



Redes En Acción

The National Hispanic/Latino Cancer Network

Latino Cancer Report

Summary Recommendations for a National
Hispanic/Latino Cancer Control Agenda

March 1, 2004

Redes En Acción:

The National Hispanic/Latino Cancer Network

Principal Investigator:

Amelie G. Ramirez, DrPH
Baylor College of Medicine
Houston/San Antonio, Texas

Co-Principal Investigators:

Northwest Region

Eliseo J. Pérez-Stable, MD
University of California, San Francisco
San Francisco, California

Southwest Region

Gregory A. Talavera, MD, MPH
San Diego State University
San Diego, California

North Central Region

Aida L. Giachello, PhD
University of Illinois at Chicago
Chicago, Illinois

South Central Region

Martha A. Medrano, MD, MPH
University of Texas Health Science
Center at San Antonio
San Antonio, Texas

Northeast Region

Jose R. Marti, MD
The Brooklyn Hospital Center
Brooklyn, New York

Southeast Region

Frank J. Penedo, PhD
University of Miami
Miami, Florida

NHMA:

Elena Rios, MD
National Hispanic Medical Association
Washington, D.C.

Consultants:

Alfred L. McAlister, PhD
University of Texas Health Science
Center at Houston
School of Public Health
Houston, Texas

Lucina Suarez, PhD
Texas Department of Health
Austin, Texas

Contact Information: *Redes En Acción*

Principal Investigator: Amelie G. Ramirez, DrPH
Chronic Disease Prevention and Control Research Center
Department of Medicine
Baylor College of Medicine
8207 Callaghan Rd., #110
San Antonio, Texas 78230
(210) 348-0255

aramirez@bcm.tmc.edu/celiat@bcm.tmc.edu



Redes En Acción: The National Hispanic/Latino Cancer Network is a major Special Populations Networks initiative supported by the National Cancer Institute, NCI Grant No. UO 1 CA 86117-01.



Foreword

The *Redes En Acción* Latino Cancer Report represents four years of research, discussion, and consensus development. It also reflects the thinking and hard work of hundreds of scientists, health care professionals, leaders of government agencies, professional and community-based organizations, and other stakeholders in Hispanic/Latino health.

The process began in 2000, with the initial meeting of the *Redes En Acción* National Steering Committee, where participants spent two days debating and prioritizing the cancer issues of primary significance and relevance to this country's 38 million Latinos. Conclusions of that meeting were subjected to scrutiny and additional input by members of *Redes En Acción's* six Regional Community Advisory Committees, representing academic institutions, clinical facilities, and diverse local and regional organizations located in every section of the United States.

Results of the National Steering Committee and Regional Community Advisory Committee meetings were then incorporated into a survey, which was administered to 624 key opinion leaders in Hispanic/Latino communities throughout the country. The data were collected and assessed, and presented once again to the National Steering Committee and, finally, to an expert review panel for synthesis into this summary document.

The *Redes En Acción* Latino Cancer Report focuses on cancer sites of greatest significance to the Hispanic/Latino population – breast, cervical, lung, colorectal, prostate, liver, and stomach, and includes recommendations for addressing the priority issues. These consensus recommendations are intended to help shape a national agenda on Hispanic/Latino cancer prevention and control issues. More specifically, the aim of this report is to assist *Redes En Acción* in its goals of promoting Hispanic/Latino cancer research, training, and public education, as well as provide advisory guidelines for national, regional and local policy makers.

Latinos are the largest and fastest-growing minority population in the United States. As this population expands and ages, it is imperative that the resources and strategies employed in the war against cancer be targeted as precisely as possible for maximum effect. *Redes En Acción* believes this Latino Cancer Report will provide a useful tool for all individuals and organizations engaged in this effort – an effort that will impact the lives of millions of Latino families and the generations that will follow.

Amelie G. Ramirez, DrPH

Principal Investigator

Redes En Acción: The National Hispanic/Latino Cancer Network



Acknowledgments

Redes En Acción would like to thank the hundreds of dedicated individuals that participated in the research and development of this document. Although too numerous to name individually, this list includes the *Redes En Acción* Co-Principal Investigators and their Project Coordinators, our Program Consultants, members of the National Steering Committee and Regional Community Advisory Committees, and participants in the nationwide Hispanic/Latino Cancer Key Opinion Leaders Survey. Finally, we would like to give special thanks to Karen Matherlee of PolicyInc. for her editorial assistance in the preparation of the final report.



Latino Cancer Report

Executive Summary

Redes En Acción: The National Hispanic/Latino Cancer Network, as part of its mandate from the National Cancer Institute, developed a national Hispanic/Latino cancer research, training, and outreach agenda. This agenda is based on contributions from a broad array of leading Hispanic/Latino scientists, health care providers, and leading authorities representing government agencies and professional and community-based organizations, as well as from 624 key opinion leaders throughout the United States.

In this executive summary, *Redes En Acción* is presenting five recommendations for cancer research priorities and two recommendations for education, training, and outreach priorities for cancer prevention and control. The agenda provides a framework for policymakers in both the public and private sectors to address cancer in the Hispanic/Latino population.

Approximately 67,400 new cases of cancer and 22,100 deaths were expected to occur among Hispanics/Latinos in 2003. Overall cancer incidence is lower for Latinos in the most common cancer sites, although disparities are present in specific sites. *Redes En Acción's* recommendations apply to the most important cancer sites: breast, cervix, lung, colon/rectum, prostate, liver, and stomach.

