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Award Number: DAMD17-00-1-0061

TITLE: 7th Biennial Symposium on Minorities, The Medically Underserved and Cancer

PRINCIPAL INVESTIGATOR: Armin D. Weinberg, Ph.D.

CONTRACTING ORGANIZATION: Baylor College of Medicine
Houston, Texas 77030

REPORT DATE: February 2001

TYPE OF REPORT: Final Proceedings

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Distribution unlimited;
approved for public release

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 074-0188

1. AGENCY USE ONLY (Leave blank)

2. REPORT DATE
February 2001

3. REPORT TYPE AND DATES COVERED
Final Proceedings (9 Feb 00 - 28 Feb 01)

4. TITLE AND SUBTITLE
7th Biennial Symposium on Minorities, The Medically Underserved and Cancer

5. FUNDING NUMBERS
DAMD17-00-1-0061

6. AUTHOR(S)
Armin D. Weinberg, Ph.D.

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)
Baylor College of Medicine
Houston, Texas 77030

E-MAIL:
arminw@bcm.tmc.edu

8. PERFORMING ORGANIZATION REPORT NUMBER

9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)

U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

10. SPONSORING / MONITORING AGENCY REPORT NUMBER

11. SUPPLEMENTARY NOTES
Report contains color graphics.

12a. DISTRIBUTION / AVAILABILITY STATEMENT
Distribution unlimited; approved for public release

12b. DISTRIBUTION CODE

13. ABSTRACT ***(Maximum 200 Words)***

The Biennial Symposium on Minorities, Medically Underserved & Cancer was initiated in 1987 to address the disproportionate cancer morbidity and mortality among minorities and persons of low level income in the United States. The Symposium goals are to: (1) exchange the latest scientific and treatment information and to share strategies for reducing the disproportionate cancer burden in the targeted communities; (2) increase the awareness and competence of health care providers, researchers, laypersons and survivors in the areas cancer prevention, early detection and treatment; and (3) promote culturally competent cancer care and services as well as ethnically balanced research, especially clinical trials.

The target audience of the Biennial Symposium includes health professionals and researchers, survivors and volunteers, policy makers and representatives of the media, from both the public and private sectors, share their experiences in four days of lectures, case presentations, panel discussions, program demonstrations, question and answer sessions, educational exhibits and poster presentations, and awards ceremonies.

For the 7th Biennial Symposium, registrants numbered 1,115. There were a total of 92 presentations and posters by health professionals, with 58 presentations and posters by undergraduate and graduate students. Conference proceedings were published in a special supplement to the journal *Cancer*.

14. SUBJECT TERMS
Cancer, minorities, medically underserved

15. NUMBER OF PAGES
119

16. PRICE CODE

17. SECURITY CLASSIFICATION OF REPORT
Unclassified

18. SECURITY CLASSIFICATION OF THIS PAGE
Unclassified

19. SECURITY CLASSIFICATION OF ABSTRACT
Unclassified

20. LIMITATION OF ABSTRACT
Unlimited

NSN 7540-01-280-5500

Standard Form 298 (Rev. 2-89)
Prescribed by ANSI Std. Z39-18
298-102

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2/28/01

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INTRODUCTION

There is a disproportionate incidence of cancer morbidity and mortality among minorities and persons of low level income in the United States. The disparities suffered by these groups have been documented through published reports. There is a critical need to develop knowledge and strategies to address this crisis with the leadership and full participation of the affected communities. The Minorities, Medically Underserved & Cancer Biennial Symposium Series was initiated in 1987 to provide a multicultural forum for this purpose. The overall goals of the symposium series are to (1) exchange the latest scientific and treatment information and to share strategies for reducing the disproportionate incidence of cancer morbidity and mortality among minorities and the medically underserved in the United States; (2) increase the awareness and enhance the competence of health care providers, researchers, laypersons and survivors in the areas of primary and secondary cancer prevention, early detection and treatment; and (3) promote culturally competent cancer care and services and ethnically balanced research, especially clinical trials. The success of the Biennial Symposium series has largely been due to the broad range of participants' backgrounds and opportunities to learn from one another. Health professionals and researchers, survivors and volunteers, policy makers and representatives of the media, from both the public and private sectors, share their experiences in four days of lectures, case presentations, panel discussions, program demonstrations, question and answer sessions, educational exhibits and poster presentations, and awards ceremonies.

BODY

This report summarizes evaluation survey data from 223 Symposium participants, representing a response rate of 20% for the 1,115 registrants. (See Appendix A.) The large majority of respondents (87.4%) felt the overall program was good (29.3%) - excellent (58.1%). As described below, there were clear patterns reflecting certain popular elements as well as some particular areas of complaint.

Content and Presentation.

Perhaps most encouraging is that 94.5% of the respondents indicated that they would both attend another Biennial Symposium on Minorities, the Medically Underserved & Cancer and also recommend the next Symposium to their colleagues. For 72.2%, the Symposium meets needs that they cannot otherwise meet and 35.6% indicated they do NOT have access to other resources that meet educational needs addressed by the Symposium.

From 82.2% - 90.4% indicated that the Symposium met its various goals. Conversely, 9.2% - 20.7% indicated that the Symposium only somewhat met its goals. Only one person (0.5%) responded that the Symposium did not meet its goals. As to meeting their personal objectives, 78.3% indicated "Yes" and 20.7% indicated "Somewhat". The amount of new information learned ranged from 1% to 98%, with a median of 50%. Regarding how applicable the content would be to their professional activity, 56.2% responded "moderately" and 35.5% responded "occasionally". Similarly, 64.8% indicated that they were "very confident" and 32.4% "somewhat confident" that they will be able to use the skills and knowledge they learned at the conference.

Regarding the conference format, 97.1% considered it to be appropriate. Presenters, their presentations, and session moderators were rated as clear, encouraging questions, provoking interesting discussions, and providing appropriate time for adequate learning by 63.9%-78.1% of respondents.

Attendance, Advertising, and Marketing

Professional representation included 27.5% health educators, 24.8% nurses, 8.6% health care administrators, 6.8% social workers, and 4.1% physicians, with 28.4% indicating "other". The most important factors influencing attendance at the Symposium were "topics/content" (50.0%) and expertise of the presenters (33.7%). These were followed by the opportunity for exchange of ideas with colleagues (7.7%) and the conference registration fee (3.8%). Only 1.0%-1.9% indicated that time, location, or need for continuing education credit influenced their decision to attend. In context of continuing education, commercial or promotional bias was noted by 4.9%, and somewhat so by an additional 7.8%.

Regarding advertising of the Symposium itself, respondents indicated that they heard about the Symposium primarily from a mailer (29.1%), brochure (25.6%), or a colleague (25.1%). These were followed by their employer (19.7%), word of mouth (17.0%), and "other" (14.8%). Least impact was from the Internet (9.9%) and journal ads (1.8%).

Logistics

In general, good-excellent ratings were given to the location of the Symposium (88.5%), the registration process (84.5%), and accommodations (80.1%). There was somewhat less satisfaction with other aspects of conference logistics, with good-excellent ratings of 63.5% for audiovisual support (34.1% poor-fair, indicating that the rooms were sometimes not properly dimmed or were at times too dark; or that computer set-ups in workshops was not smooth.); 63.0% for room comfort (35.7% felt the rooms were too cold and dark); 59.6% for conference length (36.4% felt it was only poor - fair, i.e., too long); and 56.9% for meals and breaks (42.2% gave ratings of poor-fair, complaining primarily of poor service, long lines, not enough food at times for such a large number of attendees, and nutritionally unhealthy foods for some of the breakfasts and snacks.).

Comments

When asked what they liked **most** about the conference, respondents commented most about the following: (1) high quality and expertise of the presenters; (2) the large amount, variety, and diversity of information presented and learned as well as the makeup of the participants; and (4) the opportunity to network. Less often cited were the (1) evening dinners and receptions, (2) experience or sessions related to specific ethnic groups or target populations; (3) student presentations and mentoring; (4) pre-symposium workshops and concurrent working groups; and

(5) the opportunity to interact with leaders from NCI and government; and (6) generally good organization.

When asked what they liked **least** about the conference, commonly repeated themes included (1) time, e.g., too long a day, starting too early in the morning and/or lasting too late at night; too many sessions, too much content for a limited time, too much overlap of sessions so that participants could not attend all the sessions they wanted; conversely, no repetition of popular concurrent sessions so that more people could attend; (2) food and meals, including quantity, quality, and organization; (3) not enough sessions on specific cancers, types of intervention or outreach methods, or particular ethnic groups and target populations; (4) not enough or no handout materials for presentations and workshops, and especially so that participants could get materials from concurrent sessions that they had to miss; (5) ballrooms too cold; and (6) generally poor organization.

When asked about additional topics for which they would like more information, respondents listed (1) funding for research and program interventions, including where the resources are and skills training in writing grant proposals; (2) more opportunities to interact with government officials and legislators; (3) specific cancer sites and target groups not covered sufficiently during the Symposium; (4) more on cultural competence and specific differences among groups as to how they perceive cancer and cancer risk; (5) genetics, treatment issues, and survivorship; (6) model projects; (7) software and technology for both education and screening/diagnosis; (8) advocacy

Comments about commercial and promotional bias suggest that participants did not always understand the nature of commercial or promotional bias according to the standards of continuing education. Nevertheless, especially noted were the presence of supporters such as Kellogg Corporation and the cattlemen's association. Some felt that there was a certain amount of "political bashing" and, from another perspective, putting down pharmaceutical companies even though they provide financial support for the Symposium.

KEY RESEARCH ACCOMPLISHMENTS

	Abstracts Submitted	Oral Presentations Accepted	Poster Presentations Accepted
Professional	165	42	50
Student	172	33	25

REPORTABLE OUTCOMES

- The 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer conference was held February 9-13, 2001, in Washington, D.C.
- N registered attendance = 1,115
- Publication: Wyatt SW, Jones LA, McGinnis LA, Weinberg AD, eds. Proceedings of the Intercultural Cancer Council 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer: Addressing the Unequal Burden of Cancer. *Cancer* 91/1, January 1, 2001, Supplement.

CONCLUSIONS

The large majority of evaluation responses were quite positive about the overall Symposium. However, there has developed an "embarrassment of riches" with regard to a sustained registration of over 1,000 coupled with what some perceive to be too much program crowded into too many days. Some comments reflect a desire a less pressured schedule combined with more "take home" skills, e.g., training in grant writing, proven community outreach models, and strategies for advocacy at the local level. As to advertising the next Symposium, it is to be expected that the Internet will grow in usefulness and consequent cost-benefit. Journal ads may not be cost effective unless they are provided gratis by the targeted journals.

REFERENCES

Wyatt SW, Jones LA, McGinnis LA, Weinberg AD, eds. Proceedings of the Intercultural Cancer Council 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer: Addressing the Unequal Burden of Cancer. *Cancer* 91/1, January 1, 2001, Supplement.

APPENDIX A

7th Biennial Symposium on Minorities, the Medically Underserved & Cancer
February 9-13, 2000
PROGRAM EVALUATION OF OVERALL SYMPOSIUM

Survey Responses
N Responding = 223

At the end of the Symposium, or before you leave, please complete the following evaluation and return it to the Registration Desk. Thanks!

	Yes	Some-what	No
1. Were the Symposium's goals met?			
a) Exchange the latest scientific and treatment information and to share strategies for reducing the disproportionate incidence of cancer morbidity and mortality among minorities and the medically underserved in the United States.	90.4%	9.2%	.5%
b) Enhance the competency of health care providers, laypersons and survivors in the areas of primary and secondary cancer prevention, early detection and treatment	82.2%	17.3%	.5%
c) Promote culturally competent cancer care and services and ethnically balanced research, especially clinical trials.	85.6%	13.4%	.5%
2. Were your personal objectives for attending the symposium met?	78.3%	20.7%	.9%

3. What percentage of the information presented was new to you?

Range	1.0% - 98%
Median Response	50%

4. a) What is your profession? (Check the ***one*** category that best describes your work.)

a. physician	4.1%
b. social worker	6.8%
c. health care administration	8.6%
d. nurse	24.8%
e. health educator	27.5%
f. other	28.4%

b) Will the content be applicable to your practice or professional activity? (please check only **one**)

a. Not applicable at all	7.8%
b. Occasionally applicable	35.5%
c. Moderately applicable	56.2%
d. Frequently applicable	.5%

5. How confident are you that you will be able to use the skills and knowledge you learned at this conference? (please check only **one**)

a. Not confident at all	.5%
b. Not very confident	2.3%
c. Somewhat confident	32.4%
d. Very confident	64.8%

6. Was the conference format appropriate for the content presented?

Yes	97.1%
No	2.9%

(NOTE: Comments for the following sections are summarized in the body of this report.)

7. What did you like **most** about this conference? (please be specific!)

8. What did you like **least** about this conference? (please be specific!)

9. What other topics do you want more information on? (Please be as specific as possible)

10. How did you hear about this conference? (Please select as many as apply)

a.	Journal ad	1.8%
b.	The Internet	9.9%
c.	word of mouth	17.0%
d.	My employer	19.7%
e.	mailer	29.1%
f.	A colleague	25.1%
g.	Brochure	25.6%
h.	other (See Appendix D.)	14.8%

11. What was the **single most** important factor that influenced your attending this conference? (Please select only **one**)

a.	day and time were convenient	1.0%
b.	location	1.9%
c.	needed the CME hours/CEUs	1.9%
d.	registration fee/conference	3.8%
e.	opportunity for exchange of ideas with colleagues	7.7%
f.	expertise of presenter	33.7%
g.	topic/content	50.0%
h.	other (See Appendix E.)	7.2%

Please rate the following: (please ✓ your response)	**Poor**	**Fair**	**Good**	**Excellent**	**Not Applicable**
12. Location	1.4%	9.7%	20.4%	68.1%	.5%
• City = fair. Hotel = poor					
13. Length of conference	9.9%	26.5%	31.8%	27.8%	-
• Too long - not everyone who attended the conference was lodged at the Hotel. The 7:30 hour was very difficult for DC area commuters • Too long • Could be shorter, tighter (some repetition of same info) • A little long • Too early! Too long! Too cold! • Too long					
14. Room comfort (temperature, seating, lighting)	5.6%	30.1%	33.8%	29.2%	1.4%
• Very cold! • Too cold • (tended to be too cold + dark at times)					
15. Registration process	1.4%	13.6%	25.8%	58.7%	.5%
16. Audiovisual support	5.1%	29.0%	29.9%	33.6%	2.3%
• Need more attention to dimming lights during presentations. I would like to commend the AV staff - they were VERY helpful, accessible, + friendly!!					
17. Accommodations	1.4%	10.9%	29.4%	50.7%	7.6%
• Too expensive • Little opp. For physical activity given scheduling - would be nice to negotiate free gym access given that this is a health conference • See pg #3 • More attention to disabled participants accessibility					
18. Meals and breaks	16.0%	27.2%	30.5%	26.3%	-
• Too expensive • Breakfasts were unhealthy, inadequate. Don't advertise it if you are not going to be able to really feed people. Reception Th PM - should have been dinner if you want people to sit till 9 pm. Lunches were pretty good. Don't have unhealthy food offered at meals: eg Kelloggs - junk @ breakfast. Walk the talk w/ nutrition! More low fat desserts • Service was the main problem. • Some poor, some excellent • See #8 above, also could be more healthy offerings • Thurs brft: 6 toaster slots for 1000 people! • Long lines					
19. Overall Program	-	12.6%	29.3%	58.1%	-

Regarding the overall Symposium, please rate the following: (Please ✓ your response.)

