham, C. A., and Trevino, F. M.: Acculturation and alcohol consumption in the Mexican American population of the Southwestern United States: findings from HHANES, 1982-84. Am J Public Health 80 (supp.): 42-46, December 1990.
- Haynes, S. G., et al.: Patterns of cigarette smoking among Hispanics in the United States: findings from HHANES, 1982-84. Am J Public Health 80 (supp.): 47-54, December 1990.
- 18. Mosciski, K. E., Locke, B. Z., Rae, D. S., and Boyd, J. H.: Depressive symptoms among Mexican Americans: the Hispanic health and nutrition evaluation survey. Am J Epidemiol 1: 348-354 (1989).