(1) ACCESS TO CANCER SCREENING AND CARE

Hispanics/Latinos are more likely to lack health insurance than any other group in the country. They are also less likely to have cancer screening tests, although the gap between the Latino population and other groups has narrowed substantially in the past 10 years. Sharing knowledge about different types of cancer and testing for their presence, addressing an attitude of fatalism about the efficacy of treatment if cancer is present, and promoting interval screening are priority areas to emphasize. Access to treatment after cancer has been diagnosed, adherence to a treatment regimen, and quality of care following abnormal test results show disparities in Latinos in comparison to white non-Hispanics and are understudied as research areas. For Latinos, lower health literacy and educational levels and limited English proficiency also play important roles in limiting access to the continuum of cancer prevention and care.

Recommendation: Study the quality of cancer services provided to Hispanics/Latinos compared to that received by other ethnic/racial groups and define associated factors that affect quality of care, adherence to treatment, clinical outcomes, patient-perceived quality of life, and decision making.

(2) TOBACCO USE AND CANCER

Tobacco use is the single most important risk factor for cancer and the leading cause of preventable mortality among all U.S. populations. Hispanics/Latinos smoke at lower rates than white non-Hispanics or African Americans in the United States. Latino men smoke in greater proportion than Latina women, but gender differences are minimal among youth who smoke. Cultural tailoring of cessation interventions has been developed and shown to have moderate effectiveness.

Recommendation: Study the initiation and development of tobacco dependence among Hispanic/Latino adolescents, young adults, and women in order to develop new smoking prevention and cessation strategies using peers; promote non-smokers' rights relative to involuntary smoking; and test use of medication and behavioral interventions.

(3) STATUS AND COMMUNICATION OF CANCER RISK

Hispanics/Latinos vary greatly in perceptions of cancer incidence and mortality risk. False perceptions of cancer risk and causality as well as negative attitudes about proven preventive strategies heighten the need for research on risk among Latinos. Although it is known that exposure to certain toxins can increase an individual's risk of developing cancer, the occupational and environmental risk profile of Latinos is not well-documented. Even when data on risk are available – for example, for tobacco use and certain infectious agents – various barriers hinder communication between Latino patients and clinicians. Language and cultural barriers are the most prominent, due to Latinos being underrepresented in the health professions, providers not speaking Spanish, patients having limited English skills, interpreters playing ambiguous or conflicted roles, and providers lacking cultural sensitivity.

Recommendation: Develop a risk profile for Hispanics/Latinos relative to occupational and environmental exposure, and study factors that affect patient-provider communication in the Latino community and strategies to improve it.

(4) ASSOCIATION OF INFECTIOUS AGENTS WITH CERTAIN TYPES OF CANCER

Infectious agents are strongly associated with certain types of cancer: human papilloma virus (HPV) with cervical and other genital as well as anal cancer, hepatitis B and hepatitis C viruses (HBV and HCV) with liver cancer, and *Helicobacter pylori* (*H. pylori*) with stomach cancer. Hispanics/Latinos tend to have high rates of each of these.

Recommendation: Study the role of HPV in cervical cancer in Hispanics/Latinas, investigate the roles of HBV and HCV and other known risk factors in liver cancer among Hispanics/Latinos, and conduct research on *H. pylori* in stomach cancer risk and treatment for Latinos.

(5) CANCER SURVIVORSHIP AND HEALTH-RELATED QUALITY OF LIFE

Hispanics/Latinos experienced cancer incidence of 352.1 per 100,000 population: 419.3 for males and 312.2 for females. During the same period, Hispanics/Latinos had mortality rates of 137.9 per 100,000: 176.7 for males and 112.4 for females. Time of diagnosis and effectiveness of treatment are among the clinical variables that affect survival, while psychosocial factors such as amount of life stress, educational attainment, income level, partnership status, and existence of co-morbid conditions are important as well. Strategies to increase quality of life among Latinos diagnosed with cancer include religious faith, family support, support groups, and dietary therapies.

Recommendation: Conduct qualitative and quantitative research on instruments to assess quality of life among Hispanics/Latinos diagnosed with cancer, do follow-up studies on factors that influence Latino cancer survival rates, and specifically investigate the effectiveness of treatments for breast cancer in Latinas and their adherence to them.

(6) EDUCATION, TRAINING, AND OUTREACH FOR CANCER PREVENTION AND CONTROL

Education and Training

Education and training of health care professionals and consumers are crucial to the prevention and control of cancer in the Latino community. Education and training of health care professionals address not only the number and distribution of health clinicians and health educators, but also their gender, cultural and language skills, interpersonal and communication strengths, knowledge of appropriate preventive strategies and treatment modalities, opportunities for continuing education, and roles in the conduct of research.

Recommendation: Increase the number of Spanish-speaking health care providers, improve the Spanish language skills of providers who work with the Hispanic/Latino population, make Spanish interpreter programs more effective, offer cultural competency and communications training to health providers and researchers, develop specially targeted cancer prevention and control programs (for example, to combat tobacco use and exposure to infectious agents) and assure that health professionals are fluent in them, and encourage greater participation by Latino clinicians in clinical research activities.

Outreach

Various vehicles exist for educating Hispanic/Latino consumers. They range from one-on-one communication between patient and provider (or between consumer and health educator or community worker) to public information campaigns. The latter may include community workshops, school programs, and mass media campaigns, as well as various kinds of information provided on the Worldwide Web or by individual computer programs. While Latino consumers are at the center of outreach efforts, community groups, public policymakers, employers, and others may be focal points as well.

Recommendation: Pursue culturally targeted personal, print, electronic, and other means of reaching out to and educating the Hispanic/Latino public about cancer risk conceptions and misconceptions, prevention, screening, treatment, and research.