	Yes	**Somewhat**	**No**
20. Was the length of time adequate for learning?	69.3%	26.8%	3.4%
• Too much info for any one conference [response was "no"			
• Some sessions rushed, eg coding + data session			
21. Did the presenters:			%
a. Present the information in a clear and logical manner?	69.7%	28.3%	2.0%
• In some general sessions, the lack of time at end was a deterrent [response was "no"]			
b. Encourage questions?	69.0%	27.9%	3.0%
• So many were behind time that often questions were skipped.			
• Too much info for any one conference [response was "no"]			
• Not enough Q+A time usually			
c. Provide appropriate answers to questions?	71.6%	25.8%	2.6%
• Not enough Q+A time usually			
22. Did the moderators' comments and/or questions provoke interesting discussion?	63.9%	29.2%	6.9%
23. Did the visuals contribute to the presentations?	78.1%	20.9%	1.0%
• Some hard to see			
24. Would you attend another Biennial Symposium on Minorities, the Medically Underserved & Cancer?	94.5%	5.5%	-
• Absolutely			
25. Would you recommend the next Biennial Symposium on Minorities, the Medically Underserved & Cancer to your colleagues?	94.6%	4.9%	.5%
26. Did the Biennial Symposium on Minorities, the Medically Underserved & Cancer meet needs that you cannot otherwise meet?	72.2%	21.5%	6.3%
• Mainly networking			
27. Do you have access to other resources that meet the educational needs addressed by the Biennial Symposium on Minorities, the Medically Underserved & Cancer	53.5%	35.6%	10.9%
28. Did you note any commercial or promotional bias in the program?	4.9%	7.8%	87.4%

- Good question [response was "no"]

If Yes, please describe:

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January 1, 2001

CANCER

SUPPLEMENT

Proceedings of the Intercultural Cancer Council 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Washington, DC
February 9-13, 2000

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ISSN 0008-543X CANCAR

Proceedings of the Intercultural Cancer Council 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Addressing the Unequal Burden of Cancer

Grand Hyatt Washington
Washington, DC
February 9–13, 2000

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STAFF

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Symposium Proceedings Contributing Authors

La Salle D. Leffall, Jr., MD
Howard University Hospital
Washington, DC

Stephen W. Wyatt, DMD, MPH
University of Kentucky
Lexington, Kentucky

Lovell A. Jones, PhD
University of Texas M.D. Anderson Cancer Center
Houston, Texas

Armin D. Weinberg, PhD
Baylor College of Medicine
Houston, Texas

LaMar S. McGinnis, MD
American Cancer Society
Atlanta, Georgia

Charles J. McDonald, MD
Rhode Island Hospital, Brown University
Providence, Rhode Island

Nancy C. Lee, MD
Centers for Disease Control and Prevention
Atlanta, Georgia

David Satcher, MD, PhD
Assistant Secretary for Health and Surgeon General
US Department of Health and Human Services
Washington, DC

Michel P. Coleman, MD
London School of Hygiene and Tropical Medicine
London, United Kingdom

Penny Babb, PhD
National Cancer Intelligence Centre
Office for National Statistics
London, United Kingdom

Andy Sloggett
London School of Hygiene and Tropical Medicine
London, United Kingdom

Mike Quinn
National Cancer Intelligence Centre
Office for National Statistics
London, United Kingdom

Bianca De Stavola
London School of Hygiene and Tropical Medicine
London, United Kingdom

Thomas E. Perez
US Department of Health and Human Services
Office for Civil Rights
Washington, DC

Francis S. Collins, MD
National Human Genome Research Institute
National Institutes for Health
Bethesda, Maryland

Monique K. Mansoura, PhD
National Human Genome Research Institute
National Institutes of Health
Bethesda, Maryland

Marjorie Kagawa-Singer, PhD, MN, RN
UCLA School of Public Health and Asian American Studies
Los Angeles, California

Vickie L. Shavers, PhD
Johns Hopkins University
Baltimore, Maryland

Charles F. Lynch, MD, PhD
University of Iowa
Iowa City, Iowa

Leon F. Burmeister, PhD
University of Iowa
Iowa City, Iowa

Mona M. Fouad, MD
University of Alabama at Birmingham
Birmingham, Alabama

Edward Partridge, MD
University of Alabama at Birmingham
Birmingham, Alabama

Theresa Wynn, PhD
University of Alabama at Birmingham
Birmingham, Alabama

B. Lee Green, PhD
University of Alabama at Birmingham
Birmingham, Alabama

Connie Kohler, PhD
University of Alabama at Birmingham
Birmingham, Alambama

Stephen Nagy
University of Alabama
Tuscaloosa, Alabama

James W. Hampton, MD
Troy and Dollie Smith Cancer Center
University of Oklahoma College of Medicine
Oklahoma City, Oklahoma

Gilbert H. Friedell, MD
University of Kentucky
Lexington, Kentucky

Dileep G. Bal, MD
California Department of Health Services
Sacramento, California

Thomas J. Glynn, PhD
American Cancer Society
Washington, DC

Gerald L. Woolam, MD
Texas Tech University
Lubbock, TX

Christopher N. H. Jenkins, MA, MPH
University of California, San Francisco
San Francisco, California

Chau Buu, MD, MPH
Harris County Health Department
Houston, Texas

Wendy Berger, MPH
Los Angeles County Immunization Program
Los Angeles, California

Don T. Son, MD
University of Texas Southwestern Medical Center
Dallas, Texas

Elizabeth A. Jacobs, MD
Cook County Hospital
Chicago, Illinois

Diane S. Lauderdale, PhD
University of Chicago
Chicago, Illinois

Dianne N. Ishida, PhD
University of Hawaii at Manoa
Honolulu, Hawaii

Tusitala F. Toomata-Mayer
Queen's Medical Center
Honolulu, Hawaii

Nafanua S. Braginsky
Queen's Medical Center
Honolulu, Hawaii

Thoa Nguyen
University of California, San Francisco
San Francisco, California

Phuong H. Vo, MS
University of California, San Francisco
San Francisco, California

Stephen J. McPhee, MD
University of California, San Francisco
San Francisco, California

Dennis L. Confer, MD
National Marrow Donor Program
Minneapolis, Minnesota

Joan M. Murdock, MHSA, PhD
University of Cincinnati Medical Center
Cincinnati, Ohio

Jack L. Gluckman, MD
University of Cincinnati Medical Center
Cincinnati, Ohio

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Supplement
January 1, 2001

American Cancer Society/Centers for Disease Control and Prevention Perspectives

The American Cancer Society recently set a goal to reduce age-adjusted cancer mortality rates by 50% and age-adjusted cancer incidence by 25% by 2015. With cancer screening and early detection, tobacco control and prevention, new research, and improvements to access to care, the American Cancer Society believes it can reach this goal.

There is unequal quality of cancer care in the United States, and there is a disproportionate cancer burden among racial and ethnic minority populations. A concerted effort is needed from public and private groups that are willing to work together to address the economic, behavioral, and systemic factors that affect the use of cancer control services.

Disease Burden

The unequal burden of cancer among ethnic minorities and the medically underserved represents one of public health's most difficult challenges. Addressing this problem will require an unwavering commitment to finding real solutions.

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Michel P. Coleman, Penny Babb, Andy Sloggett, Mike Quinn, and Bianca De Stavola

Socioeconomic differences in cancer survival were identified for 44 of 47 adult cancers in England and Wales over the period 1971–1995 after adjustment for socioeconomic differences in background mortality. Elimination of these inequalities would have avoided approximately 2500 deaths that occurred each year within 5 years of diagnosis.

Policy Issues

217 **Health and Civil Rights**

Thomas E. Perez

Racial discrimination is one factor that contributes to racial and ethnic disparities in health. Eliminating racial and ethnic disparities is both a civil rights and a public health challenge, and the Office for Civil Rights at the U.S. Department of Health and Human Services is working to eliminate discriminatory barriers that may prevent communities of color from accessing quality health care.

221 **The Human Genome Project: Revealing the Shared Inheritance of All Humankind**

Francis S. Collins and Monique K. Mansoura

The Human Genome Project has generated information with the potential to revolutionize the practice of medicine. In addition, genetic research raises complex ethical, legal, and social issues. To be truly successful, the information derived from the Human Genome Project and the benefits of genetic research must reach everyone.

226 **From Genes to Social Science: Impact of the Simplistic Interpretation of Race, Ethnicity, and Culture on Cancer Outcome**

Marjorie Kagawa-Singer

Over the last 30 years, dramatic advances have been made in the understanding of the cell biology of cancer and the genetic changes involved in oncogenesis, and overall, cancer mortality has decreased significantly. To accelerate these trends, the American Cancer Society set goals for the year 2015 to reduce the burden of cancer in the U.S. However, to achieve these goals changes must occur in cancer control research and programming. Greater resources must be directed toward social and behavioral research and conceptual clarity must be developed so that refinements can be made in the methodologies used to study the effects of cultural differences on health behavior.

233 **Factors That Influence African-Americans' Willingness to Participate in Medical Research Studies**

Vickie L. Shavers, Charles F. Lynch, and Leon F. Burmeister

The underrepresentation of African-Americans among medical research participants is receiving considerable attention because of recent government mandates for the inclusion of all racial/ethnic groups in human subject research. In the current study, the authors attempt to determine factors that affect the willingness of racial/ethnic minorities to participate in medical research studies.

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Statewide Tuskegee Alliance for Clinical Trials: A Community Coalition to Enhance Minority Participation in Medical Research

M. Fouad, E. Partridge, T. Wynn, B. L. Green, C. Kohler, and S. Nagy

Cancer mortality rates for all anatomic sites are reported to be nearly 2.5 times greater for African-Americans compared with whites and data exist that indicate cancer treatment outcomes for minorities are unfavorable compared with whites. Whether this is due to poor access to health care or a biologic property of the malignancies occurring in specific populations remains to be determined. However, targeting minorities for clinical trials may contribute to the reduction of the overall morbidity and mortality associated with specific cancers.

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Cancer Surveillance: A Problem for Native Americans and Appalachian Populations

James W. Hampton and Gilbert H. Friedell

Cancer surveillance in two populations, the Native American population and the rural, poor, predominantly white population of Appalachia, demands more attention from the data collectors because of the problem with racial misclassification of the former and the sparse information on the socioeconomic status of the latter. It would be incorrect to assume that progress in the national fight against cancer is being met for these populations.

Primary and Secondary Prevention Issues

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Tobacco Wars: The Successes, the Challenges, and Some Failures

Dileep G. Bal, Thomas J. Glynn, and Gerald L. Woolam

The war on tobacco use has resulted in the development of specific methods and strategies that can be effective. The implementation of these methods will become crucial in the United States and worldwide, with the health burden of tobacco use expected to increase geometrically unless there is some dramatic action taken.

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Liver Carcinoma Prevention among Asian Pacific Islanders: Getting Hepatitis B Shots into Arms

Christopher N. H. Jenkins, Chau Buu, Wendy Berger, and Do T. Son

Under current immunization practices, the authors estimate that nearly 13,000 Asian and Pacific Islander children living in the United States today will become infected with the hepatitis B virus, resulting in more than 600 liver carcinoma deaths. It is essential that cancer control agencies in the United States take leadership in raising awareness about the role of the hepatitis B virus in the etiology of liver carcinoma and that of the hepatitis B vaccine in preventing it.

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Receipt of Cancer Screening Procedures among Hispanic and Non-Hispanic Health Maintenance Organization Members

Elizabeth A. Jacobs and Diane S. Lauderdale

The objective of this study was to examine whether Hispanic patients in health maintenance organizations (HMOs) receive cancer screening at the same rate as a general patient population when both groups are insured and have a regular source of care. The authors found that under these conditions Hispanic HMO members receive cancer screening at the same high rate as a general HMO population.

Treatment Research

CANCER American Cancer Society®

91/1 Supplement
January 1, 2001

Interdisciplinary International Journal of the American Cancer Society

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CANCER (ISSN 0008-543X) is published semi-monthly except tri-monthly in February, April, June, August, October, and December, for the American Cancer Society by Wiley-Liss, Inc., a subsidiary of John Wiley & Sons, Inc., 605 Third Avenue, New York, NY 10158-0012, (212) 850-6995, toll-free (800) 511-3989. Periodicals postage paid at New York, NY, and at additional mailing offices. Send subscription inquiries to: John Wiley & Sons, Inc., Subscription Department, 605 Third Avenue, 9th Floor, New York, NY 10158-0012. Annual subscription prices: 30 issues (includes 6 issues of CANCER CYTOPATHOLOGY section): Institutional rate: Within United States, $437.00; Canada and Mexico, $577.00; all other countries except Japan, $655.00. Individual rate: Within United States, $219.00; Canada and Mexico, $304.00; all other countries except Japan, $414.00. 24 issues—CANCER only—Individual rate: Within United States, $165.00; Canada and Mexico, $250.00; all other countries except Japan, $312.00. 6 issues—CANCER CYTOPATHOLOGY only—Individual rate: Within United States, $72.00; Canada and Mexico, $72.00; all other countries except Japan, $107.00. Add 7% GST for all Canadian orders; Wiley's GST number is R891028052. All subscriptions outside the U.S. will be sent by air. Payment must be made in U.S. dollars drawn on a U.S. bank. All payments for CANCER must be sent to John Wiley & Sons, Inc., P.O. Box 7247-7126, Philadelphia, PA 19170-7126

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INDEXED BY: BIOSIS, Chemical Abstracts Service, Current Contents/Clinical Medicine, Current Contents/Life Sciences, Index Medicus/MEDLINE, Reference Update, Research Alert (ISI), Science Citation Index (ISI), SCISEARCH Database (ISI).

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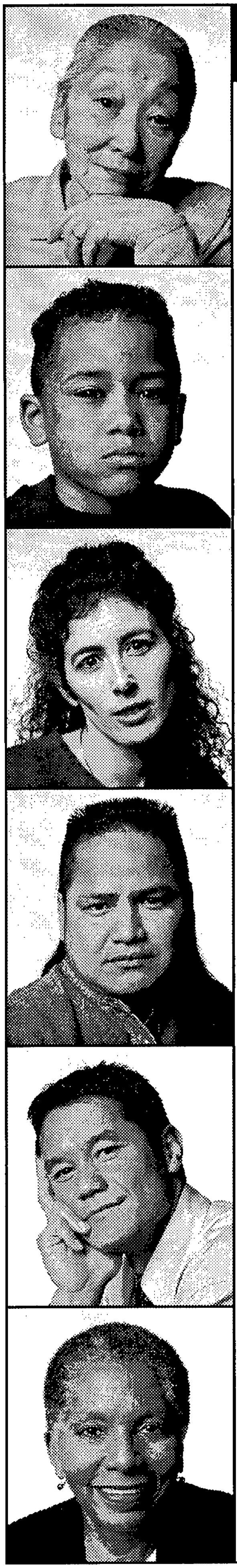

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Foreword

I would like to thank the co-chairs of the Intercultural Cancer Council, Dr. Lovell Jones and Dr. Susan Shinagawa, for helping bring this Symposium together. I also would like to thank our special symposium guests who have authored articles for this supplement to *Cancer:* Dr. David Satcher, Surgeon General and Assistant Secretary of Health, Dr. Charles McDonald, immediate past president of the American Cancer Society; Dr. Francis Collins, Director, National Human Genome Research Institute; and Thomas Perez, Director, Office of Civil Rights, United States Department of Health and Human Services.

It was my pleasure to provide opening remarks for the Intercultural Cancer Council (ICC) 7th Biennial Symposium on Minorities, the Medically Underserved, and Cancer, which was held in Washington DC from February 9–13, 2000. We convened the nation's foremost experts on a wide array of issues to:

- exchange the latest scientific and treatment information and to share strategies for reducing the disproportionate incidence rate of cancer morbidity and mortality among minorities and the medically underserved in the U.S.
- increase the awareness and enhance the competence of health care providers, researchers, laypersons, and survivors in the areas of primary and secondary cancer prevention, early detection, and treatment; and
- promote culturally competent cancer care and services and ethnically balanced research

This symposium and the presence of each attendee speaks volumes on their commitment to helping the communities they serve. I ask that they continue their commitment and dedication to the mission of the ICC, which proudly sponsors the Biennial Symposium Series.

As we are well aware, the ICC promotes policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the U.S. and its associated territories.

The Symposium had a full itinerary of activities, including:

- A congressional reception on Capitol Hill, hosted by Senator Kay Bailey Hutchinson and Representative Ken Bentsen of Texas;
- A wide spectrum of informative and interactive workshops;
- A public policy luncheon to address the "Unequal Burden of Cancer in the 21st Century" featuring Senator Patrick Kennedy and Representative John Lewis;
- The Cancer Education Resources Program;
- A spectacular survivorship reception featuring Eric Davis of the St. Louis Cardinals;
- The graduate and undergraduate oral presentations;
- The HOPE and Height Awards Celebration;
- The La Salle D. Leffall, Jr. Awards Banquet;
- And, back by popular demand, the Great American Poster Picnic.

Nearly 30 years ago, President Richard Nixon signed the National Cancer Act, a measure that infused funds, resources, and personnel to conquer cancer. The 21st century now is upon us, and our generation and new generations of young Americans bear witness every day to new advances and technologic improvements that were never dreamed possible.

However, unfortunately not all Americans have shared in this progress. For far too long, core segments of our country, our ethnic minority and medically underserved populations, have been overlooked, not studied adequately, or omitted entirely from research and access to care that are key to saving the lives of millions of Americans.

If we apply all we currently know regarding cancer prevention, control, and treatment and continue to make advances in research, we can reduce the cancer incidence rate by 25% and cancer mortality by 50% among the ethnic minority and medically underserved populations in the U.S.

Think about what that simple statement is saying: reorder funding priorities!

In the war on cancer we may have won some skirmishes but we still are losing the battle against cancer in our minority and medically underserved populations.

Although cancer is indiscriminate (striking all people, regardless of race, color, or creed), it is a fact that minorities and the medically underserved continue to suffer much higher cancer mortality rates.

- African-American men still have the highest rates of prostate carcinoma in the world: 32 times higher than among white American men;
- Although endometrial carcinoma has decreased 27% in white women, it actually is on the rise in African-American women;
- Hispanic and African-American women are twice as likely as the majority of white women to develop cervical carcinoma, but the incidence rate of cervical carcinoma in the rural, poor communities of central Appalachia also is as high as that for Hispanic and African-American women;
- Although 85% of non-Hispanic women survive breast carcinoma after 5 years, only 76% of Hispanic/Latina women will survive;
- American Indians and Alaska Natives have the poorest survival rates from most cancer sites than any other racial or ethnic group in the U.S.;
- The death rate among American Indians due to tobacco usage is twice that of the U.S. population;
- Deaths due to cancer have increased at a faster rate among Asian-Americans and Pacific Islanders than any other racial/ethnic population;
- Poor white men in central Appalachia have the highest mortality rates from lung carcinoma in the U.S.;
- In fact, our medically underserved communities share the same unequal burden of cancer; for example, the cancer mortality rate is > 33% higher in Wirt County, West Virginia, than the mean for the entire nation.

The reality for poor communities and people of color in the U.S. is a parade of horribles:

- a disproportionately high incidence rate of cancers, many of them preventable;
- a disproportionately high mortality rate for treatable or curable cancers;
- an excessive morbidity rate for treatable side effects and associated problems from cancer; and
- a devastating and heartbreaking diminished period of survival.

The bottom line is that people have died of cancer when they should not have died, and people still are dying of cancer when they should not be dying, at least not in this country. Without a major change in strategy and a reordering of funding priorities, the U.S. will lose the war on cancer altogether! We no longer can ignore the unequal burden of cancer in our fastest growing (our minority and medically underserved) populations.