Latino Cancer Report Summary Recommendations for a National Hispanic/Latino Cancer Control Agenda

Introduction

With a population of approximately 38 million, Hispanics/Latinos are the fastest-growing minority group in the United States. At about 13 percent of the total population, Latinos are the country's largest ethnic/racial minority group, surpassing African Americans. In addition to the sheer number of Hispanics/Latinos, an important consideration is the fact that this is an extremely widespread population. Although concentrations are particularly large in 10 states (New Mexico, California, Texas, Arizona, Nevada, Colorado, Florida, New York, New Jersey, and Illinois) and Puerto Rico, in recent decades Latinos have become an integral element of state populations nationwide. However, significant demographic differences exist among Hispanic/Latino groups, particularly in median age, household size, education, and family income. The majority of Latinos face barriers to health care access, including a lack of health insurance coverage, underrepresentation in health care fields, and cultural and language differences. These distinct demographic characteristics and barriers have a direct impact on the risk of cancer in Latinos and on the development of prevention and control strategies.

Redes En Acción: The National Hispanic/Latino Cancer Network, as part of its mandate from the National Cancer Institute, developed a national Hispanic/Latino cancer research, training, and education and outreach agenda. This

agenda, based on contributions from leading Hispanic/Latino cancer researchers, scientists, and providers as well as from key opinion leaders throughout the country, has guided *Redes En Acción's* multi-faceted approach to cancer prevention and control.

In this background document, *Redes En Acción* is presenting six sets of recommendations, along with some prefatory comments. The recommendations were approved in August 2003 by *Redes En Acción's* National Steering Committee, made up of experts on Hispanic/Latino health and cancer issues from throughout the United States. Members of the committee are drawn from the fields of epidemiology, biostatistics, public health, sociology, medicine, and nursing. They reviewed and discussed a series of proposals and developed "consensus recommendations" on cancer research as well as on education, training, and outreach priorities for the Hispanic/Latino population. The consensus recommendations form a national agenda on cancer prevention and control to guide *Redes En Acción* in its work, to advise the National Cancer Institute in its efforts, and, on a broader scale, to provide a framework for policymakers in both the public and private sectors to address the growing incidence of and mortality from cancer in the Hispanic/Latino population.

BACKGROUND ON HISPANICS/LATINOS AND CANCER

Approximately 67,400 new cases of cancer were expected to occur among Hispanics/Latinos in 2003, according to the American Cancer Society. About 22,100 Hispanics/Latinos were anticipated to die in 2003 from various forms of cancer, which is the second-leading cause of death in the Hispanic/Latino population after heart disease.¹ Drawing a profile of the Hispanic/Latino population is difficult, due to the diversity of its subgroups, which vary in risk behaviors, geography, environment, and practices as well as in access to health services. Overall, as indicated in Table 1, the profile varies according to cancer site, with marked differences between incidence and mortality.

Whether in incidence or mortality or both, it is clear that cancer in these sites, and in other sites, exacts a high toll from Hispanics/Latinos. Each statistic represents a human face, with the array of statistics making a compelling case for the United States to establish cancer research, training, and education and outreach initiatives for the prevention and control of cancer in this nation's largest and fastest-growing minority group.

APPROACH TO THE PROBLEM (SURVEY METHODOLOGY AND REVIEW PROCESS)

Redes En Acción, working through its network of regional investigators, administered a survey to 624 key opinion leaders in the spring of 2001. The survey was based upon the recommendations of Hispanic/Latino cancer researchers, scientists, and providers, as reviewed and revised by regional panels of local cancer experts within *Redes En Acción's* network in San Antonio, San Diego, San Francisco, Chicago, Miami, and New York. Of the 624 participants, 64 percent were Hispanic/Latino, 28 percent were non-Latino white, and the remaining 8 percent had other ethnicities; 52 percent were from community-based organizations and 39 percent were from academic institutions, with the remainder from other settings.

The survey respondents reviewed cancer-related topics and ranked recommendations under each in terms of their importance to the participants' Hispanic/Latino constituents. These topics included (1) access to cancer screening and care; (2) tobacco use; (3) status and communication of cancer risk (patient-clinician communication, risk communication, and

TABLE 1. Most Important Cancer Sites

1 Breast Cancer

Cancer of the breast is the most frequently diagnosed cancer in U.S. Latinas, although the incidence in Hispanic women is less than that of non-Hispanic women. Breast cancer is also the leading cause of cancer death among Latinas (rather than lung cancer, which ranks first for women of other ethnic/racial groups). (Age-adjusted SEER incidence statistics per 100,000 persons, 1996-2000: white Hispanic females, 92.7; overall Hispanic females, 89.8; white non-Hispanic females, 148.3)²

2 Cervical Cancer

The incidence of cervical cancer in U.S. Latinas is twice that of Anglo women, while the death rate from cervical cancer is 40 percent higher. (SEER data: white Hispanic, 17.5; overall Hispanic, 16.8; white non-Hispanic, 7.6)³

3 Lung Cancer

Lung cancer ranks fourth in cancer diagnoses in U.S. Hispanic/Latino men and women combined. It is the leading cause of cancer death in Hispanic/Latino men, who have a higher incidence of the disease than Latina women; it ranks second as the cause of cancer death in Latinas. Hispanics/Latinos tend to have lower rates of lung cancer than non-Hispanics, in part because of traditionally lower use of tobacco products, especially by Latina women. (SEER data for lung and bronchus: white Hispanic males, 47.4; overall Hispanic males, 46.1; white non-Hispanic males, 80.5; white Hispanic females, 25.1; overall Hispanic females, 24.4; white non-Hispanic females, 53.9)⁴

4 Colorectal Cancer

Colorectal cancer ranks third in incidence in Hispanics/Latinos. It ties with prostate cancer in being the second cause of cancer death in Latino men. It is the third cause of cancer death in Latina women. (SEER data: white Hispanic males, 51.4; overall Hispanic males, 49.8; white non-Hispanic males, 64.6; white Hispanic females, 33.6; overall Hispanic females, 32.9; white non-Hispanic females, 47.5)⁵

5 Prostate Cancer

Although prostate cancer is the most frequently diagnosed cancer in Hispanic/Latino men, its incidence is approximately 25 percent less in Hispanic than in non-Hispanic men. As already indicated, prostate cancer ties with colorectal cancer in being the second most frequent cause of cancer death in Latino men. (SEER data: white Hispanic males, 139.6; overall Hispanic males, 137.2; white non-Hispanic males, 163.3)⁶

6 Liver Cancer

The liver cancer rate in Hispanics/Latinos is approximately twice that in non-Hispanics. The death rate from liver cancer is 60 percent higher in Latinos than in non-Hispanics. (SEER data: white Hispanic males, 14.3; overall Hispanic males, 13.8; white non-Hispanic males, 6.2; white Hispanic females, 5.8; overall Hispanic females, 5.6; white non-Hispanic females, 2.4)⁷

7 Stomach Cancer

The rate of stomach cancer is 75 percent higher in U.S. Hispanics/Latinos than in non-Hispanics, according to 2002 data from the American Cancer Society. Mortality rates reflect a similar proportion. (SEER data [1996-2000]: white Hispanic males, 18.7; overall Hispanic males, 18.1; white non-Hispanic males, 10.0; white Hispanic females, 10.3; overall Hispanic females, 10.0; white non-Hispanic females, 4.3)⁸

occupational and environmental risk); (4) infectious agents; and (5) cancer survivorship and health-related quality of life. They also ranked participation in clinical trials and genetic testing and education as well as four other topics – nutrition, alcohol, physical activity and weight management, and sexual practices – some elements of which are incorporated into this report.

Draft recommendations based on the topics were presented to *Redes En Acción's* National Steering Committee on August 14, 2003. This document reflects refinements to the recommendations made by the National Steering Committee, including the suggestion that overlapping recommendations dealing with education, training, and outreach be combined into one section (6) of this report.

Recommendations

(1) ACCESS TO CANCER SCREENING AND CARE

Comments

Hispanics/Latinos tend to underutilize cancer screening procedures for several reasons, chief among them lack of knowledge about different types of cancer and tests for their presence. Another reason may be fatalism about the efficacy of treatment if cancer is present, according to a Massachusetts study of urban Latinas in which perceptions that “not much can be done” about breast cancer correlated with lower mammography rates.⁹ While some studies show that Hispanics/Latinos have lower rates of screening than non-Hispanics, not only for breast cancer but also for cervical and colorectal cancer, periodic or ongoing testing may be more of a problem than initial screening. Interval screening rates generally are not included in national surveys, which tend to ask respondents whether they were screened in the last two years or whether they were ever screened.

Some of the factors that may underlie the Hispanic/Latino population's reluctance or failure to be screened include age (a greater proportion under age 30), education (a smaller proportion of high school graduates), income (a significantly lower median income), insurance coverage (high percentages of uninsured and underinsured), proficiency in the English language (8 of 10 speaking Spanish at home), and cultural beliefs, as well as various health system barriers.¹⁰ In fact, those factors, such as education and income, that comprise socioeconomic status (SES) may account for differences in screening rates, as opposed to the differences being strictly a function of ethnicity.

While underutilization of screening procedures is a significant problem, access to treatment, compliance with a treatment regimen, and quality of care following positive screening tests may be even more important. Hispanics/Latinos are less likely than the general population to have regular health care providers for primary services

and specialty referrals, and are 1.5 times more likely to use the hospital emergency room than the population as a whole.¹¹ Research indicates that persons from ethnic/racial minority groups, including Hispanics/Latinos, are “less likely to receive appropriate staging procedures, procedures to monitor for cancer recurrence, and adjuvant radiation and chemotherapy.” They are also less likely “to receive aggressive therapy in cases where this therapy is considered appropriate or, as in the case of prostate cancer, where evidence of the efficacy of more aggressive treatment is lacking.”¹²

Health care expenditures reflect this disparity, as seen in the significant proportions of Hispanic/Latino cancer patients with either no or limited insurance coverage. Data for the period of 1996-1999 show that 12 percent of Hispanic/Latino cancer patients were uninsured, 11 percent had Medicaid, 43 percent had Medicare, 3 percent had other public insurance, and only 31 percent had private insurance. Of cancer patients under 65 years of age, 20 percent of those identified as Hispanic were uninsured. “Uninsured cancer patients incurred a little more than half (55%) of the health care spending of privately insured patients.”¹³ These figures are explained in part by Latinos' having low health insurance coverage rates, even though their participation in the labor force is high. For example, according to the Pew Hispanic Center, Latinos comprise 13 percent of the labor force and were responsible for more than 50 percent of labor-force growth from the end of 2000 through the end of 2002.¹⁴

Research Recommendations – Access

- (1A) Study the quality of cancer services provided to Hispanics/Latinos compared to that received by other ethnic/racial groups by various health care settings and health care providers.
- (1B) Study the mediators and moderators that might help explain the differences in quality of care.
- (1C) Study the factors that contribute to adherence by Hispanics/Latinas to mammogram screening guidelines.
- (1D) Study prostate cancer screening, treatment, and outcomes for Hispanics/Latinos. Focus on how Hispanic/Latino men make decisions on screening and treatment options (i.e., radiation treatment, surgery, or hormonal treatment adjusted by stage) and what kinds of outcomes they experience as a result.