Last year, at the ICC's urging, Congress asked the Clinton Administration to increase the emphasis on cancer in ethnic minority and medically underserved populations. The Fiscal Year 2000 Omnibus Appropriations report encouraged the National Institutes of Health (NIH) to develop a strategic plan to address the recommendations in the January 1999 Institute of Medicine (IOM) report on these issues. We urge the NIH to produce this strategic plan without further delay.

We also have urged the NIH to increase funding for:

- population, behavioral, sociocultural, communications, and community-based research;
- expansion of recruiting and training efforts to attract more individuals from ethnic minority and medically underserved populations in all areas of cancer research;
- increased coordination with the Centers for Disease Control and Prevention (CDC) to improve the country's efforts in cancer prevention and control, diagnosis and treatment, and data collection and management;
- improved dissemination of research results; and
- the expansion and enhancement of the nation's surveillance capabilities, for without accurate and comprehensive data, we will never know whether we truly are successful in addressing our nation's health disparities.

The ICC is young, but it stands tall as the only organization in the U.S. dedicated to eradicating the unequal burden of cancer in minority and medically underserved populations.

Our concern is not unfounded, for time and again we have witnessed unfulfilled promises and commitments that never make it out of committee, all while people's lives and health are on the line. We commend Senators Arlen Specter, Tom Harkin, and Connie Mack and Representatives Nancy Pelosi and Jesse Jackson Jr. for their successful efforts to spur the NIH to focus more cancer research funding in Fiscal Year 2000 on minority and medically underserved populations in the U.S. For Fiscal Year 2001, we call on Congress to double the funding for cancer research and cancer control targeted to address the unequal burden of cancer. The President's budget requests take us a few steps forward, but it is time for a marathon! The ICC will work as a catalyst for that change. For too long, minorities and other medically underserved groups have been excluded from critical research, and have been denied the opportunity to fight for their lives.

I am sure I can count on the ICC to make the change so that the federal government no longer overlooks and underfunds the plight of these communities. I challenge each of us to make this an issue with the presidential candidates and each of our members of Congress. We will seek the commitment of candidates and legislators to endorse, support, and advocate for additional federal funding dedicated to serving the populations the ICC represents. And they should listen, because although they may not realize it now, these audiences will be the crucial and much coveted swing votes that candidates from both parties will be trying to secure. The ICC strongly urges that the candidates include ICC action items as part of their platforms and gain their support and commitment as a campaign promise that the ICC can count on in the future.

The ICC also strongly urges the Clinton Administration and Congress to redouble their efforts to launch an aggressive, comprehensive, and multidimensional program to close the gap and reverse the disastrous upward trend in cancer incidence and mortality rates among the nation's fastest growing populations.

The ICC reiterates its call on the NIH to act on Congress's directive to begin accountable implementation of a 5-year strategic plan, with targeted funding to implement the recommendations of the January 1999 study by the IOM.

At the 7th Biennial Symposium, we asked the directors of the NIH and the National Cancer Institute to report to us on the ways they are implementing the IOM's recommendations. We should continue to request and challenge these organizations to do more and spend more of their funds on research and cancer control activities targeted toward our minority and medically underserved populations.

We will continue to wage war on the tobacco companies. We must turn up the heat and force their hand. In what has become the latest and most recent ploy by the tobacco companies, the maker of Virginia Slims cigarettes, currently is running an ad campaign that targets young, minority women. Having been stopped from marketing their deadly, carcinogenic products to teens, the company now has set its sights on minority women, and placed them directly in the line of fire. Their campaign overtly wages war on America's minority women. We must take action and compel them to stop the strategic targeting of the nation's minority populations.

This is the worst kind of enemy to have. They will spare no expense and leave no stone unturned to achieve their goal: to make money at the expense of those least prepared to survive the attack. They have set their sights on minority women, and would gladly make a profit at the expense of their well-being and health. We implored all attendees to encourage their representative organizations and solicit their support to join with the ICC; the American Indian, Alaska Native, and Hawaiian Caucus (in affiliation with the American Public Health Association [APHA]); Asian and Pacific Islander American Health Forum; Atlanta Campaign Against Marlboro Milds; Health Care for All; Hispanic/Latino Tobacco Education Network of California; Latino Caucus (in affiliation with APHA); National Black Leadership Initiative on Cancer, South Carolina Coalition; National Black Women's Health Project; Youth UNITED!; and Shape magazine to refuse to accept funding from the tobacco industry.

At this Symposium, we were shocked to learn that states are not using their monies from the state tobacco settlements for cancer control, prevention, and treatment, nor for health in general. We must lobby the appropriate authorities to redirect this funding to fight the war on cancer, especially in minority and medically underserved communities.

The ICC will continue its push for a strategic plan to determine the NIH's implementation of the IOM report recommendations released over 1 year ago.

The ICC will establish benchmarks for measuring funding for the implementation of the IOM recommendations, including what amounts will be targeted to cancer research in minority and medically underserved populations out of the President's proposed $1 billion increase in biomedical research at the NIH as well as the NIH's investment of $20 million to establish a new Center For Research on Minority and Medically Underserved Health.

We will continuously monitor progress to target funding to minority cancer initiatives. We will measure increases, if any, for cancer control, screening, and data collection.

The ICC wants, at a minimum:

- $300 million more for NIH entities directing cancer research, especially for population, behavioral, sociocultural, communications, and community-based research, and for recruiting and training efforts;
- $50 million more for the CDC's Breast and Cervical Cancer Screening Program, a significant in-

crease over the $5 million President Clinton has urged;

- $100 million more to improve cancer data collection and management (with $42 million for the Surveillance, Epidemiology, and End Results (SEER) Program;
- $48 million for the CDC's National Program for Cancer Registries; and
- $10 million for the National Center for Health Statistics to expand the National HANES Survey.

Although the road we have to travel is a long and arduous one, a cure can be found that not only will save lives but will be just as colorblind in curing people with cancer as cancer has been in striking its victims. I ask that you continue to challenge others to help in our mission to conquer cancer.

–La Salle D. Leffall, Jr., M.D., CHAIR

7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Introduction

The Intercultural Cancer Council 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer was held in Washington, DC, February 9–13, 2000. The purpose of the conference was to provide a forum for scientific discussion and the dissemination of information related to cancer in minorities and the medically underserved. This supplement to *Cancer* provides a collection of articles that were presented during that meeting. The articles were reviewed internally by the editorial committee and selected reviewers who are listed. The articles are a portion of those that were presented. Selected articles presented by the student researchers and their mentors have been published in another periodical. The proceedings herein are organized into six sections.

The first section is comprised of the foreword and this introduction. The second section includes the perspectives of two coinitiators of the symposium (the American Cancer Society and the Centers for Disease Control and Prevention). The third section is comprised of articles presented by Surgeon General David Satcher and Dr. Michel Coleman. The fourth section is a broad-based cancer policy section that addresses a variety of critical issues ranging from cancer surveillance to participation in clinical trials and includes a contribution from internationally recognized scientist Dr. Francis Collins. The fifth section includes contributions in the areas of primary and secondary prevention concerning issues ranging from tobacco control to the delivery of preventive services in a managed care setting for a medically underserved population. Finally, the sixth section highlights two critical treatment issues for the medically underserved, including a contribution from Dr. Dennis Confer regarding stem cell transplantation.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

The American Cancer Society Addressing Disparities and the Disproportionate Burden of Cancer

Charles J. McDonald, M.D.

Department of Dermatology, Rhode Island Hospital, Providence, Rhode Island.

As an organization, the American Cancer Society (ACS) recently adopted some simple, but very ambitious goals for the year 2015. We have committed ourselves to reducing age-adjusted cancer mortality rates by 50% and reducing age-adjusted cancer incidence by 25%. We strongly believe these goals are attainable. It is the American Cancer Society's belief that the most important key to reducing death and suffering from cancer is to prevent cancer from occurring in the first place, or, if it does occur, to find it at its earliest, most treatable stage. Further, we believe to achieve these goals, cancer as it exists today in a number of population groups, must be addressed, specifically cancer in ethnic minorities, the poor, the underserved, and the elderly. As we strive to control cancer in these groups, we cannot continue to do business as usual. The data are clear. Certain groups of people are unduly burdened by cancer, and poor Americans are more likely to develop and die from cancer. In addition, today our country is facing a new and distressing problem; unprecedented numbers of people are now moving into older age groups. They are living longer and many are underinsured. We know that cancer risk increases with age; hence, we know that we will soon see a corresponding increase in the absolute numbers of cancer cases—which in turn will cause increased burdens on medical, personal, family, and governmental resources. Currently, older Americans make up 12% of the population but account for approximately 36% of total personal health care costs. Medicare beneficiaries account for greater than 50% of all cancer diagnoses and 60% of cancer deaths. Alarmingly, between the years 2010 and 2030 our aging population will contribute more to overall health care costs than it has in the preceding 80 years.

By making substantial investments in prevention and early detection, the American Cancer Society believes we can begin to control the problem. As we go about the task of achieving our 2015 goals, our plan is to focus on several key areas including:

- Cancer screenings and early detection
- Tobacco control and prevention
- Cancer research
- Access to care.

CANCER SCREENING AND EARLY DETECTION

Greater than half of all cancer cases occur in screening accessible sites such as the breast, prostate, colon, rectum, skin, and cervix. Cancer screening and early detection can actually extend life, reduce treatment, and improve the quality of life for cancer patients. The 5-year

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Address for reprints: Charles J. McDonald, M.D., Department of Dermatology, Brown University, Rhode Island Hospital, APC10, 593 Eddy Street, Providence, RI 02903.

Received April 1, 2000; accepted August 31, 2000.

relative survival rate for cancers of the breast, colon, cervix, and rectum is approximately 77%. This means approximately 77% of patients with cancer in those sites will be alive 5 years after diagnosis. This number would increase to greater than 95% if all Americans participated in regularly scheduled cancer screenings. A side benefit to this higher survival rate is a dramatic cost savings because screenings often allow cancers to be detected in an early stage when treatment is often less expensive. From a quality-of-life perspective, treating cancers early often can be less invasive than treating late stage disease.

I must warn you that there are some who insist that the cost of screening all appropriate individuals is more than the savings we gain from early detection. To counter those claims, I offer the following examples:

- If a colon cancer patient is not diagnosed until symptoms are exhibited, the chance of survival is only 8%, and care during the remaining years of life can cost up to $100,000. However, the survival rate increases to 90% if a patient's colon carcinoma is caught in the very early stages through a screening test that costs approximately $125.
- The cost of treating a rectal carcinoma that is detected early is approximately $6000, or approximately 75% less than the estimated $30,000 to $40,000 that it costs to treat rectal carcinoma detected late in its development.
- Treatment costs for breast carcinoma diagnosed early, before it has metastasized, may be as much as 30% lower than for breast carcinoma diagnosed after it has spread.
- Cervical carcinoma screening among low-income women saves approximately 3.7 years of life and approximately $6000 for every 100 Pap tests performed.

TOBACCO CONTROL AND PREVENTION

At least 30% of all cancer deaths are directly attributed to tobacco use. The most common cancer death is lung cancer, and most of those deaths are preventable. Simply put, it is extremely easy to prevent lung cancer. Just don't smoke. It is quite evident that if we are to substantially impact cancer incidence and mortality in the new millennium, efforts to control the use of tobacco must be part of our strategy. We believe that tobacco control efforts must be prioritized at the national, state, and community level to ensure that future generations of children and adults do not needlessly suffer from tobacco-related disease and death.

We also know that tobacco control and prevention strategies work. Several states with good, comprehensive, tobacco control campaigns have reduced their smoking rates faster than anywhere else in the country. For example, after just a 1-year dedicated, comprehensive tobacco control effort in Florida, 10% of middle school students were less likely to attempt smoking and smoking by high school students fell by 11%.

CANCER RESEARCH

New treatments, new diagnostic tools, and early detection and prevention methods will only come from research. To achieve our 2015 goals, the ACS believes research into the cause and treatment of cancer is fundamental. In addition, a specific type of clinically oriented research, clinical trials, needs to remain high on the agenda. It is through the use of clinical trials that new laboratory findings are translated into real-life applications that improve the detection and treatment of cancer.

Numerous studies have shown that patients participating in approved clinical trials often experience better health outcomes than patients treated independently. And yet, the National Institutes of Health has noted that enrollment in clinical trials is steadily decreasing. Clinical researchers across the country have stated that the refusal of third party payers to cover routine patient care costs for patients enrolled in approved clinical trials is contributing to this decline. If this is true, this is an area that needs to be addressed by all who have an interest in quality care and better health outcomes.

ACCESS TO CARE

When addressing health problems relating to ethnic minorities, the poor, the elderly, and the underserved, access to care is a common underlying theme. Cancer screenings are a sound idea, but it takes considerable effort and time to convince those of modest means to regularly visit a doctor when there are no disease symptoms to speak of. To emphasize early detection is fine, but think of how many in the poor and underserved populations live with nagging disease symptoms and are resigned to accept them as a normal part of life. Yes, patient participation in clinical trials is often beneficial, but if you are not aware of their existence, or don't have adequate transportation, and can't pay for incidentals, or can't read and understand densely written consent forms, then you may not be motivated to find out if a clinical trial is appropriate for you.

We must remember, ensuring access to care is a very important aspect of prevention, early detection, and early treatment.

In summarizing what I have spoken about, we know that the problems are the following:

- Ethnic minorities, the poor, and the underserved are at greater risk for developing and dying from certain types of cancer.
- The U.S. population is aging and cancer is primarily a disease of age. And we feel that we know what some of the solutions are.
- We must increase participation by ethnic minorities, the poor, and underserved in regular cancer screenings.
- We need to prevent people from smoking cigarettes and helping those who do smoke to quit.
- We need to invest more in research.
- We must ensure equal access to quality health care for all Americans.

How then do we create and implement programs to achieve those solutions?

RESEARCH ON HOW BEST TO MEET ACS GOALS

For almost two decades, the Society has engaged in a major initiative to understand and address the needs of populations at high risk for cancer, such as ethnic minorities, the poor, and underserved.

For years we have convened conferences, held public hearings, sponsored sociologic research, issued health reports, funded demonstration projects, conducted health education and outreach, and advocated for changes in public policy.

And in the end, we knew there remained an enormous gap between what we wanted to do and how we should effectively do it. So, we went to the people who are representative of the communities we wanted to help.

We asked, through focus groups and telephone interviews, the opinions of numerous individuals who are members of the targeted populations. In addition to seeking information, we also asked for advice. How can we, as an organization give assurances that there is a commitment to solving the cancer problem throughout the entire nation and in all segments of the population? The overwhelming answer we heard is that people want to know what has been or is being done in the fight against cancer. We heard too that we need to ensure access to good health care, to clinical trials, and to appropriate and effective medicines for all. What did we learn?

- Cancer is the single most identifiable health problem in the community.
- The loss of health care and insurance was the number one critical issue mentioned by the respondents, followed by concern for personal and family health.
- Approximately one-quarter (24.8%) of the respondents said that community members themselves could do the most to solve the health problems in their communities, followed by the government and by health and social service agencies.
- Only 11% of the respondents said they were aware of lawmakers talking about cancer and only 15% said they had confidence that politicians were working to solve the cancer problem.
- 44.3% said they would be willing to help influence the government about cancer.

What is the importance of these findings? And what do they tell us? They are extremely important because they tell us ethnic minorities, the poor and underserved may not trust large majority-run organizations, but they trust each other. They also tell us that our cancer control programs need to be delivered through recognized community resources such as churches and YMCAs, social clubs, and organizations. And just as important, those who were interviewed told us they were willing to help the Society in its government advocacy efforts.

Based on the information I just shared and that from other similar studies, the American Cancer Society has developed numerous cancer control programs in partnership with many local and national community-oriented organizations.

Throughout the organization, in our national nominating process, our deliberations, discussions, and personnel selections, the ACS recognizes that to achieve 2015 goals it needs diversity of opinion and perspective, internally as well as externally.

In addition, the Society strives to make its volunteers and staff better prepared to deliver its cancer control programs in any community by offering training programs, such as "Cultural Diversity and the Workplace," "Recruiting for Diverse Thought," and "Diversity and the Cancer Burden."

The Society's National Government Relations Office in Washington, DC has worked tirelessly in developing collaborative relationships and projects with other national organizations that have extensive grassroots and political influence, particularly those that represent ethnic minorities and underserved populations. The office also is developing a grassroots advocacy network to effectively recruit, educate, and mobilize ACS volunteers, with special emphasis on involving survivors and ethnically and racially diverse constituencies.

The ACS provides some unique resources for the community; among them is our 800 number. Simply by calling 1-800-ACS-2345, one may talk with a trained oncology nurse about specific cancer-related topics or be referred to available resources in his or her community. The information provided by the database in this service is vast. Efforts are underway to translate this database into Spanish and other languages.

In addition to the toll-free number, interested persons can reach the ACS through its web site, HYPERLINK http://www.cancer.org www.cancer.org, where they can learn about the organization, about specific types of cancer, local resources, and more. A process is being developed to enable responses to e-mail messages in languages other than English.

To make a significant and specific impact on the control of cancer, the American Cancer Society has targeted 10% of its annual research budget to support research that will result in greater access to cancer information, detection, and treatment by ethnic minorities, the poor, and the underserved. Research funded under this program will address a variety of behavioral, epidemiologic, public policy, health delivery, and clinical and basic science issues.

Support will be provided to include research on national and local policies that affect the availability of health care and health care delivery to specific population groups. Studies to identify molecular determinants that may put poor and underserved populations at higher risk of cancer incidence and progression, with the specific purpose of developing strategies to overcome or eliminate these risks, also will be considered.