(2) TOBACCO USE AND CANCER

Comments

Although the proportion of adult Hispanics/Latinos who are current cigarette smokers is less than the proportions of the non-Hispanic white and black adult populations in the United States, cigarette smoking is nonetheless a serious problem. According to 2002 National Health Interview Survey data, 15.9 percent of Hispanics/Latinos have smoked at least 100 cigarettes in their lifetimes and smoke every day or some days, compared with 24.1 percent of non-Hispanic whites and 22.5 percent of non-Hispanic blacks.¹⁵ Earlier data indicate that the percentage of Hispanic/Latino men who smoke is greater than that of Hispanic/Latina women, and that lung cancer is the leading cause of death from cancer in the Hispanic/Latino population. The statistics for Hispanic/Latino high school students reflect the same trends, with some indications that rising percentages leveled off by 1999.

Cigar smoking is also prevalent, with Cuban American men reflecting higher use than Mexican American and Puerto Rican men.¹⁶ Secondhand smoke, which subjects people to the same carcinogens as smokers, is also a problem; a northern California study indicated that, among nonsmokers, Asians and Hispanics/Latinos are more likely to be exposed than other ethnic/racial groups.

“The need for a culturally appropriate smoking-cessation intervention for Latinos is based on data on current patterns of tobacco use, possible targeting by the tobacco industry, and the lack of smoking-cessation interventions that are appropriate to the cultural characteristics of Latino smokers,” according to findings from the *Programa Latino Para Dejar de Fumar* initiative in San Francisco. For example, the proportion of Latina women who smoke seems to increase with acculturation, and smoking and depression appear to have a positive correlation.¹⁷

Research Recommendations – Tobacco

- (2A) Study adolescent smoking onset and continuation.
- (2B) Study the adoption, continuation, and cessation of smoking in Hispanic/ Latino men and women.
- (2C) Study parent-child communication strategies and the use of peers for smoking prevention in children and adolescents.
- (2D) Evaluate attitudes and behavior of the Hispanic/Latino population regarding involuntary smoking.
- (2E) Evaluate advocacy skills and empowerment strategies for tobacco control in the Hispanic/Latino population.
- (2F) Study the use of pharmacotherapy in the Hispanic population.

(3) STATUS AND COMMUNICATION OF CANCER RISK

Risk Communication Comments

Hispanics/Latinos also show great variation in perceptions of cancer incidence and mortality risk. For example, a study comparing perceptions of cancer risk by immigrant Hispanic/Latina and Anglo women in Orange County, California showed that the Latinas tended to link cancer incidence to stress and trauma to the body (such as blows to the breast) and behavioral choices (such as having multiple sex partners), while the Anglo women were more likely to use epidemiologically based interpretations of cancer risk.¹⁸ Another California study indicated that Hispanic/Latina women (56 percent of whom were Mexican American) were more likely than Anglo women to view “sugar substitutes, bruises, microwave ovens, spicy foods, breast-feeding, and antibodies” as causes of cancer.¹⁹ A Texas study that compared attitudes between Mexican American and African American women showed that the former were more fearful of and fatalistic about a diagnosis of cancer.²⁰

False perceptions of cancer risk and causality as well as negative attitudes about proven preventive strategies (“it wouldn’t matter anyway”) heighten the need for research on risk communication in the Hispanic/Latino population. The Institute of Medicine included cultural and behavioral attitudes, beliefs, and lifestyle patterns as factors that “have not received as much attention as biological differences among ethnic/racial groups.”²¹ Other factors deserving of research attention include age, gender, and SES.

Research Recommendations – Communication

- (3A) Study how to communicate cancer risks to Hispanic/Latino patients.
- (3B) Provide training in risk communication and decision making among culturally distinct Hispanic/Latino groups.

Occupational and Environmental Risk Comments

Exposure to environmental toxins increases an individual's risk of developing cancer. While there are extensive data on the relationships between specific toxins and rare types of cancer, the risk profile for Hispanics/Latinos is not well-documented. The most important environmental risk for the Hispanic/Latino population, as well as for all population groups, is involuntary smoking. For example, a study in Missouri showed that involuntary smoking accounted for 8 percent of lung cancer in women whose spouses smoked.²²

Various studies are underway on the relationships between certain toxins, such as pesticides, and the risks of breast cancer, prostate cancer, leukemia, and other cancers in Hispanics/Latinos. For example, there are studies in progress on the effects of toxins on migrant and farm workers and their families in agricultural areas.^{23, 24} Moreover, researchers are exploring connections between SES (indices on which Hispanics/Latinos tend to lag behind other populations) and environmental risks.²⁵

A study of members of the United Farm Workers of America (a California labor union that primarily has Hispanic/Latino members) indicated that migrant workers have higher rates of certain types of cancer, such as leukemia and stomach, cervical, and uterine cancer, than other Californians.²⁶ A study of death certificates in 24 states found that migrant and seasonal workers were more likely to have died of stomach and cervical cancer, as well as certain oral and throat cancer and cancer of the skin, although not all of these diagnoses can be traced to occupational and environmental risks.²⁷

Research Recommendations – Environment

- (3C) Assess exposure to environmental pollutants/toxicants in Hispanic/Latino communities (especially U.S.-Mexico border areas and inner-city and rural areas).
- (3D) Identify high-risk occupations and environments for Hispanics/Latinos by using geographic information systems (GIS) techniques.
- (3E) Study cancer risks of migrant farm workers and their families.

Patient-Clinician Communication Comments

Various barriers hinder communication between Hispanic/Latino patients and clinicians, such as physicians, nurse practitioners, and physician assistants. Language and cultural barriers are the most prominent, due to Latinos being underrepresented in the health professions, providers not speaking Spanish, patients having limited English skills, interpreters playing ambiguous or conflicted roles (particularly in terms of privacy issues), and providers lacking cultural sensitivity.²⁸ Negative physician attitudes toward Latinos and difficulty in getting referrals to specialists also pose barriers.²⁹

Numerous strategies exist for providing access to reliable health information, using effective techniques in conveying the information, and improving encounters between patients and providers. For example, the National Academies Press in 2002 published *Speaking of Health: Assessing Health Communication Strategies for Diverse Populations*.

Research Recommendations – Patient-Clinician

- (3F) Study strategies to improve communication, decision making, and behavioral skills among Hispanic/Latino patients.
- (3G) Study cultural and gender factors that affect patient/health care provider communication in the Hispanic/Latino community.
- (3H) Study the effects of limited English proficiency among some Hispanics/Latinos on the quality of health care in various settings, such as health maintenance organizations (HMOs) and Medicaid programs.

(4) INFECTIOUS AGENTS

Comments

Infectious agents are strongly associated with certain types of cancer: human papilloma virus (HPV) with cervical and other genital as well as anal cancer, hepatitis B and hepatitis C viruses (HBV and HCV) with liver cancer, and *Helicobacter pylori* (*H. pylori*) with stomach cancer. Hispanics tend to have high rates of each of these cancers. For example, according to the Centers for Disease Control and Prevention, data from a 1992-1999 study showed that, “except for women aged 20 to 29 years, incidences (of cervical cancer) for Hispanic women were significantly higher than those for non-Hispanic women, regardless of stage at diagnosis.”³⁰ In 1999, the rate of liver cancer in Hispanics/Latinos was 8.0 per 100,000, compared with 4.7 in Anglos, 6.9 in African Americans, 6.3 in Native Americans, and 13.7 in Asians/Pacific Islanders.³¹ A study of *H. pylori* infection in adults by ethnic/racial group indicated that it is especially prevalent in Mexican Americans: 61.6 percent age-adjusted prevalence, compared with 26.2 percent in non-Hispanic whites and 52.7 percent in non-Hispanic blacks. Researchers noted that “the high prevalence of *H. pylori* infection among non-Hispanic blacks and Mexican Americans is partially explained by other factors associated with infection.”³²

Research Recommendations – Infectious Agents

- (4A) Conduct cancer-related studies looking at HPV, HBV, HCV, and *H. pylori* among Hispanic/Latino population subgroups.
- (4B) Study the role of HPV in cervical cancer in Hispanics/Latinas. Correlate sexual norms and beliefs to incidence of HPV. Consider the validity of current Pap smear guidelines for Latinas in light of the epidemiology. Make sure that Latinas are included in clinical trials and at-risk-population protocols for the new HPV vaccine.
- (4C) Study the role of HBV and HCV and other known risk factors in liver cancer among Hispanics/Latinos.
- (4D) Study the role of *H. pylori* in Hispanic/Latino stomach cancer risk. Investigate treatment of *H. pylori* infection among Hispanics/Latinos.

(5) CANCER SURVIVORSHIP AND HEALTH-RELATED QUALITY OF LIFE

Comments

According to the National Cancer Institute, from 1996 through 2000, Hispanics/Latinos experienced an incidence of 352.1 per 100,000 population: 419.3 for males and 312.2 for females. During the same period, Latinos had mortality rates of 137.9 per 100,000: 176.7 for males and 112.4 for females.³³ While the five-year survival rate for all ethnic/racial groups is approximately 62 percent, there are significant differences among the populations of each relative to the risks of incurring and dying from cancer. Moreover, incidence and mortality rates have improved: for Latinos, incidence by 2 percent and survival by 0.9 percent a year during the reporting period of 1992 to 1998.³⁴

The clinical variables that affect survival include time of diagnosis and effectiveness of treatment, while psychosocial variables consist of such factors as amount of life stress, educational attainment, income level, partnership status, and existence of co-morbid conditions. Religious faith, family support, support groups, and dietary therapies are some strategies identified as increasing quality of life among Hispanics/Latinos.

Research Recommendations – Survivorship

- (5A) Conduct follow-up studies to determine the biological and psychosocial factors that influence cancer survival rates among Hispanics/Latinos.
- (5B) Conduct qualitative and quantitative research using culturally appropriate instruments to assess quality of life among Hispanics/Latinos with cancer.
- (5C) Assess the adaptability or suitability of existing quality-of-life measures for Hispanics/Latinos with cancer.
- (5D) Study the effectiveness of breast cancer treatments, factors that affect adherence to them, and the impact of the treatments on the quality of life in Latinas.

(6) EDUCATION, TRAINING, AND OUTREACH FOR CANCER PREVENTION AND CONTROL

Education and Training Comments

Education and training of health care professionals and consumers are crucial to the prevention and control of cancer in the Hispanic/Latino community. According to the 2000 Census and professional associations, persons of Hispanic/Latino origin made up 11.8 percent of the population but accounted for only 3.4 percent of physicians^{35,36} and were similarly underrepresented in the ranks of registered nurses. For non-Latino providers, being able to speak Spanish and having an understanding of Latino culture and subcultures are important skills in screening, diagnosing, and treating Hispanic/Latino patients, although effective interpreter programs may help fill in gaps. Interpersonal and communication strengths, knowledge of appropriate preventive strategies and treatment modalities, opportunities for continuing education, and roles in the conduct of research are also important in educating and training clinicians to prevent and control cancer in the Hispanic/Latino population.