The American Cancer Society feels strongly that achieving parity with regard to cancer incidence and mortality is not solely the responsibility of the government or of health care organizations, it is the responsibility of all of us. And with all of us working together, surely we can make a difference.

I end my discussion with a saying from Frederick Douglass, famous African-American abolitionist, "without struggle there is no progress." As mentioned today, our poor and underserved communities are struggling with the devastating effects of cancer in their community. Although, our nation has made some significant progress in the "war against cancer" more needs to be done. As we embark into the year 2000 and enter a new millennium, many communities still have high rates of cancer mortality. My peers, the struggle continues, and we, as a nation, must remain steadfast for all Americans in our battle against cancer. I challenge all of us to view the elimination of cancer not as a dream deferred but as a reality.

7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

The Unequal Cancer Burden

Efforts of the Centers for Disease Control and Prevention to Bridge the Gap through Public Health

Nancy C. Lee, M.D.

Centers for Disease Control and Prevention, Atlanta, Georgia.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Dr. Lee gratefully acknowledges the assistance provided by her colleague Mary Kaeser in preparing the presentation for the 7th Biennial Symposium and the *Cancer* supplement article.

Address for reprints: Nancy C. Lee, M.D., Centers for Disease Control and Prevention K52, 4770 Buford Highway NE, Atlanta, GA 30341.

Received April 1, 2000; accepted August 31, 2000.

Despite the broad advances made in cancer research and interventions in the last quarter of a century, inequality still persists as we confront challenges arising from the unequal burden of cancer among Americans. Some racial and ethnic minorities, people with low incomes, those in rural areas, and other medically underserved populations suffer disproportionately from cancer. We know, for example, that African Americans are about 34% more likely to die of cancer than whites and more than two times more likely to die of cancer than Asian/Pacific Islanders, American Indians, or Hispanics.

Disparities also exist among the major racial and ethnic groups in health-risk behaviors, such as cigarette smoking, and use of clinical preventive services, such as screening for breast, cervical, and colorectal cancers. The Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS), which was developed in cooperation with federal, state, and private-sector partners, has equipped us with knowledge of variations in health risks as well as information about differences among racial and ethnic groups for health-risk behaviors. Results from the 1997 BRFSS Survey showed that American Indians/Alaska Natives were most likely among all groups to report cigarette smoking. Hispanic and American Indian/Alaska Native women were less likely than women in other racial and ethnic groups to use preventive services, such as Papanicolaou testing and mammography. These statistics are disheartening and remind us that much work remains to remove the disproportionate burden of cancer among our nation's diverse populations.

Achieving better cancer control within minority and underserved populations in the United States is an important CDC goal. In its commitment to reducing disparities in the nation's cancer burden, CDC focuses its cancer control resources on support for surveillance systems that provide high quality cancer data for all Americans and on the design and implementation of interventions that promote the prevention and early detection of cancer, with emphasis on the underserved.

Cancer Surveillance

Surveillance activities are at the foundation of public health practice, and they are the primary way we gain an understanding of cancer's effect on populations. Chief among CDC's cancer surveillance systems is the National Program of Cancer Registries (NPCR), which was established by Congress in 1992. Through the NPCR, CDC supports complete, timely, and standardized reporting of cancer data—within

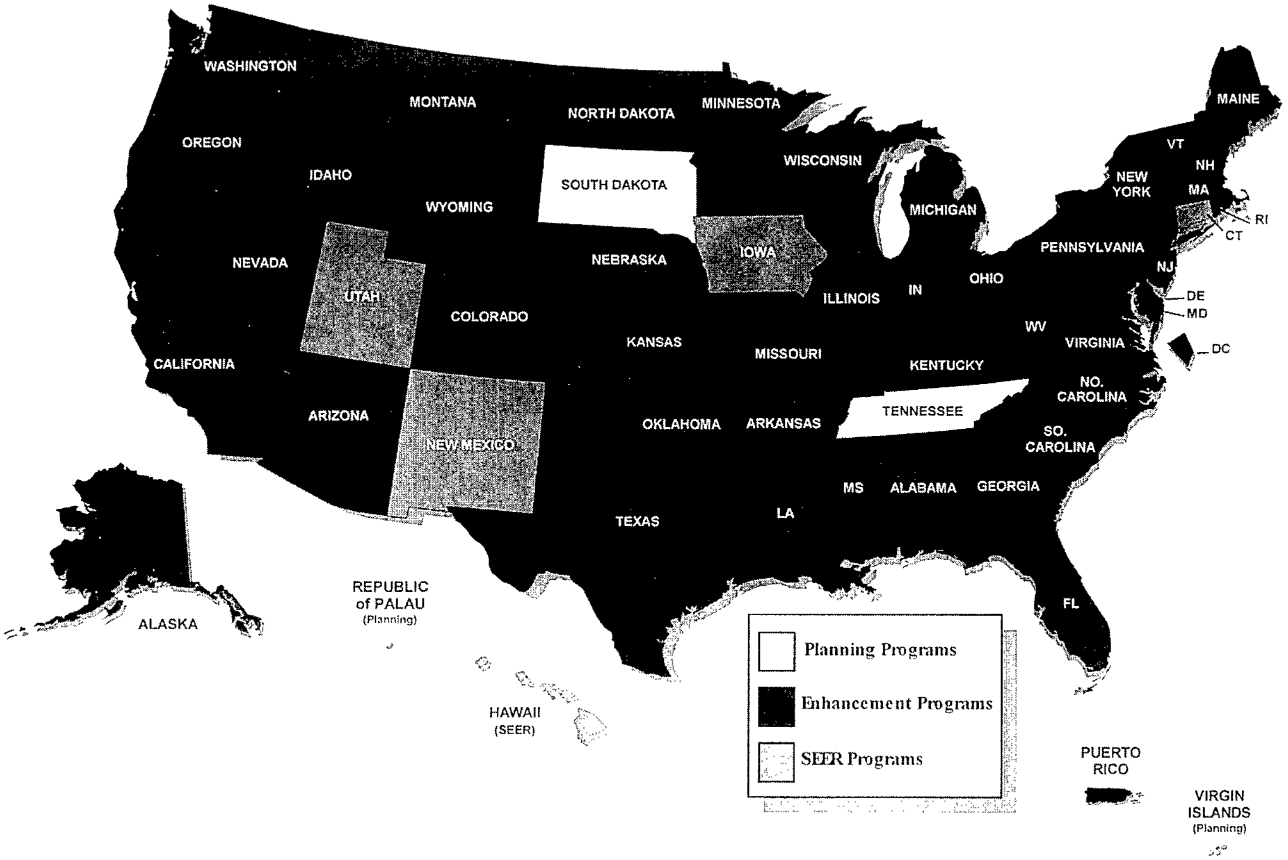

FIGURE 1. Map from the Centers for Disease Control and Prevention showing the National Program of Cancer Registries funding for the year 2000. SEER Program: Surveillance, Epidemiology, and End Results Program. Source: National Program of Cancer Registries, Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, July 1, 2000.

a state, between states, and between regions. CDC's NPCR will be an effective mechanism for monitoring cancer trends and will be an invaluable data source for identifying the burden of disease among racial and ethnic minority populations. NPCR data also will be helpful in directing cancer control efforts and research, developing and evaluating prevention and control programs, and ensuring that health resources are directed where they are most needed.

The NPCR complements the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program. The SEER program gathers in-depth cancer data on the population in five states (Connecticut, Hawaii, Iowa, New Mexico, and Utah); in the metropolitan areas of Atlanta, Detroit, Los Angeles, San Francisco-Oakland, San Jose-Monterey, and Seattle-Puget Sound; and in selected populations of American Indians in Arizona, Alaska Natives in Alaska, and residents of 10 rural counties in Georgia, covering about 14% of the U.S. population. NPCR supports central cancer registries in 45 states, 3 territories, and the District of Columbia; 45 of these areas are enhancing established registries, and 4 are developing and implementing registries in areas where none existed previously or where registries operated only in a limited capacity (Fig. 1). SEER-supported regional registries provide their data to the NPCR-supported state central registry. The NPCR covers 96% of the U.S. population.

NPCR-supported registries are expected to meet CDC data standards as well as standards incorporated for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR). NAACCR, a collaborative organization for North American cancer registries, governmental agencies, professional associations, and private groups interested in enhancing the quality and use of cancer registry data, has established a certification process for registries to recognize those that have complete, high quality, and timely cancer incidence data.

As of spring 2000, 29 NPCR registries and all SEER state and regional programs are independently certified by NAACCR (Table 1). This accomplishment illustrates the large improvement in cancer registration

TABLE 1
North American Association of Central Cancer Registries: Certified Cancer Registries in the United States[a]

- National Program of Cancer Registries
  - Alaska
  - Arizona
  - California
  - Colorado
  - Delaware
  - District of Columbia
  - Florida
  - Idaho
  - Illinois
  - Kansas
  - Kentucky
  - Louisiana
  - Maryland
  - Massachusetts
  - Minnesota
  - Montana
  - Nebraska
  - New Hampshire
  - New Jersey
  - New York
  - North Carolina
  - Oregon
  - Pennsylvania
  - Rhode Island
  - South Carolina
  - Washington
  - West Virginia
  - Wisconsin
  - Wyoming
- Surveillance, Epidemiology, and End Results Program
  - State registries
    - Connecticut
    - Hawaii
    - Iowa
    - New Mexico
    - Utah
  - Regional registries (metropolitan areas)
    - Atlanta
    - Detroit
    - Los Angeles
    - San Francisco-Oakland
    - San Jose-Monterey
    - Seattle-Puget Sound

[a] Certified to meet the North American Association of Central Cancer Registries standards for completeness, timeliness, and quality.

that has occurred since the early 1990s, when 10 states had no registry. Many of the 40 states that did have operating registries lacked the financial and staff support needed for gathering complete, timely, and accurate data on their population and ensuring that the data collected met minimum standards of quality. The United States now has much better data on many more Americans as well as data that could be used to analyze regional differences in cancer rates, including data on minority groups.

The primary reason for collecting, analyzing, and disseminating data, of course, is to use the information to advance cancer prevention and control. For example, one special study is using cancer registry data to analyze differences between African Americans and whites in colorectal cancer incidence and stage of disease at diagnosis. This analysis, using 1991–1995 data from 21 population-based cancer registries, was conducted by the Cancer Incidence Reporting Committee of NAACCR and included more than 216,000 cases of colorectal cancer.

Preliminary results of this study showed that African Americans were less likely to be diagnosed with localized colorectal cancer, and African-American men had the highest rates. African Americans also were more likely than whites to be diagnosed with disease involving the proximal colon. This information may be important when determining which colorectal cancer screening methods may be most suitable for African Americans as well as for designing appropriate messages for health communications.

Additional examples of using cancer surveillance activities to identify the unequal cancer burden are evident in studies conducted in Illinois and California. The Illinois State Cancer Registry studied Hispanic identification procedures and subsequently established a policy to foster more accurate documentation of Hispanic ethnicity among persons reported with cancer. In California, the Cancer Registry routinely reports cancer rates for Hispanics and for Asian and Pacific Islanders, including Chinese, Filipino, Japanese, Korean, and selected Asian subgroups. A recent report from a California Cancer Registry study suggested that the state's tobacco control program may have helped decrease rates for lung cancer among racial and ethnic minority women.

During the past year, CDC has begun implementing the NPCR-Cancer Surveillance System (NPCR-CSS), which is a major step forward in addressing the need for a comprehensive cancer data base. When it is fully operational, the NPCR-CSS will receive, assess, enhance, aggregate, and disseminate data from NPCR programs. This system will provide public-use data files of cancer incidence; more accurate and stable estimates of cancer incidence for special population groups, including racial and ethnic minorities, medically underserved groups, and other subpopulations; more accurate analysis of the cancer burden on a regional and national level; a basis for special studies, including studies involving rare cancers, cancers among children, and cancers among racial and ethnic minority populations; and valuable feedback to registries for improving data quality and use. In addition, the NPCR-CSS will provide information to aid in the task of assessing the unequal quality of cancer care in this country.

The first official "call for data" for the NPCR-Cancer Surveillance System is scheduled for January 2001. Once a registry's data meet quality standards, the data can be included in special research data bases that can be made available to public health practitioners and cancer researchers.

The need for a national data base has been recognized by various organizations involved in cancer control, including the Institute of Medicine (IOM). After a National Cancer Policy Board workshop in October 1999 that was designed to address the need for enhanced data systems to improve the quality of cancer care, the IOM recommended broader support for U.S. registry operations. For example, expansion of registry activities could support inclusion of follow-up data for survival analyses; at present, the NPCR supports data collection primarily for cancer incidence reporting. Major additional resources would be required to provide the extra capacity for assessing treatment and survival after cancer diagnoses. However, the infrastructure is now there. When it is fully implemented and functioning, the NPCR will provide the most comprehensive data to show cancer incidence and mortality among all Americans.

Tobacco Control

In addressing tobacco-related cancers, the CDC's tobacco control efforts include research and surveillance activities as well as support for state health programs. In 1998, CDC issued the first Surgeon General's Report on tobacco and minorities. This report clearly showed tobacco's increasing grip on racial and ethnic minorities. The report concluded that: 1) Cigarette smoking is a major cause of disease and death among the Hispanics, African Americans, American Indians/Alaska Natives, Asian Americans, and Pacific Islanders studied for this report; African Americans currently bear the greatest tobacco-related disease burden. 2) Tobacco use varies within and among racial and ethnic minority groups; among adults, American Indians/Alaska Natives have the highest prevalence of tobacco use; African-American and Southeast-Asian men also have a high prevalence of smoking. Asian-American and Hispanic women have the lowest prevalence. 3) Among adolescents, the prevalence of cigarette smoking increased in the 1990s among African Americans and Hispanics after several years of substantial decline. This increase is particularly striking among African-American youths, who had the greatest decline in smoking rates during the 1970s and 1980s.

CDC now supports comprehensive programs for preventing and controlling tobacco use in all 50 states, the District of Columbia, and 8 U.S. territories. These activities are targeted to reach multiple populations, especially high risk groups such as young people, racial and ethnic minority groups, and persons with low income. CDC provides extensive technical assistance and training to support these programs. The agency also supports tobacco-related symposia, such as the one on "Issues in Research: Tobacco Use in Racial/Ethnic Groups" that was conducted at the 2000 conference of the Society for Research on Nicotine and Tobacco. In addition, CDC has provided scientific and technical assistance for the National Youth Tobacco Survey. This survey revealed that the prevalence of current cigarette smoking among African-American middle school students (9%) was similar to that among white (9%) and Hispanic (11%) middle school students, which may be an early indication that the differences in smoking rates between African-American and white students may be disappearing.

Colorectal Cancer Control

Colorectal cancer is another area in which the excess burden of cancer among minorities is evident. We know, for example, that African Americans are more likely than whites to be diagnosed with colorectal cancer at a more advanced stage and are more likely to die of the disease. We also know that several effective screening tests for colorectal cancer exist, but screening usage rates are low among all groups in the United States.

In collaboration with the American Cancer Society, CDC supports the National Colorectal Cancer Roundtable—a coalition of public, private, and voluntary organizations—to promote awareness and use of colorectal cancer screening. Partners include professional organizations, medical societies, federal agencies, health departments, consumers, cancer survivors, managed care organizations, and the medical communications media. In addition, CDC is supporting several colorectal cancer research activities that focus on minority populations. For example, CDC is working with the NCI to enhance recruitment of African-American men for participation in the 15-year randomized, controlled trial of screening for prostate, lung, colorectal, and ovarian cancers (PLCO). The focus of the colorectal screening in the PLCO trial is flexible sigmoidoscopy. CDC also is collaborating with Memorial Hospital of Rhode Island to identify sociocultural and psychological influences affecting Hispanics' beliefs, attitudes, and practices associated with cancer prevention, including colorectal cancer screening.

CDC, with support from the Health Care Financing Administration and the NCI, has launched a national media campaign—"Screen for Life"---to promote screening for and early detection of colorectal cancer. This campaign also highlights Medicare's coverage for colorectal cancer screening. Public service announcements have been developed specifically for African-American audiences. CDC also is helping develop "Screen for Life" educational materials that are targeted directly to Alaska Native populations. This special project is designed to increase awareness of colorectal cancer among Alaska Natives, increase awareness of colorectal cancer screening tests, and provide language for persons to use in discussing colorectal cancer screening with their health care providers.

Early Detection of Breast and Cervical Cancer

Although effective screening tools for breast and cervical cancer are available, many women are not taking advantage of early detection methods because of financial, educational, or cultural factors. Through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), CDC is increasing the awareness, availability, and use of screening for underserved women. Racial and ethnic minority women and women with low income are high priority populations. Now in its 10th year, the NBCCEDP operates in all 50 states, the District of Columbia, 6 U.S. territories, and 12 American Indian/Alaska Native organizations, providing free or low-cost screening and diagnostic services for women. More than 2 million screening examinations have been provided since the program started in 1991. A review of program data reveals that almost half of the women screened by the NBCCEDP have been from a racial or ethnic minority.

CDC has begun a research project that will identify and describe successful strategies and approaches used by CDC-sponsored tribal organizations participating in the NBCCEDP. Results from this research project will be useful for improving the delivery of these important services to American Indian/Alaska Native women. Five tribal organizations are participating in this qualitative research effort that uses a case-study model. Focus groups will be conducted with program providers as well as with women clients in the program. This project has the potential to be an outstanding example of participatory research. From the earliest planning stages, the tribal program providers and managers have been involved. In addition, two expert American Indian researchers have been an integral part of the research team.