Education & Training Recommendations

- (6A) Increase the number of Hispanic/Latino health care professionals and Spanish-speaking health care providers, improve the Spanish language skills of providers who work with the Hispanic/Latino population, and make Spanish interpreter programs more effective; offer cultural competency and communications training to health providers and researchers.
- (6B) Develop specially targeted cancer prevention and control programs (e.g., to combat tobacco use and exposure to infectious agents) and assure that health professionals are fluent in them; encourage greater participation by Latino clinicians in clinical research activities.

Outreach Comments

Various vehicles exist for educating Hispanic/Latino consumers. On a one-to-one basis, the relationship between the patient and clinician, or between the consumer and health educator or community health worker, is crucial to conveying information about cancer prevention and control. Community education, whether through community meetings, school programs, or local media, is also an important means of outreach to Latino consumers. On a wider scale, use of the Worldwide Web for getting health information is growing among Latinos. For example, 51 percent of Hispanic/Latino adults sought health information on the Worldwide Web in 2001, according to the Pew Internet and American Life Project. While the percentage is lower for Hispanics/Latinos than for whites and blacks (each 57%), there was a 25 percent growth rate from July-August 2000 to July-August 2001, due to “an influx of young people (under age 34), women, and those from modest-income (less than \$40,000) households.”³⁷ While Latino consumers are at the center of outreach efforts, community groups, public policymakers, employers, and others may be focal points as well.

Outreach Recommendations

- (6C) Pursue culturally targeted personal, print, electronic, and other means of reaching out to and educating the Hispanic/Latino public about cancer risk conceptions and misconceptions, prevention, screening, treatment, and research.

Conclusion

As birth and immigration contribute to high growth rates in the Hispanic/Latino population in this country, addressing Hispanic/Latino cancer incidence and mortality and tackling high priority cancer issues in the Latino population are becoming increasingly acute. This report is a first step in meeting the need for an agenda that not only presents some of the statistics and studies on important cancer sites and cancer issues among Hispanics/Latinos but also provides recommendations from key opinion leaders, regional panels, and *Redes En Acción's* National Steering Committee.

Some of the statistics on the incidence and mortality of cancer among Hispanics/Latinos are startling, such as breast cancer being the leading cause of cancer death among Latinas and lung cancer ranking first in cancer mortality among Latino males. The first two topics – access to cancer screening and care and tobacco use – go to the core of cancer prevention and control in both instances, highlighting the importance of an agenda that identifies priorities and provides a framework for action on them.

The need for increased demographic, cultural, epidemiological, and clinical data centers not only on Hispanics/Latinos relative to other ethnic/racial groups but also on each individual Hispanic/Latino population group. The recommendations presented here provide a framework for *Redes En Acción* to present and pursue a research agenda to help address this need. Not only is a research agenda essential in empowering investigators and educators, as well as providers, payers, and patients, to collaborate on cancer prevention and control, but it also is crucial in informing and motivating policy makers to recognize the gravity of cancer for Hispanics/Latinos. As policy makers at the federal, state, and local levels deal with concerns about access to care, health promotion and disease prevention, health professions education and training, public outreach, and communications modalities in the health field, they need to take into account the health care needs of the burgeoning Hispanic/Latino population and ways in which those needs can be met.

Sources

- 1 American Cancer Society. Cancer facts and figures for Hispanics/Latinos, 2003-2005. Accessed July 7, 2003, at <http://www.cancer.org/downloads/STT/CAFF2003HispPWSecure.d.pdf>, 4.
- 2 National Cancer Institute. Table IV-12, SEER cancer statistics review. Accessed July 30, 2003, at http://seer.cancer.gov/csr/1975_2000/results_merged/topic_race_ethnicity.pdf, 3.
- 3 National Cancer Institute. Table V-7, SEER cancer statistics review, 5.
- 4 National Cancer Institute. Table XV-14, SEER cancer statistics review, 15.
- 5 National Cancer Institute. Table VI-14, SEER cancer statistics review, 6.
- 6 National Cancer Institute. Table XXII-7, SEER cancer statistics review, 22.
- 7 National Cancer Institute. Table XIV-9, SEER cancer statistics review, 14.
- 8 National Cancer Institute. Table XXIII-9, SEER cancer statistics review, 23.
- 9 Laws MB, Mayo SJ. The Latina Breast Cancer Control Study, year one: factors predicting screening mammography utilization by urban Latina women in Massachusetts. *Journal of Community Health*, 1998, 23, 251-67.
- 10 Ramirez AG, Villarreal R, Suarez L, Flores ET. The emerging Hispanic population: a foundation for cancer prevention and control. Accessed June 4, 2003, at <http://enaccion.bcm.tmc.edu/emerg.pdf>, 4-6.
- 11 Intercultural Cancer Council, Hispanics/Latinos with cancer. Accessed June 4, 2003, at <http://iccnetwork.org/cancerfacts/cfs4.htm>.
- 12 Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *Journal of the National Cancer Institute*, 2002, 94, 334-57.
- 13 Thorpe KE, Howard D. Health insurance and spending among cancer patients. *Health Affairs*, April 9, 2003. Accessed June 4, 2003, at <http://www.healthaffairs.org/WebExclusives/2203Thorpe.pdf>, W3/193-194.
- 14 Pew Hispanic Center. Press release, October 7, 2003. Accessed January 18, 2004, at <http://www.pewhispanic.org/site/docs/pdf/recession%20press%20release.pdf>.
- 15 Centers for Disease Control. Age-sex-adjusted prevalence of current smoking among adults 18 years and older, by race/ethnicity: United States, 2002 (Figure 8.4). Early Release of Selected Estimates Based on Data from the 2002 National Health Interview Survey. Accessed July 7, 2003, at http://www.cdc.gov/nchs/data/nhis/earlyrelease/200306_08.pdf, 41.
- 16 National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control. Hispanics and tobacco. Accessed July 7, 2003 at http://www.cdc.gov/tobacco/sgr/sgr_1998/sgr-min-fs-hsp.htm, 1.
- 17 Marin G, Perez-Stable EJ. Effectiveness of disseminating culturally appropriate smoking-cessation information: Programa Latino Para Dejar de Fumar. *Journal of the National Cancer Institute Monograph*, 1995 (18), 155-163. Also Perez-Stable EJ, Marin G, Posner SF. Ethnic comparison of attitudes and beliefs about cigarette smoking. *Journal of General Internal Medicine*, March 1998, 13(3), 167-174.
- 18 Chavez LR, Hubbell FA, McMullin JM, Martinez RG, Mishra SI. Structure and meaning in models of breast and cervical cancer risk factors: a comparison of perceptions among Latinas, Anglo women, and physicians. *Medical Anthropology Quarterly*, 1995, 9, 40-74.
- 19 Perez-Stable EJ, Sabogal F, Otero-Sabogal R, Hiatt RA, McPhee SJ. Misconceptions about cancer among Latinos and Anglos. *Journal of the American Medical Association*, 1992, 268, 3219-3223.
- 20 Suarez L, Nichols DC, Brady CA. Use of peer role models to increase Pap smear and mammogram screening in Mexican American and black women. *American Journal of Preventive Medicine*, 1993, 9(5), 290-296.
- 21 Institute of Medicine. The unequal burden of cancer: an assessment of NIH research and programs for ethnic minorities and the medically underserved. Washington, DC: National Academy Press, 1999, 4.
- 22 Alavanja MC, Brownson RC, Benichou J, Swanson C, Boice JD Jr. Attributable risk of lung cancer in lifetime nonsmokers and long-term ex-smokers (Missouri, United States). *Cancer Causes Control*, 1995, 6, 209-16.
- 23 National Center for Environmental Research, Environmental Protection Agency. ORD/NCER STAR grants. Accessed June 4, 2003, at <http://es.epa.gov/ncer/publications/topical/pesthhr.html>.