CDC also is coordinating and managing the Racial and Ethnic Approaches to Community Health (REACH) demonstration projects. REACH is part of the U.S. Department of Health and Human Services' response to the President's Race Initiative and the Healthy People Goals for 2010 to eliminate the disparities in health status experienced by racial and ethnic minority populations. Through REACH, CDC is supporting community coalitions in 18 states; 6 of these coalitions are being funded this year to address racial and ethnic disparities in breast and cervical cancer. REACH awards put funds into the hands of minority health organizations to develop effective community-oriented strategies. Both public and private agencies have expressed interest in supporting or participating in the REACH 2010 Program. Evaluation of these projects will be critically important in documenting whether these strategies are successful in reducing health disparities among racial and ethnic minority populations.

Prostate Cancer Initiatives

Prostate cancer burden, which affects African-American men disproportionately, is another example of the health disparities among America's racial and ethnic populations. At all ages, African-American men are diagnosed with prostate cancer at later stages and die of prostate cancer at higher rates than white men. Screening tests can detect the disease at early stages, but scientists are unsure whether early detection and treatment actually reduce mortality from this disease. Furthermore, the treatment procedures after the early detection of prostate cancer can have serious consequences.

In the absence of expert consensus on the effectiveness of screening in reducing mortality from prostate cancer, public health agencies face a significant challenge in determining how best to address this major cause of cancer death. CDC's current efforts focus on building the science base for understanding the best strategies for prostate cancer control. A case–control study supported by CDC is under way to evaluate the effect of prostate cancer screening (prostate specific antigen testing and digital rectal examination) on prostate cancer mortality. To maximize the likelihood that study results will be useful for African-American men as well as for white men, the study was designed to over-sample African-American men for the control group. To help CDC and the states design better public health programs to control prostate cancer, CDC has funded state cancer registries to collect and report better information regarding prostate cancer, especially with regard to disease stage of diagnosis, and racial and ethnic information.

CDC also is working with the Henry Ford Health System in Detroit, the University of Alabama at Birmingham, and the NCI to increase the recruitment of African-American men into the PLCO cancer screening trials. The prostate cancer arm of these trials is designed to answer the critical question of whether screening for prostate cancer actually reduces death rates. Lessons learned from the Detroit study about increasing recruitment of African-American men are being applied to the University of Alabama recruitment process.

CONCLUSIONS

CDC has learned many lessons about advancing cancer prevention and control. We have learned that providing effective interventions to the target populations requires building a broad cancer control infrastructure, which takes time. We have learned that the success of a national cancer screening program, such as the National Breast and Cervical Cancer Early Detection Program, depends on the integration and coordination of key components: research, quality assurance, public and professional education, health communications, and surveillance and evaluation systems. We have learned about the challenges in reaching diverse populations. Outreach strategies for priority populations must be developed if we are to improve their access to cancer screening services. Health communication messages must be tailored to be linguistically appropriate and culturally relevant to reach different population groups.

Finally, we know that addressing the complex array of public health challenges in cancer prevention and control requires a concerted effort by nonprofit organizations, government agencies, and businesses—groups that are willing to work together to address the economic, behavioral, and systemic factors that affect the use of cancer control services. Dynamic partnerships are absolutely critical to the success of cancer prevention and control efforts. For example, CDC has collaborated with more than 60 private, public, and federal organizations in implementing the NBCCEDP. Our collective efforts will continue to move us forward toward eliminating the disproportionate cancer burden in America's racial and ethnic communities. Working together, we can eliminate the disparities; working together, we can accomplish social justice in the public health arena through effective cancer prevention and control for all Americans.

7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

The Unequal Burden of Cancer

David Satcher, M.D., Ph.D.

Assistant Secretary for Health and Surgeon General, Office of Public Health and Science, Department of Health and Human Services, Washington, DC.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Address for reprints:

Received April 1, 2000; accepted August 31, 2000.

The unequal burden of cancer among ethnic minorities and the medically underserved represents one of public health's most difficult challenges. It will require an unwavering commitment to finding real solutions to address this complex problem.

I know that this work can be especially challenging at times. It reminds me of the story Neal Lane told of a man flying in a hot air balloon who suddenly realizes he's lost. He reduces height and spots a man in a field. He lowers the balloon farther and shouts, "Excuse me, sir, can you tell me where I am?" The man below says, "Yes, you're in a hot air balloon, hovering approximately 30 feet above this field."

"You must work in science," says the balloonist.

"I do," replies the man. "How did you know?"

"Well," says the balloonist, "your answer is technically correct, but it's of absolutely no use to anyone."

The man below replies, "You, sir, must work in policy."

"I do," replies the balloonist, "but how'd you know?"

"Well," says the man, "you don't know where you are, or where you're going. You're in the same position you were before we met, but now it's my fault."

This is the same position that we, in public health, often find ourselves—trying to find the manageable balance between public health and policy. Public health is science on one hand and policy on the other, with a great deal occurring between the time we start in the lab and the time we get to the people.

In February of this year, the Department launched Healthy People 2010, the nation's health plan for the next decade. Healthy People 2010 is the third in a series of decade-long health plans that date back to 1979, when Dr. Julius Richmond launched Healthy People 1990, the first version. Ten years later, we followed with Healthy People 2000, which just ended.

Our findings show that at the conclusion of Healthy People 2000, we were moving in the right direction on a majority—60%—of our goals. But we also found that we were moving in the wrong direction for 20% of our objectives. As for the remaining 20%, we just don't have enough data to know where we are.

We hope to do even better with Healthy People 2010, even though the challenges are greater. We have named two very important goals. The first goal is to increase the number of years and improve the quality of healthy life. The second goal is to eliminate racial and ethnic disparities in health care. The quality-of-life goal addresses the issues of pain and suffering and disability, areas that heretofore have been overlooked and that grow in significance as the nation ages. The disparities goal, which is particularly critical as it relates to cancer, addresses the rapid population shifts that are occurring in this country that will result in minorities becoming the majority population by 2040. These shifts also will place increasing demands on our health care system if we do not address the current disparities that exist in this country. Achievement of both goals is important in alleviating the burden of cancer on minorities.

THE CANCER BURDEN

We know that cancer is the second leading cause of death among Americans, and that the burden is unequal when it comes to racial and ethnic minority populations, including blacks, Hispanics, American Indians and Alaska Natives, and Asians and Pacific Islanders. Although these groups are among the fastest growing populations in America, in many respects, they are also among those who are poorest in health and who remain chronically underserved by the health care system.

Healthy People 2010 calls for a reduction in the number of new cancer cases as well as the illness, disability, and death caused by cancer. The mortality rates for cancer show the striking disparities that exist in this country. Look at the following examples:

- Although the incidence of breast cancer is greater for white women, African-American women are more likely to die from the disease.
- Vietnamese women living in this country experience cervical cancer at five times the rate of white women—Hispanic women older than age 65 years have twice the risk.
- Asian Americans are three to five times more likely to die from liver cancer.

We know that to the extent that we care for the needs of the most vulnerable among us, we do the most to protect the health of the nation.

In addition to the two goals, Healthy People 2010 has 467 objectives. Having 467 objectives is wonderful on the one hand because it allows for broad participation—they are comprehensive enough that they will allow individuals and communities the opportunity to pick and choose which areas are best suited to address their health concerns. We hope that individuals, communities, labor and business, and organizations from all across the country will partner with us in adopting the objectives that are most relevant to them.

We also realize that the sheer number of objectives can be unwieldy to manage. That's why we have divided them into 28 focus groups. Cancer is one of those focus groups with its own set of objectives. We hope that you will adopt these objectives dealing with cancer in minorities.

For the first time this year, we named 10 leading health indicators, which we hope the entire nation will rally around. We believe they will be critical in helping to end the unequal burden of cancer on underserved minorities. Unlike the objectives that may vary from state to state, community to community, and individual to individual, these leading health indicators are for everyone. Consider them the leading economic indicators for health, and they will serve as the mechanism for monitoring our progress to see how well we are doing in meeting our goals and objectives. That is why we need everyone's participation.

These indicators can be summed up into two categories: the first category relates to lifestyle indicators and the second relates to health systems indicators. Although we are still trying to uncover all of the reasons why minorities and underserved populations suffer disproportionately from cancer, we do know some of the reasons, and we are addressing them through these indicators.

We have named five lifestyle indicators as areas that concern us the most. They are tobacco use, obesity and being overweight, physical activity, substance abuse (especially alcohol), and responsible sexual behavior. Four of five of these areas relate directly to cancer. In fact, we estimate that as much as 50% or more of cancer overall can be prevented through smoking cessation and improved dietary habits, such as reducing fat consumption and increasing fruit and vegetable consumption.

Physical activity is another important lifestyle indicator when it comes to cancer. The Nurse's Study conducted by Harvard Medical School and Brigham and Women's Medical Center probably has taught us more about the benefits of physical activity in the past few years than anything else. When coupled with weight control and good nutrition, physical activity also can help prevent cancer. That is why we suggest at least 30 minutes of moderate physical activity at least 5 days a week.

The five health systems indicators are equally as important. They include mental health, injury and violence, environmental quality, immunization, and access to health care. Let me discuss environmental quality and access to health care—two that pertain directly to cancer:

We are concerned about environmental quality, including exposure to toxic substances that may cause breast and cervical cancer, birth defects, or other diseases. We are concerned that minorities—African Americans and Hispanics, to be specific—disproportionately live near waste sites and are exposed to toxins and environmental hazards that may cause cancer. In fact, even though minorities constitute only approximately 25% of the population in this country, they represent 40% of the people who live within 2 miles of hazardous waste sites, and an even a greater percentage are children.

We know that there are disparities in gaining access to health care overall, and in cancer care, in particular. Minorities, especially Hispanics and blacks, lag behind the rest of the nation in health insurance coverage. The rate of uninsured people has increased by more than 8.3 million people over the last decade, resulting in more than 44 million people who are left off the insurance rolls. According to the Cambridge Hospital/Harvard Medical School Study, blacks and Hispanics accounted for greater than 50% of the increase in the uninsured.

Being uninsured increases the likelihood that people will not have a regular physician, that they will have limited choice of physicians, and that they will have difficulty paying for care. In fact, 46% of Hispanics and 39% of black adults do not have a regular physician, whereas 26% of white adults do not.

That means women who should receive screenings for breast and cervical cancer probably will not, or, if they do, they may not get proper management.

It means men who should be screened for prostate cancer, probably will not be, because African-American men are less likely to have a regular source of care.

It means those groups who are most at risk are more likely to wait until the late stages of disease before they seek care and that that care usually will be through an emergency room.

But the issues surrounding access to health care do not end there. Disparities exist in the quality of care and in outcomes, which means our chances of early detection to decrease the mortality rate from these diseases diminish. We believe strongly, based on the best available science together with expert opinions, that screenings could play a significant role in reducing deaths from cancer of the breast, cervix, and colon/rectum. That is why we must make sure that we continue to focus on programs like the Centers for Disease Control's National Breast and Cervical Cancer Early Detection Program, which focuses on poor and underserved women.

Aside from these issues of insurance, lack of access to quality care is exacerbated by other factors such as culture and language. For example, many non-English speaking minorities experience difficulty in finding specialists who are able to communicate in their native language or who can match their cultural characteristics. We are examining this area carefully and have requested public comment on cultural competency standards.

But there's another important factor to consider—racism. More and more studies are showing what many of us have suspected for years: provider bias—whether knowingly or unknowingly—can and often does affect quality of care, and it can possibly affect health outcomes. As a result, we are posing some serious questions to deal with this factor. What happens even when a minority receives an early diagnosis? Will they receive the same quality of care as a white person? Will they have access to state-of-the-art technology and cutting edge treatments?

Last February's groundbreaking study published in the *New England Journal of Medicine* found that blacks and women with identical complaints of chest pain are less likely than whites and men to be referred to physicians for sophisticated cardiac tests. Other reports have followed with similar results. So we must work to change that trend, including the finding that black patients with lung cancer are less likely to be referred for surgical resection.

WHERE DO WE GO FROM HERE?

The leading health indicators provide a tremendous opportunity for public–private partnerships and for everyone to intervene to close the gap on disparities and to improve the overall quality of life for all.

A key element to alleviating the unequal burden of cancer is to begin addressing lifestyle issues and health systems issues early in the life cycle. For example, we need to ensure that children have an optimal opportunity for a healthy start in life. When that happens, we increase the likelihood that they will continue to have healthy lifestyle habits throughout their lifetime.

However, we also must address health systems issues when it comes to children. We must improve in-school lunches so that they are nutritious and focus on the five food groups. We recommend people consume at least five servings of fruits and vegetables a day, cut back on fats and sweets, and increase grains and fiber. And we must challenge the systems that do not require physical activity in schools. Currently, no state in the Union requires physical activity in kindergarten through 12th grade. We also can work together to improve access to quality health care in our community and in our nation and to make environments clean and safe for children and families.

Although we have come a long way toward reducing disparities in health based on race and ethnicity, we realize that the road that leads toward eliminating disparities is difficult. A major focus of that effort includes alleviating the burden of cancer in minorities and the underserved. We are committed to meeting that goal by 2010, and we believe, with your help, one of the greatest achievements in public health will be realized. Let me leave you with this quote from Health, Education and Welfare Secretary John Gardner, who used to like to say: "Life is filled with golden opportunities carefully disguised as irresolvable problems."

7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Socioeconomic Inequalities in Cancer Survival in England and Wales

Michel P. Coleman, M.D.[1,2]
Penny Babb, Ph.D.[2]
Andy Sloggett[3]
Mike Quinn, Ph.D.[2]
Bianca De Stavola, Ph.D.[1]

[1] Cancer and Public Health Unit, London School of Hygiene and Tropical Medicine, London, England.

[2] National Cancer Intelligence Centre, Demography and Health Division, Office for National Statistics, London, England.

[3] Centre for Population Studies, London School of Hygiene and Tropical Medicine, London, England.

BACKGROUND. Cancer survival often has been reported as lower for the poor than the rich, but, to the authors' knowledge, systematic national estimates of deprivation gradients in survival over long periods of time have not been available.

METHODS. The authors estimated national population-based survival rates for almost 3 million people who were diagnosed with 1 of 58 types of cancers (47 in adults, 11 in children) in England and Wales during the 20-year period 1971–1990 and followed through December 31, 1995. Cancer patients were assigned by their address at diagnosis to 1 of 5 categories (quintiles of the national distribution) of material deprivation by using a standard index derived from census data on unemployment, car ownership, household overcrowding, and social class that was available for all 109,000 census tracts in Great Britain. The authors used relative survival rates: the ratio of observed survival among the cancer patients to the survival that would have been expected if they had had the same background mortality as the general population. Background mortality differed widely among socioeconomic categories, and the authors constructed life tables from raw national mortality data by gender, single year of age, calendar period of death, and socioeconomic category to adjust for it. The authors used variance-weighted least squares regression to estimate both time trends in age standardized survival and socioeconomic gradients in survival. The number of avoidable deaths was estimated from the observed mortality excess compared with the expected mortality in each group of patients.

RESULTS. Survival rose steadily for most cancers over 25 years to 1995 in England and Wales, but inequalities in survival between patients living in rich and poor areas were geographically widespread and persistent over this period of time. These patterns existed for 44 of 47 adult cancers examined but not for 11 childhood cancers. These inequalities in survival represented more than 2500 deaths that would have been avoided each year if all cancer patients had had the same chance of surviving up to 5 years after diagnosis as patients in the most affluent group.

CONCLUSIONS. The largest national cancer survival study has provided strong evidence of systematic disadvantage in outcome among patients who lived in poorer districts compared with those who lived in wealthier districts. ***Cancer*** **2001; 91:208–16.** *© 2001 American Cancer Society.*

KEYWORDS: cancer survival, socioeconomic status, material deprivation, survival trends and analysis, England and Wales, breast, lung, bowel, prostate, malignant neoplasms.

In direct contrast to the United States of America (USA), the United Kingdom (UK) National Health Service (NHS) is government funded from general taxation revenue, and health care is available without fee to all residents. In principle, equity of access to health care is axiomatic. In practice, the UK government has recognized that there is

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

URL: http://www.cancer-public-health.net

Address for reprints: Michel P. Coleman, M.D., London School of Hygiene and Tropical Medicine, Keppel Street, London WC1E 7HT, UK; fax: +44 207 436 4230; E-mail: m.coleman@lshtm.ac.uk

Received April 1, 2000; accepted August 31, 2000.

inequitable access to high quality cancer treatment and care within the NHS[1] and has made a commitment to rectify this inequity.[2,3]

Socioeconomic differences in investigation and treatment have been reported in the UK for patients with cancers of the breast[4–7] and cervix.[8] Variations in investigation or departure from treatment guidelines have been reported for cancers of the breast,[9–11] uterus,[12] ovary,[13] and large bowel.[14] Inequalities in access to radiotherapy services have been reported in the North and West Region of England.[15] A UK national audit showed that 28% of cancer patients waited longer for radiotherapy than the maximum acceptable delay in professional guidelines and attributed this to lack of equipment and staff.[16]

Randomized trials measure the best survival that is achievable. Population studies measure the average survival actually achieved. Time trends in population-based cancer survival can indicate how quickly new and better treatments become available to patients and whether the improved outcome is seen equally in all geographic regions and in all groups of the population. Thus for children with acute lymphocytic leukemia, the dramatic improvement in 5-year survival, from less than 10% in the 1960s to nearly 75% for those diagnosed from 1986–1990,[17–20] provides evidence that effective chemotherapy has become available for almost all children. To assess improvements in survival for all cancer patients, data from population-based cancer registries are indispensable.[21,22]

The goal of the current study was to examine socioeconomic differences in population-based cancer survival and national survival trends for every cancer up to 1995. A major reorganization of UK cancer treatment services has been underway since 1995.[1] The results presented provide a baseline for assessing the impact of this reorganization on the equity of cancer survival in affluent and deprived groups of the populations of England and Wales.[23]

MATERIALS AND METHODS

We analyzed the survival of 2,887,690 patients who were diagnosed with cancer in England and Wales during a 20-year period from 1971–1990 and followed them through December 31, 1995. The 39 solid tumors and 8 types of leukemia and lymphoma examined in adults accounted for 93% of all primary malignant neoplasms, and the 11 neoplasms examined in children accounted for more than 80% of those occurring in the age range 0–14 years.[23]

Cancer incidence and survival data for England and Wales are compiled by the Office for National Statistics from data on individual cancer patients collected by the regional cancer registries, which collectively have covered the entire national population of some 50 million since 1962. These data are linked subsequently with national death registrations and emigrations to produce information on the survival of all patients diagnosed with cancer. The national cancer database is person-based, and second or subsequent tumors in the same person are linked. Analyses were based on first primary invasive malignant tumors; benign and in situ tumors were excluded. The anatomic location of tumors was coded to the Eighth[24] or Ninth[25] Revision of the International Classification of Diseases (ICD-8 and ICD-9), and morphology was coded to the Manual of Tumor Nomenclature and Coding[26] (MOTNAC) or to the International Classification of Diseases for Oncology[27] (ICD-O). For childhood malignancies, we adapted the 1987 classification by Birch and Marsden[28] to cover the period 1971–1990.

Cancer patients were assigned to one of five categories of material deprivation, from affluent to deprived, using the Carstairs index,[29] a standard index derived from characteristics of the small area in which the patient was living when diagnosed. This index of deprivation has been used widely in the UK to explore health inequalities.[30,31] It is measured at the level of the census enumeration district (ED). At the last census, there were 109,578 EDs in Great Britain (England, Wales, and Scotland) with an average of 200 households and 500 inhabitants each.

We obtained from the decennial censuses for 1981 and 1991 the percentage of households in each ED for each of 4 categories: car ownership, household overcrowding (more than one person per room), head of household in Social Class IV or V (partly skilled or unskilled), and male unemployment (log transformed because of skewness). The four percentage values for each ED were standardized by subtraction of the corresponding national mean for Great Britain and division by its standard deviation. The sum of these four normalized scores provided the Carstairs index, and quintiles of its distribution were used to assign a deprivation category — from 1 (most affluent) to 5 (most deprived) — to each ED. Contemporary dictionaries of correspondence between postal codes and census EDs were used to assign a deprivation category to each patient on the basis of the ED in which he or she was a resident at diagnosis. For the period 1986–1990, a deprivation category was assigned in this way to 98.8% of adult cancer patients and 98.8% of children included in the analyses.

Relative survival is the ratio of the survival observed in the group of cancer patients under study and the survival that would have been expected had they been subject only to the mortality rates of the general population.[32,33] It reflects the excess mortality in the cancer patient group relative to this background mortality. Socioeconomic differences in mortality in Great Britain are wide; however,[34,35] the risk of death in men aged 15–59 years in 1990–1992 was 18% for the most deprived group and 8% for the most affluent, a twofold ratio. Use of a single national life table for all deprivation groups can lead to bias in estimating relative survival:[36,37] if affluent groups have better survival rates, the socioeconomic gradient will be exaggerated.[23] Official life tables were not available by deprivation category. We therefore used raw data on individual deaths to construct 256 tables of mortality rates for England and Wales by single year of age at death up to age 99 years. We constructed a table for every combination of deprivation category, gender, and administrative region of the National Health Service for each of two time periods. The numbers of deaths in each ED in the pericensal years 1980–1982 and 1990–1992 were added across the same socioeconomic categories that we used for the cancer patients. The annual average number of deaths was applied to the corresponding population denominators from the 1981 and 1991 censuses. These life tables represent background mortality in the very same EDs that were used to construct the quintiles of deprivation for cancer patients, and the life tables enabled a direct estimate of excess mortality to be made for each quintile.

Relative survival estimates for patients diagnosed in each 5-year period from 1971–1975 to 1986–1990 were computed with an algorithm[23] developed in STATA statistical software (Stata Corporation, College Station, Texas) using the method of Estève et al.[38] Variance-weighted least squares regression was used to estimate the gradient in relative survival across the five deprivation categories separately for each calendar period. The "deprivation gap" was estimated as the difference between the fitted rates in the affluent and deprived groups. To estimate survival trends up to 1995, relative survival rates for each cancer were standardized directly for age using as weights the national distribution of patients diagnosed with that cancer during 1986–1990 across the 6 age groups 15–39 years, 40–49 years, 50–59 years, 60–69 years, 70–79 years, and 80–99 years. Trends were then estimated from variance-weighted linear regression of the age standardized relative survival rates for the four 5-year periods of diagnosis from 1971–1975 to 1986–1990. Significance of trends was assessed from the standard error of the regression slope. Trends were reported as the average change in the survival rate between successive 5-year periods of diagnosis.

Excess deaths for a given group of cancer patients were estimated by subtracting the number of deaths expected on the basis of background mortality alone from the number of deaths actually observed. Avoidable deaths were estimated by applying the relative survival rates observed in the most affluent group to each of the other four groups, specific for each age and gender, and then subtracting the total of excess deaths that would be expected on this basis (i.e., in the absence of a socioeconomic gradient in survival) from the observed number of excess deaths.

RESULTS

Relative survival rates for adults diagnosed in England and Wales during 1986–1990 and followed up to December 31, 1995 are shown for 13 selected cancers and all cancers combined in Table 1 with the average rate of increase in survival up to 1995. Five-year survival for breast cancer among women diagnosed 1986–1990 was 66%, having increased by an average 4.4% every 5 years (from 52% for women diagnosed 1971–1975). Lung cancer survival at 5 years was 5% in men and women and had barely changed since the early 1970s. For prostate cancer, 5-year survival rose by an average of 3.5% every 5 years, but all of this improvement occurred in the 1970s, and survival for men diagnosed 1986–1990 (41%) was no higher than for men diagnosed 5 years earlier. Five-year survival from melanoma increased more rapidly than for any other cancer in adults—an average of 7.6% every 5 years in men and 5.8% in women, reaching 68% for men and 82% for women diagnosed from 1986–1990. Five-year survival from all cancers combined increased by about 4% every 5 years in men and women, reaching 31% in men and 43% in women diagnosed from 1986–1990.

Five-year survival rates for the 13 selected cancers are shown in Table 2. Data from patients in the most affluent group who were diagnosed from 1986–1990 are provided with the deprivation gap in survival between patients in the most affluent and most deprived groups (the difference between the regression-fitted survival rates in the two categories). The deprivation gap in survival from these cancers ranged from 3–7% 1 year after diagnosis and from 1–12% 5 years after diagnosis. Significant socioeconomic differences were seen at 1 year and/or 5 years after diagnosis for 44 of the 47 adult cancers examined. No significant survival advantage among deprived patients was seen for any cancer.

We estimated the deprivation gradient in survival for all cancers combined among patients diagnosed from 1986–1990, after excluding 6 rare malignancies (nasopharynx, thymus, spinal cord, adrenal, pituitary, monocytic leukemia) that collectively accounted for less than 0.3% of all cancers. The remaining 41 cancers still represented 93% of all adult malignancies. The

TABLE 1
Cancer Survival in England and Wales; Adults Diagnosed 1986–1990

		One year after diagnosis		Five years after diagnosis	
	No. of patients	Survival rate (%)	Average increase (%)	Survival rate (%)	Average increase (%)
Breast					
Men	856	90	2.5	70	3.9
Women	116,883	89	2.2	66	4.4
Lung					
Men	101,688	19	1.4	5	0.4
Women	44,387	19	1.9	5	0.5
Colon					
Men	31,651	59	6.7	38	5.3
Women	36,830	59	6.5	39	5.4
Bladder					
Men	35,539	80	4.6	62	6.0
Women	13,779	72	4.5	57	5.4
Rectum					
Men	25,064	65	5.0	36	3.9
Women	19,324	66	5.0	39	4.0
Non-Hodgkin lymphoma					
Men	12,639	62	4.7	41	4.6
Women	11,080	65	4.9	45	4.5
Prostate					
Men	51,910	76	4.1	41	3.5
Larynx					
Men	7195	83	2.0	63	2.1
Women	1592	79	2.1	57	3.1
Melanoma					
Men	5964	90	3.9	68	7.6
Women	9976	94	2.1	82	5.8
Oral cavity					
Men	2301	72	1.4	43	1.6
Women	1393	74	1.4	52	1.5
Cervix					
Women	19,108	82	2.3	61	3.2
Hodgkin disease					
Men	2931	87	4.1	71	5.4
Women	2090	86	2.6	73	4.5
Uterus					
Women	16,508	84	2.0	70	2.9
All malignancies					
Men	387,052	51	4.9	31	4.2
Women	395,550	62	3.4	43	4.0

Selected cancers, by gender: number of patients, 1- and 5-year relative survival (age-standardized), and average increase in survival between successive 5-year periods of diagnosis.

difference in survival between adults in the most affluent and most deprived categories from these 41 cancers combined was 12.7% for 1-year survival and 11.1% for 5-year survival (Table 1, Figure 1). These figures are weighted averages of the survival gradients for each cancer, but they reflect also the differences in composition of all cancers combined in each deprivation category. The most common cancers in deprived groups (e.g., lung cancer) had lower survival rates than the most common cancers in affluent groups (e.g., breast cancer). The large difference in survival from all cancers combined between men and women (Table 1) had a similar explanation, even though women did have a small survival advantage over men for many individual cancers (data not shown): the most common cancers in men had lower survival rates than the most common cancers in women.

Survival trends and socioeconomic patterns were very different for childhood cancers (data not shown).[23] Survival for 6 of the 11 childhood malignan-

TABLE 2
Avoidable Deaths within 5 Years of Diagnosis in England and Wales; Adults Diagnosed 1986–1990

		5-year survival (%)		Excess deaths[b]		Avoidable deaths[c]	
Cancer	No. of patients[a]	Affluent	Gap	Observed	Expected	No.	%
Breast	116,169	70.9	−7.6	39,646	36,841	2806	7.1
Lung	144,604	6.0	−1.0	136,924	135,601	1325	1.0
Colon	67,741	40.3	−4.3	41,778	40,490	1289	3.1
Bladder	48,722	66.3	−7.0	19,274	18,001	1273	6.6
Rectum	43,870	40.2	−5.4	27,570	26,505	1063	3.9
Non-Hodgkin lymphoma	23,477	47.8	−6.9	13,487	12,776	709	5.3
Prostate	51,354	43.0	−2.9	30,315	29,688	629	2.1
Larynx	8671	68.4	−9.3	3308	2752	555	16.8
Melanoma of skin	15,703	81.8	−8.1	3705	3372	333	9.0
Oral cavity	3663	53.9	−11.6	1985	1655	330	16.6
Cervix	18,868	66.4	−4.4	7294	6976	317	4.4
Hodgkin disease	4950	78.9	−8.4	1405	1204	203	14.4
Uterus	16,261	74.1	−3.6	4961	4792	169	3.4
Other cancers[d]	205,907			161,250	159,504	1744	1.1
Total[d]	769,960	43.4	−11.1	492,902	480,157	12,745	2.6

[a] Patients included in analyses and with a known deprivation category.

[b] Number of deaths in excess of general population mortality within 5 years of cancer diagnosis. Observed-actual number. Expected–estimated as if patients in each deprivation category were to experience the same relative survival rate as patients in the most affluent category.

[c] Avoidable deaths—difference between observed and expected. Percentage of observed excess deaths for a given cancer or for a given deprivation category. Estimated numbers of deaths are rounded to integer: small discrepancies in totals or subtractions are due to rounding.

[d] All cancers combined, excluding six rare malignancies (nasopharynx, thymus, spinal cord, adrenal, pituitary, monocytic leukemia). Total still represents 93% of all malignancies.

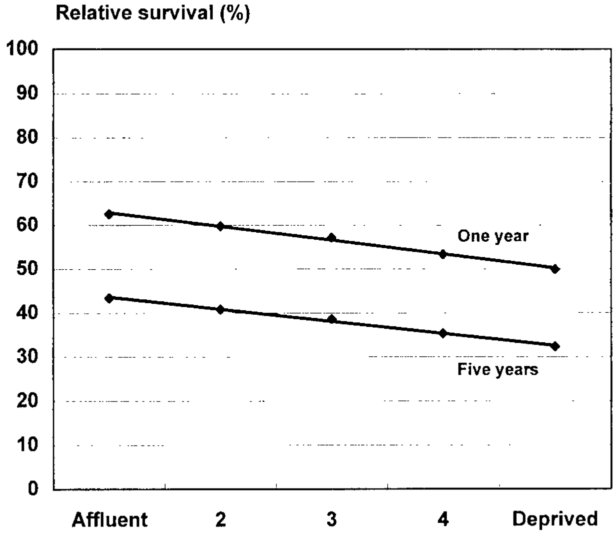

FIGURE 1. Relative survival rates 1 and 5 years after diagnosis by deprivation category, all cancers combined: England and Wales, adults diagnosed 1986–1990.

cies examined increased by an average of 10% or more every 5 years, compared with about 4% for adults, and no significant socioeconomic survival gradient was seen.

Among the 769,960 adult patients in the known deprivation category who were diagnosed from 1986–1990 and who were included in the analyses, 492,902 deaths occurred in excess of general population mortality within 5 years of diagnosis. The 6 rare cancers that accounted for less than 0.3% of all adult cancers (nasopharynx, thymus, spinal cord, adrenal, pituitary, monocytic leukemia) were excluded from this estimate. If, for each cancer, age group, and gender, patients in each deprivation category had experienced the 5-year relative survival rates observed in the most affluent category, only 480,157 excess deaths would have been expected. On this basis, 12,745 excess deaths would have been avoided in the absence of the observed socioeconomic gradients in survival. This represented some 2500 avoidable deaths within 5 years of diagnosis in England and Wales each year, or some 2.6% of the expected excess mortality.

Avoidable deaths within 5 years of diagnosis in each deprivation category have been estimated by summing avoidable deaths for each of 41 cancers in adults diagnosed from 1986–1990 (Table 3). For patients in the second deprivation category, approximately 1000 excess deaths would have been avoided if they had shared the relative survival rate seen in the most affluent category for each cancer at each age and for each gender, representing 1.1% of the expected excess mortality in this group. On the same basis,

TABLE 3
Avoidable Deaths within 5 Years of Diagnosis by Deprivation Category: All Cancers Combined, England and Wales; Adults Diagnosed 1986–1990

Deprivation category	Patients[a]	Excess deaths[b]		Avoidable deaths[c]	
		Observed	Expected	No.	%
Affluent	146,387	86,611	86,611	—	—
2	163,128	100,395	99,337	1,058	1.1
3	166,753	106,352	103,983	2,369	2.2
4	160,860	107,228	103,027	4,201	3.9
Deprived	132,832	92,316	87,199	5,116	5.5
Total[d]	769,960	492,902	480,157	12,745	2.6

[a–d] See footnotes to Table 2.

more than 5000 deaths (5.5% of the expected excess mortality) would have been avoided if deprived patients had had the same survival as patients in the affluent category.

DISCUSSION

The results reported here were derived from the largest national study of population-based cancer survival reported to date. For adults diagnosed in England and Wales during 1971–1990 and followed up to the end of 1995, survival improved steadily for many adult cancers (e.g., breast, melanoma, bladder, large bowel) but improved very little for the common cancers of the lung, pancreas, and esophagus. Socioeconomic inequalities in relative survival existed for 44 of 47 adult cancers, even when socioeconomic differences in background mortality were taken into account.

Cancer survival in the UK often has been described[39] as a lottery, but this popular formulation inverts the truth. Lotteries are fair. A lottery ticket buys the same chance of winning for rich and poor alike. For most major cancers, however, there is evidence that patients in affluent areas have higher survival than patients in deprived areas and that the differences are not due simply to chance[40–45] or to the extent of disease at diagnosis.[46] Similar socioeconomic differences in cancer survival have been identified for many cancers in the UK[40,42,44,46–48] and in other countries.[49–58] Artifact is an unlikely explanation.

The terms "affluent" and "deprived" used here for groups of cancer patients apply strictly to the population of the census enumeration district in which the patients were living at diagnosis, and the degree of material deprivation of individuals living within such districts will vary. To that extent, the ecological measure of deprivation used here is likely to underestimate the actual gradient in survival between socioeconomic groups. Differences in background mortality among these groups were taken into account by the use of deprivation-specific life tables. This produced a more conservative gradient than if a single national life table had been used. The census enumeration districts used to assign each patient to a deprivation category were so small that, in most parts of the country, general practitioners and hospitals all would have seen patients from every type of area, from affluent to deprived. Socioeconomic gradients in survival were unlikely to be due to differential proximity to hospitals.

When survival differs among population subgroups, it is clear that survival trends are influenced by factors other than the efficacy of available treatment. Such factors include the speed with which patients seek medical help when experiencing symptoms suggestive of cancer; the speed of referral for specialist attention; the stage of disease at diagnosis; the thoroughness of investigation and diagnosis; the differences in subsite or histologic type of disease; the quality of treatment and compliance with it, and the general health of patients who develop cancer.[59,60]

Stage of disease at diagnosis is a key prognostic factor, but it was not available in the national data. Even after adjustment for stage at diagnosis, however, socioeconomic inequalities in survival from cancers of the lung, breast, large bowel, bladder, prostate, uterus, or cervix were found between patients in affluent and deprived areas of Southeast England.[36,61] Deprivation categories were defined in identical fashion to those used here. If delay in seeking health care and late stage at diagnosis[62–65] do underpin socioeconomic survival gradients, it should be possible to devise suitable health education measures and, within the NHS, to streamline the referral process for investigation and specialist treatment.