- 24 Environmental Health Advanced Systems Laboratory, Colorado State University. Pesticides, other chemical exposures, and the risk of childhood leukemia. Accessed June 4, 2003, at <http://ehasl.cvmb.colostate.edu/projects/chem.pesticides.leukemia.html>.
- 25 See Evans GW, Kantrowitz E. Socioeconomic status and health: the potential role of environmental risk exposure. *Annual Review of Public Health*, 2002 (23), 303-31. Accessed at <http://arjournals.annualreviews.org/doi/pdf/10.1146/annurev.publhealth.23.112001.112349>.
- 26 Mills PK, Kwong S. Cancer incidence in the United Farmworkers of America (UFW), 1987-1997. *American Journal of Industrial Medicine*, 2001 (40), 596-603.
- 27 Colt JS, Stallones L, Cameron LL, Dosemeci M, Zahm SH. Proportionate mortality among US migrant and seasonal farmworkers in 24 states. *American Journal of Industrial Medicine*, 2001 (40), 604-11.
- 28 Ramirez AG, Villarreal R, Suarez L, Flores ET. The emerging Hispanic population, 6-7. Also, Institute of Medicine. *Speaking of health: assessing health communication strategies for diverse populations*. Washington, DC: National Academies Press, 2002.
- 29 Department of Health and Human Services. Goal 2: eliminate disparities in cancer screening and management. *Eliminating Racial and Ethnic Disparities in Health*. Accessed June 4, 2003, at <http://raceandhealth.hhs.gov/3rdpgBlue/Cancer/3pgGoalsCancer.htm>.
- 30 Centers for Disease Control. Invasive cervical cancer among Hispanic and non-Hispanic women—United States, 1992-1999. *MMWR Morbidity and Mortality Weekly Report*, 2002 (51), 1067-1070. Accessed June 4, 2003, at <http://cisat.isciii.es/mmwr/preview/mmwrhtml/mm5147a2.htm>.
- 31 National Cancer Institute, Surveillance SEER*Stat database: incidence—SEER 9 regs public use. November 2002 (for 1973-2000).
- 32 Everhart JE, Kruszon-Moran D, Perez-Perez GI, Tralka TS, McQuillan G. Seroprevalence and ethnic differences in *Helicobacter pylori* infection among adults in the United States. *Journal of Infectious Diseases*, April 18, 2000, 181(4), 1359-1363. Accessed June 4, 2002, at http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10762567&dopt=Abstract.
- 33 National Cancer Institute. Age-adjusted SEER incidence and US death rates by race/ethnicity, and sex. Accessed July 7, 2003, at http://seer.cancer.gov/csr/1975_2000/results_merged/topic_race_ethnicity.pdf.
- 34 National Cancer Institute. Cancer care issues in the US: quality of care, quality of life. President's Cancer Panel Meeting January 1, 1997 to December 31, 1998. Bethesda (MD): National Cancer Program, National Cancer Institute; 1998. Also American Cancer Society. *Cancer facts and figures for Hispanics/Latinos, 2003-2005*.
- 35 U.S. Census Bureau. *Statistical Abstract of the United States, 2001*. Section 1: population, table 10. Accessed December 13, 2003, at <http://www.census.gov/prod/2002pubs/01statab/pop.pdf>, 13.
- 36 American Medical Association. Total Physicians by Race/Ethnicity—2001. Accessed December 13, 2003, at <http://www.ama-assn.org/ama/pub/article/168-187.html>.
- 37 National Cancer Institute. Cancer communications update: July-August 2001. Accessed June 4, 2003, at http://dcccps.nci.nih.gov/eocc/july_aug_01/hispanic.html.