Survival improved more rapidly for childhood malignancies than for cancer in adults, and significant socioeconomic differences were not seen. This striking contrast was likely because effective chemotherapy is available for many childhood malignancies, treatment is highly centralized in a small number of specialist centers, and recruitment into randomized trials is common.[18,66–68] The Royal College of Radiologists reported in 1991 that there were too few oncologists in the UK and that their caseloads of new patients were too high.[69] One population-based study in England suggested that 5-year survival from breast cancer might increase by 4–5% if the best surgical practices were used by all clinicians.[70]

Survival for many cancers in the UK, even for the most affluent patients,[23] is lower than in economically comparable European countries[71,72] or the areas covered by the Surveillance, Epidemiology and End Results program in the USA.[23] For most cancers, survival differences between Europe and the USA are most marked for older patients.[73] Some of these differences are attributable to international differences in defining disease and in employing different methods of diagnosis, particularly for prostate and bladder cancer.[74] Differences in survival from cancers of the colon and breast are especially marked in the first 6 months after treatment, suggesting that there are effects from stage at diagnosis and/or access to optimal care.[75–77]

To devise suitable interventions it is essential to understand the links between deprivation and poor cancer outcomes. Further research is required to determine the role of potential contributing factors among patients from deprived areas. These include poorer general health, worse access to care, lower uptake of screening or treatment, lower tolerance of therapy and lower quality of health care services.[78] Racial differences in survival from cancers of the colon and lung in the USA have been shown to be influenced by treatment differences.[79,80] As Brawley and Freeman[81] have said, "Equal treatment yields equal outcome among patients with the same stage of disease, regardless of race." The pervasive socioeconomic differences in cancer survival observed in this study in England and Wales may have a similar explanation.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Health and Civil Rights

Thomas E. Perez, J.D.

U.S. Department of Health and Human Services, Washington, DC.

KEYWORDS: health, disparities, discrimination, race, minorities, Office for Civil Rights, U.S. Department of Health and Human Services.

It is hard to talk about race. Discussions about race in general and racial discrimination in particular are potentially unnerving, which explains in large measure why such conversations are so few and far between. All too frequently, these discussions take place only after a horrific incident that draws public attention to race, such as the brutal dragging death of James Byrd Jr. in Jasper, Texas, or the Good Ol Boy Roundup in Tennessee, or the white supremacist in Los Angeles who went on a racially motivated crime wave and murdered an Asian-American postal worker and shot at young children in a Jewish day care center.

In the health context, discussions about race are particularly rare. But that is beginning to change. Over the past year, widespread attention has been focused on eliminating racial and ethnic disparities in health. President Clinton and Secretary of the Department of Health and Human Services Donna Shalala have committed the nation to the ambitious yet reachable goal of eliminating racial and ethnic disparities by 2010 in six areas of health status while continuing the progress we have made in improving the overall health of the American people.[1] The six areas of focus are infant mortality, cancer screening and management, cardiovascular disease, diabetes, human immunodeficiency virus infection/acquired immune deficiency syndrome, and immunization.

Racial disparities in these areas are well documented, disturbing, and preventable.[2,3] Before we can eliminate racial and ethnic disparities, however, we must identify all of the root causes. All too often, we ignore the role that racial discrimination plays in health disparities. Instead, racial and ethnic disparities are defined in terms of economics—if you are poor, you are less likely to have access to quality health care. In addition, disparities are defined in terms of geography, if you live on the wrong side of the train tracks, and near the toxic waste dump, you are likely to have similar problems. Disparities are sometimes explained in terms of genetic factors—certain races or ethnicities may have a genetic predisposition to certain illnesses. Finally, disparities are sometimes framed in terms of education—if we could simply teach better habits.

All of these explanations are true, but it is equally true that forces of discrimination are also at work. How do I know this? Recent research coupled with the enforcement experience of the Department of Health and Human Services (HHS) and the Office for Civil Rights (OCR) highlights the role of discrimination as one explanatory factor for racial and ethnic disparities. On the enforcement front, a brief

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Address for reprints: Thomas E. Perez , U.S. Department of Health and Human Services, 200 Independence Avenue, SW, Suite 515F, Washington, DC 20201; fax: (202) 619-3437; E-mail: tperez@os.dhhs.gov

Received April 1, 2000; accepted August 31, 2000.

snapshot of recent OCR cases illustrates that discrimination regrettably is alive and well in the health care setting:

- We reached a settlement with a national home health agency that had engaged in medical redlining, that is, it refused to serve a predominantly minority area of New Haven, Connecticut.
- We reached an agreement with a national pharmacy chain that had repeatedly failed to fill the prescription of an African-American Medicaid recipient in Texas.
- We reached a settlement with a hospital in South Carolina that had a policy in effect of not giving epidurals to women who did not speak English.
- We reached a settlement with a hospital in Philadelphia whose lack of an effective policy for treating patients who do not speak English created serious problems for a pregnant woman who needed emergency care.

In the research arena, Kevin Schulman, M.D., a professor at Duke University, and his colleagues last year stimulated a robust dialogue about racial bias in physician decision making. In their study,[4] Dr. Schulman and his research team meticulously controlled for all factors and found that a patient's race and gender influence a physician's treatment decision. Subsequent studies have documented the potential role of racial bias in explaining certain racial and ethnic disparities. In my career enforcing civil rights laws in a variety of settings, I have seen that racial bias can infect the corporate boardrooms, the schoolrooms, the police precinct rooms, and the courtrooms. The Office for Civil Rights's enforcement experience, coupled with Dr. Schulman's research, has demonstrated that racial bias can affect who gets to the operating room. Indeed, eliminating racial and ethnic disparities in health is both a civil rights and a public health challenge. If we ignore the former and focus solely on the latter, we will not be fully successful.

Eliminating racial and ethnic disparities in health will require a comprehensive strategy that focuses on a variety of areas, including: 1) a comprehensive research agenda; 2) disease prevention and health promotion; 3) education and empowerment of patients; 4) education of the health care profession, especially on the issue of cultural and linguistic competence; 5) appropriate measures to ensure that the health care profession reflects the increasing diversity of our nation; 6) appropriate data collection; and 7) aggressive civil rights enforcement. One of my principal duties as the director of OCR is to support the department's overall initiative to eliminate racial and ethnic disparities by 2010 by ensuring that there is aggressive enforcement of antidiscrimination laws. The Office for Civil Rights's efforts on racial and ethnic disparities focus on four elements: 1) dialogue; 2) education and prevention; 3) proactive investigation; and 4) aggressive efforts to address the unique needs of immigrant populations.

DIALOGUE

We must continue to discuss racial disparities publicly, and we must not shy away from discussing the role of racial discrimination. A California newspaper reported on an African-American woman who went to the emergency room of a county hospital in Los Angeles for treatment of a broken arm.[5] The hospital was affiliated with the University of Southern California (USC). Interns asked her to position her arm "like she would a [having a] beer on a Saturday night." The patient replied "Do you think I'm a person on welfare?" "Well aren't you?" was the response. The patient was Dean at the USC Medical School. This vignette lends some graphic real world context to the Schulman study.

The Office for Civil Rights has initiated a dialogue about racial and ethnic disparities in a number of settings across the country. This is not simply dialogue about the civil rights aspects of racial disparities, but a broader dialogue about the overall challenge. For instance, in New York City, the OCR has convened a series of meetings with all stakeholders—providers, advocates, faith communities, foundations, medical societies, hospital associations, and others in an effort to develop a greater understanding of the root causes of racial and ethnic disparities, as well as a blueprint for eliminating disparities. This dialogue has been extremely productive, and talk has led to constructive action.

As part of the dialogue, it is critical to educate providers and the public at large about what discrimination means in the health care setting. Discrimination is a scary word that often conjures up images of people who deliberately come together in a nefarious effort to prevent communities of color from obtaining equal access to a particular service or benefit. Discrimination can be intentional, but when it exists, it is frequently more subtle, as the Schulman study suggests. As a result, part of the public dialogue must involve discussion of stereotypes and how we must all search our collective consciences and root out bias so that we will not consciously or subconsciously judge people by the color of their skin, what they are wearing, or whether they speak with an accent.

Discrimination under federal civil rights laws does not require proof that the individual or entity acted with malice or otherwise intentionally discriminated.

In fact, most OCR cases of alleged racial discrimination in the health context involve so-called "disparate impact" cases under Title VI of the Civil Rights Act of 1964 and its implementing regulation. In these circumstances, an entity may have a facially neutral policy or practice that has a disproportionate adverse effect on the basis of race, color, or national origin. In such circumstances, this policy or practice may constitute a violation of the Title VI regulation. For example, a hospital that has a policy or practice of requiring all patients to communicate in English with hospital treatment professionals in all likelihood is in violation of Title VI, because the entity has a facially neutral policy or practice that has a disproportionate adverse impact on the basis of national origin. That is, people who cannot speak English tend to be of certain national origins. As a result, this policy or practice has a disproportionate adverse impact based on national origin. Overall, it is critically important to understand that discrimination in health can take many forms.

EDUCATION AND PREVENTION

Education and prevention are critical to the OCR's work. We spend considerable time and energy educating providers about their responsibilities under federal civil rights laws, and providing policy guidance and technical assistance so that we can prevent potential problems from occurring. For instance, we have spent considerable time educating hospital staff and health care providers on how to comply with their legal obligation to ensure that people who have limited English proficiency have meaningful access to health care. Hospitals and other health care providers have a legal obligation to ensure that they can communicate meaningfully with all patients. Relying on the hospital janitor, the cafeteria worker, or the patient's relative to interpret is not sufficient.

As a former prosecutor, I am comfortable in a courtroom setting. Nobody questions a defendant or witness's right to an interpreter in a courtroom proceeding. If we provide interpreters when a person's liberty is at stake, then shouldn't we do the same when a person's life is potentially at stake in a hospital? Health care providers must do a better job of ensuring that they can communicate meaningfully with *all* patients. This is a legal requirement, and a moral imperative. The Office for Civil Rights stands ready to assist any health care provider that would like to learn more about building an effective program of communicating with patients with limited English proficiency.

Health care providers should not only be able to communicate meaningfully with patients; they should also be culturally competent. It is time for more medical schools, hospitals, and other health care providers to develop training programs to ensure that all health care professionals are culturally competent. Only about a dozen medical schools currently require students to enroll in such a course. This must change. As Dr. Schulman's study demonstrates, doctors are human too.

We should not only educate doctors and other health care providers; we must also educate patients. All too frequently, victims of discrimination in the health care setting do not even know that they have been discriminated against. They are simply grateful that somebody looked at them. We must teach patients that it is OK to ask for a second opinion, it is OK to demand an explanation from a doctor about what he or she is planning to do, and it is OK to complain when they have not received adequate, respectful treatment.

PROACTIVE INVESTIGATION

Education and prevention are often the best enforcement tools, but there are times when it is necessary to take the next step—investigation. As outlined earlier, the OCR has negotiated settlements in a wide variety of areas relating to racial discrimination in health, such as redlining. We will continue these efforts. In addition, we have begun to look at data pertaining to hospitals and ask the following types of tough questions through a civil rights prism:

- Why is it that of the scores of high-tech medical procedures (e.g., cardiac catheterization) that a provider performed over a given period, only a handful were performed on minorities?
- Why is it that a particular facility with a sizeable minority population within its service area has extremely low utilization rates among this population?

It may be that the explanation for these statistical disparities does not implicate civil rights laws. Whether the explanation for the disparities turns out to be economics or some other factor instead of discrimination, is beside the point. The disparities must be eliminated, and the OCR and HHS are committed to identifying solutions that will eliminate these disparities.

ASSISTING IMMIGRANT POPULATIONS

America is becoming increasingly multiracial and multiethnic, and it is critical to be sensitive to the unique forces that inhibit or prevent immigrant populations from accessing critical health services. For immigrant populations, fear is a major factor that prevents them from accessing critical services. Fear can take a variety of forms, such as:

- A fear that accessing health benefits such as Medicaid or Children's Health Insurance Program (CHIP) will jeopardize eligibility for citizenship
- A fear that accessing benefits will require that other members of the household who may not be eligible to receive benefits will be reported to the Immigration and Naturalization Service (INS)
- A general fear of the government and authority figures such as physicians.

The government must address these fears, because they adversely affect many legal immigrants' willingness to access critical health care and other benefits to which they are entitled. Working in partnership with other federal agencies, the OCR has played an important role in a number of efforts that are designed to alleviate fear and encourage legal immigrants to seek critical benefits to which they are entitled. These initiatives include:

- Public charge guidance: the OCR has worked with the INS and other federal agencies on the development of a regulation that clarifies for immigrants that they can access critical health benefits such as Medicaid and CHIP without jeopardizing their chances of becoming a citizen.
- Making the application process for benefits user friendly for immigrants: many otherwise eligible immigrants are being deterred from seeking Medicaid or CHIP because the application form asks irrelevant questions. For instance, one state's application form for Medicaid requires all applicants to certify under penalty of perjury that every member of the household is documented. The only relevant question is the immigration status of the Medicaid applicant him or herself. The effect of such a question is that the parent of a citizen child may be reluctant to seek benefits because a relative is undocumented and may be reported to the INS. The Office for Civil Rights is working to eliminate these and other similar barriers that deter legal immigrants from accessing these critical benefits.

Martin Luther King Jr. once said that "peace is not simply the absence of violence but the presence of justice." As I look at the overall landscape of racial and ethnic disparities, and the specific barriers confronting immigrant populations, I cannot help but conclude that this is not peace, and this is not justice. But I have a tremendous sense of optimism that we can meet President Clinton's goal of zero disparities by 2010, and I believe the civil rights model is a vitally useful frame of reference.

Civil rights is about coalition building. Every major piece of civil rights legislation over the past 40 years was the product of bipartisan coalition building, borne out of a collective sense of moral outrage at the gross injustices that were occurring before our very eyes. Eliminating racial and ethnic disparities in health is about building coalitions and bringing all stakeholders to the table to craft solutions that work. When I think about racial and ethnic disparities, I do not see problems. I only see opportunities. The coalitions are already forming throughout the country; the sleeves are rolled up, and it is time to get to work. The Office for Civil Rights is committed to working with each and every stakeholder to ensure that we meet the President's goal of eliminating racial disparities by 2010.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

The Human Genome Project:

Revealing the Shared Inheritance of All Humankind

Francis S. Collins, M.D., Ph.D.
Monique K. Mansoura, Ph.D.

National Human Genome Research Institute, National Institutes of Health, Bethesda, Maryland.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Dr. Collins is grateful to Dr. Harold P. Freeman for his strong leadership on the President's Cancer Panel and for the important role he has played in my personal education on these issues. The authors thank Dr. Lawrence Brody, Dr. Clifton Poodry, Dr. Bettie Graham, Dr. Ron King, Ms. Elizabeth Thomson, Dr. Jean McEwen, and Mr. Craig Higgins for their thoughtful comments on this article.

Address for reprints: Francis S. Collins, M.D., Ph.D., National Human Genome Research Institute, National Institutes of Health, Building 31, Room 4B09, 31 Center Drive, Bethesda, MD 20892-2152; Fax: (301) 402-0837; E-mail: fc23a@nih.gov

Received April 1, 2000; accepted August 31, 2000.

The information derived from the Human Genome Project, an international effort to decode the information embedded in the human genome, will revolutionize the practice of medicine in the 21st century by providing the tools to determine the hereditary component of virtually all diseases. This will lead to improved approaches to predict increased risk, provide early detection, and promote more effective treatment strategies. To be ultimately successful, these improvements in research and health care must reach everyone. This success will depend on participation from a broad spectrum of the population. such as scientists, clinicians, research participants, and active discussants, in deliberations of ethics and public policy. The Human Genome Project has helped to inform us about how remarkably similar all human beings are—99.9% at the DNA level. Those who wish to draw precise racial boundaries around certain groups will not be able to use science as a legitimate justification. However, studying the 0.1% of human genetic variations, particularly the distribution of single nucleotide polymorphisms, between affected and nonaffected individuals will significantly inform biomedical researchers about the genetic contributions to complex diseases such as cancer, diabetes, and mental illness. We must all work together to ensure that the risks of such research are considered carefully and that the medical benefits are made available to all. ***Cancer* 2001;91:221–225.** *© 2001 American Cancer Society.*

KEYWORDS: hereditary component, human genome, medical ethics, social issues.

Some intend to measure the success of the Human Genome Project (HGP), an international effort to decode the information embedded in the human genome, by the date of deposition of the final base pair of the human genome sequence into public data bases or by the number of genes identified within this genetic code. However, the most critical measure of the success of the HGP will be determined by the answer to this question: To what extent did the scientific and medical advances derived from the HGP reduce the burden of disease for *all* people?

In this report, we discuss how the HGP will be beneficial to all of humankind provided we all work together to achieve that end. The HGP is laying the foundation for a 21st century revolution in biomedical research and medicine that promises longer, healthier lives for everyone.

The HGP was initiated in 1990 primarily for medical reasons. It is international in scope and is funded in the United States through the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH) and the Department of Energy. It has long been known that diseases tend to run in families. In other words, close relatives have a shared risk of particular diseases that have affected a family member. In fact, virtually every disease has a genetic component, including such common diseases as cancer. The objective of the HGP is to unravel some of these mysteries of disease by unraveling the thread of DNA present in nearly every cell in our bodies. The genetic code within DNA holds many potential insights for individual susceptibilities and resistances to disease.

The HGP is distinct from most other biomedical research in that it has been defined by a series of very specific and quantifiable goals.[1] We are happy to report that essentially all of these milestones have been achieved ahead of schedule and under budget. Early accomplishments included the construction of genetic and physical maps. These maps are research tools that have proven invaluable in the identification of more than 100 genes involved in diseases such as Huntington disease, achondroplasia, colon cancer, and breast cancer. These maps also provided a framework on which to proceed with the most visible goal of the HGP: sequencing the approximately 3 billion base pairs, or letters, that constitute the human genome.

The genetic code in humans as well as in all animal and plant species is spelled out in an exquisitely simple four-letter alphabet. The four chemical constituents of each DNA molecule are abbreviated A (adenine), C (cytosine), G (guanine), and T (thymine). What the genetic alphabet lacks in variety, it makes up for in volume. The DNA contained in a human cell is packaged in 23 pairs of chromosomes, each one containing millions of letters. If all 3 billion letters of the human genome were printed out on standard paper and stacked up, then the pile of paper would be as high as the Washington Monument.

Improvements in technology and the efforts of thousands of scientists throughout the world have resulted in an accelerated timetable for sequencing the human genome. A working draft of 90% of the human genome is on the brink of completion, and a finished, polished product in which gaps are closed and ambiguities resolved is anticipated by 2003. Progress can be monitored at a web site of the National Center for Biotechnology Information (http://www.ncbi.nlm.nih.gov/genome/seq), where a public data base, *GenBank*, holds all of the genetic information deposited by the international contributors to the HGP. Since 1996, participants in the public effort have held to the principle that newly generated genetic sequence data will be deposited into public data bases such as GenBank on a daily basis.

The study of the human genome and variations in it may shed light on how we are all different and, just as importantly, how we are all the same. What does the study of genetics tell us about concepts of race and ethnicity? Let us start with this observation from historian Evelyn Brooks Higginbotham: "When we talk about the concept of race, most people believe that they know it when they see it but arrive at nothing short of confusion when pressed to define it."[2]

When we look around at the people who surround us in our multiethnic society, we tend to focus on differences rather than similarities. We see superficial variations in skin and hair color and facial features, yet all externally visible traits represent only a tiny fraction of the genetic endowment of individuals.[3] It is a much more profound revelation to realize how similar we are at the most fundamental molecular level.

In fact, the study of human genetic variation has enlightened our understanding of just how similar we are. It is estimated that the DNA sequence between any two individuals is 99.9% identical.[4] Although genetic variations do exist, they seldom segregate in a manner that conforms to the racial boundaries constructed by sociopolitical means. The distribution of this 0.1% of differences among us is revealing. Studies have proven that the vast majority of these genetic variations are found *within* and not *between* populations,[5] indicating that these variations were present in our shared ancient human founder group. This reflects the relatively young age and historically small size of our species. Research supports the hypothesis that modern humans originated from a founder population of about 10,000 individuals in Africa and that there was an expansion and outward migration 40,000–100,000 years ago. Furthermore, the evolution of our species really cannot be drawn correctly as a tree, with branches that never intersect. Instead, because gene flow has occurred in many directions, the history of the human population is more like a trellis with multiple interconnections. It is increasingly clear that there is no scientific basis for defining precise ethnic or racial boundaries. Those who wish to draw such exact boundaries cannot use science as a legitimate justification.

Although it will not provide scientific support for sharply defined racial categorization, cataloging the 0.1% variation in the human genome is currently a focus of intense research, because the data will provide information about increased susceptibilities or resistances to disease. The most common variations are called single nucleotide polymorphisms (SNPs).[6] In collaboration with a private-sector consortium, the NHGRI is supporting research to identify SNPs from a common pool of 450 samples representing individuals whose geographic origins are Africa, Asia, Europe, and the Americas before colonization.[7] These samples were obtained from individuals who provided full, informed consent and whose individual background and identity will remain unknown, because all identifiers have been removed from the samples. A vast, dense catalog of SNPs will enable researchers to perform association studies that compare affected and unaffected individuals with common, complex diseases, such as cancer, heart disease, and mental illness. These case–control studies will look for correlations or "associations" between particular SNPs and diseases, most of which will apply to many different populations.

However, what about diseases such as sickle cell anemia that have a higher prevalence in the African-American population? Although sharp racial boundaries are meaningless at a molecular level, we are all part of historic extended families. The sickle variant arose in a "founding" individual thousands of years ago. (There actually appear to be at least three independent origins of the sickle mutation.) Positive selective factors, in this case, resistance to malaria afforded to carriers of a single copy of this variant, caused this variant to reach high frequency in descendants of the founder. A gene variant like this that appears at high frequency in offspring of an original common ancestor often suggests selective advantage but also can occur by a more random process known as "genetic drift."

What about other diseases, such as some cancers, that disproportionately affect certain racial and ethnic minorities? For example, African-American men are 32% more likely to develop prostate cancer than white men. Does this imply some environmental cause or a genetic cause, such as a founder effect? The answer is not yet known, although a number of studies are beginning to address this question.[8] Studies of hundreds of families, most of them white, with multiple males affected with prostate cancer have identified regions of chromosome 1 and chromosome X that are likely to harbor variations in genes that lead to increased susceptibility to the disease,[9,10] although the precise genes involved have not yet been identified. However, almost all studies looking for genetic contributions to common, complex diseases have been conducted primarily on white populations. Historically, minority communities have been hesitant to participate in genetic research.[11–14] Members of minority communities will not easily forget the misuses and abuses of the not-so-distant past, such as the Tuskegee experiment or the debacle in the 1970s with sickle cell screening.[15–17] The biomedical community has an obligation to work to regain the trust of communities that have undergone such troubling experiences. Individuals must be provided with sufficient information and be given the opportunity to balance risks with the possible benefits of participation in present day research. If minority communities do not fully participate in this research, then they may not experience the expected benefits. Knowing the factors, both genetic and environmental, that contribute to susceptibilities to disease will be essential to designing effective prevention, screening, and treatment strategies.

Broader inclusion of minorities as biomedical researchers also will facilitate the inclusion of minorities as participants in research trials. The recruitment and retention of individuals from populations that traditionally have not been involved in the health research enterprise has been an ongoing concern of many in the scientific and medical research communities. This is of particular importance for the NHGRI, given the far-reaching implications of genetic information and technologies for both individuals and groups. In addition to participating in traditional NIH recruitment mechanisms, such as the minority supplement and the predoctoral fellowship programs, the NHGRI has initiated a number of new and innovative training programs. These include a new career award for individuals from disadvantaged backgrounds and the ongoing short course in genomics for faculty at minority institutions.

Two years ago, the NHGRI began a productive collaboration with Howard University investigator, Dr. Georgia Dunston, on hereditary factors in African-American prostate cancer. With significant support from Dr. John Ruffin and the Office of Research on Minority Health at the NIH, the objective of this project is to uncover genetic variations in African-American men that are associated with increased susceptibility to prostate cancer. Family histories and tissue samples are being collected at seven sites throughout the United States, including Detroit, Chicago, Washington DC, New York, Houston, Atlanta, and Columbia. At most locations, African-American urologists serve as principal investigators who are involved in all aspects of the research project, including sample acquisition, data analysis and interpretation, and the publication of results. We currently have enrolled over 40 families in the study, and twice as many are expected to participate by the end of 2001. Preliminary data suggest involvement of genomic regions other than the previously identified chromosome 1 and chromosome X linkages. From this study, we hope to learn whether specific hereditary factors make prostate cancer so common and sometimes fatal in African-American men; then, that information will be used to develop better diagnostic tests and therapeutic interventions.

Such scientific advances were envisioned over a decade ago by the planners of the HGP. They recognized that the information gained from mapping and sequencing the human genome would have profound implications for the health of individuals, families, and society. In addition to the potential for this research to dramatically improve human health, they realized that it would also raise a number of complex ethical, legal, and social issues. How should this new genetic information be interpreted and used? Who should have access to it? How can people be protected from the harm that may result from its improper disclosure or use? To address these issues, the Ethical, Legal and Social Implications (ELSI) Program was established as an integral part of the HGP. The ELSI Program was designed to provide a new approach to scientific research by identifying, analyzing, and addressing the ethical, legal, and social implications of human genetics research at the same time that the basic scientific issues were being studied.

The ELSI Program is viewed as essential to the success of the genome project in the United States and is supported with federal HGP funds. From its onset, the NHGRI has committed 5% of its annual research budget to study ELSI issues. One of the ELSI research goals for the current 5-year plan is to "explore how socioeconomic factors, gender, and concepts of race and ethnicity influence the use, understanding, and interpretation of genetic information, the utilization of genetic services, and the development of policy." To begin addressing this goal, NHGRI recently issued a Request for Applications for grant proposals that examine ELSI issues surrounding the study of sequence variation research, with a particular focus on racial, ethnic, and socioeconomic issues. Such research will be vital to developing resources, including properly trained health care professionals in minority and underserved communities and culturally sensitive educational materials. These efforts, combined with an informed and involved community, will be an important step toward reducing barriers to access and avoiding unequal benefits of new genetic technologies as they become increasingly integrated into health care.

The NHGRI is expanding efforts to establish and maintain working relations with voluntary health organizations, such as the Intercultural Cancer Council, and to offer opportunities for dialogue with the public. In November 1999, the NHGRI hosted the first annual Consumer Day to inform participants about the NHGRI, the HGP, and how this research into "genetic medicine" may affect the lives of present and future generations (http://www.nhgri.nih.gov/consumer_day99/). In addition to presenting the latest advances in research and technology, the program offered sessions on genetic testing, genetic counseling, and genetic information resources and an update on protections for the privacy and fair use of genetic information. We were encouraged by the very favorable response to last year's program and look forward to repeating this event later this year and for years to come.

The NHGRI also has contributed to important gains in the policy arena. The NHGRI has followed a model of cosponsoring workshops on topics like the fair use and privacy of genetic information in the workplace that have been attended by members of voluntary health organizations, professional societies, and other interested parties. The findings and recommendations of the workshop participants have been published and offer guidance for state and federal policy makers to protect individuals against genetic discrimination.[18–20] In 1996, Congress passed the Health Insurance Portability and Accountability Act (HIPAA).[21] HIPAA was the first step toward implementation of a number of the recommendations for protecting against health insurance discrimination; however, gaps remain. More recently, President Clinton took an important step toward protecting federal employees from genetic discrimination in the workplace when he signed the first Executive Order of the 21st century last February (http://www.nhgri.nih.gov/NEWS/Executive_order/index.html). This Executive Order prevents federal employers from accessing or using genetic information in hiring or promotion decisions among the 2.8 million federal employee workforce. It is important for individuals to participate in the policy process to work toward extending these protections against genetic discrimination to everyone.

The NHGRI will continue to work to extend opportunities that will ensure broad inclusion in all aspects of the HGP. Participation in research, training, ethical discussions, and policy development by individuals representing diverse communities will be vital to its success. We stand at the dawn of the 21st century, and our generation is the first to witness the remarkable identity of the universal thread of life encompassed within the cells of all people. We hold great hope that, by working together, our shared inheritance at the molecular level will translate into shared benefits in the application of the revolutionary medical discoveries that the HGP will enable.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

From Genes to Social Science: Impact of the Simplistic Interpretation of Race, Ethnicity, and Culture on Cancer Outcome

Marjorie Kagawa-Singer, Ph.D., M.N., R.N.

Department of Community Health Sciences, University of California at Los Angeles School of Public Health and Asian American Studies, Los Angeles, California.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington DC, February 9–13, 2000.

Address for reprints: Marjorie Kagawa-Singer, Ph.D., M.N., R.N. Department of Community Health Sciences, University of California at Los Angeles School of Public Health and Asian American Studies, 650 Charles Young Drive South, Los Angeles, CA 90095-1772; Fax: (310) 794-1805; E-mail: mkagawa@ucla.edu

Received April 1, 2000; accepted August 31, 2000.

Over the last 30 years, dramatic advances have been made in understanding the cell biology of cancer and the genetic changes involved in oncogenesis. Many tumors now are curable and overall, cancer mortality has decreased significantly. Cancer has been transformed from a primarily fatal disease into a chronic condition. To accelerate these trends, the American Cancer Society has set its goals for the year 2015 to reduce the burden of cancer in this country. The goals are to decrease mortality by 50% and decrease the rate of incidence by 25%, as well as increase the quality of life for all individuals with cancer. However, to achieve these goals, changes must occur on two levels, in cancer control research and programming. Greater resources must be directed toward social and behavioral research, and conceptual clarity must be developed so that refinements can be made in the methodologies used to study the effects of cultural differences on health behavior. This paper provides a broad overview of the complex, intricate, and interrelated interaction that is emerging as a salient area of study. To our knowledge, the information to date is in disparate disciplines and needs to be integrated within an overarching framework for cancer control in diverse populations.

Currently, only approximately 5–10% of cancers are known to be caused by inherited genetic abnormalities. The remaining 90% are attributable to life-style factors.[1,2] Life-style emanates from cultural beliefs, values, and practices. International studies show that the incidence rates of cancer appear to be approximately the same worldwide, but the types of cancer differ considerably.[3] Studies of migrant populations show that when groups immigrate, both their types and incidence rates of cancer begin to change to mirror those of the host culture, often in as little as 10 years.[4] For example, Asian women from Asia have approximately 50% to 25% the rates of breast carcinoma of white American women, but after 1 generation the rates of breast carcinoma for Asian-American women approach those of white women.[5] Thus culture (which drives such life-style practices as diet, exercise patterns, weight norms, work environments, birth rates, age at first birth, and health-seeking patterns) plays a major role in health promotion and maintenance. Figure 1 shows the relation between biologic, social, psychologic, and cultural factors and the development of disease from a holistic perspective.[6]

Changing Demographics

In 1996, the American Cancer Society, the National Cancer Institute, and the U.S. Centers for Disease Control and Prevention announced

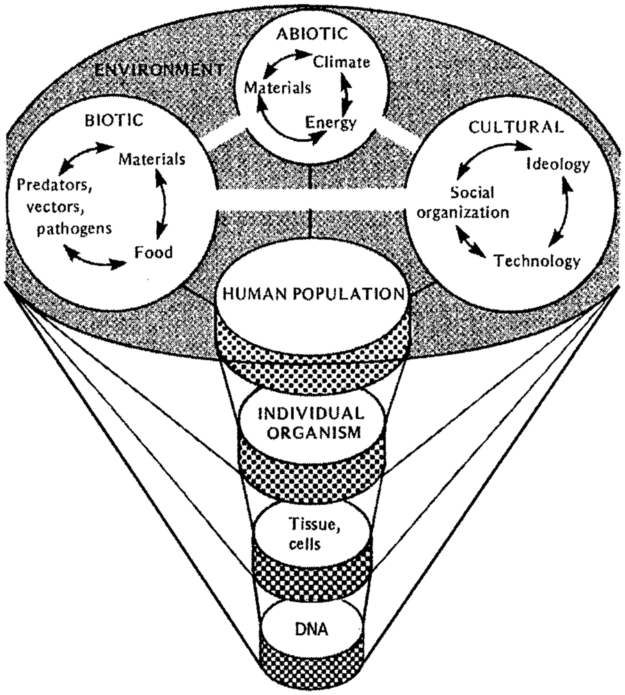

FIGURE 1. Physical, biologic, and cultural components that influence the health of individuals and populations. Modified and reprinted with permission from McElroy A, Townsend PK. Medical anthropology in ecological perspective. 3rd edition. Boulder, CO: Westview Press, Inc., 1996.

the first-ever sustained decline in overall, age-adjusted cancer mortality rates.[7] However, what has been less recognized is that this achievement is distributed unevenly across all groups. The recent Institute of Medicine Report[8] indicates that ethnic minority and medically underserved populations carry an unequal burden of cancer. The rates for cancer incidence and mortality in ethnic minority populations overall have stayed the same or continue to rise.[9] If the goals of the American Cancer Society are to be achieved, the disparity in cancer care outcomes must be addressed using skills from social and behavioral science to focus on the 90% rate of oncogenesis that may be amenable to behavior modification.

The disparities in both incidence and mortality rates for cancer by racial/ethnic minority populations are reported by the five racial/ethnic categories of the Office of Management and Budget (OMB) Directive 15 (Non-Hispanic white, black/African-American, American Indian/Alaska Native, Hispanic, and Asian-American/Pacific Islander),[10] yet the relation between factors that contribute to these disparities is less clearly understood. However, what is implicit is the belief that race/ethnicity and culture are key to the differential outcomes in both incidence rate and treatment outcomes.[11]

Race or ethnicity, in and of themselves, are not risk factors for these populations. Rather, these indicators are proxies for complex interactions among myriad variables encompassing life-style choices and social, historic, and socioeconomic circumstances that result in differential outcomes due to differential access to care, utilization, and treatment.[12]

Some studies have targeted particular, discrete, static cultural values or behaviors. For example, *fatalismo* for Hispanics and *face* for Asian-Americans have been identified as significant barriers to timely and adequate cancer treatment.[13,14] The fatalistic attitude of fatalismo interferes with the Hispanic's ability to seek care because it is believed that cancer always is fatal anyway, and one's affliction is God's will. Therefore, the disease and its consequences must be borne with acceptance of one's fate in silence and with dignity.[15] The concept of face in Asian cultures exerts significant social control on behavior. Face is a construct that represents the honor and reputation of one's family and social network. Loss of face is not just for an individual, but more important, it affects one's entire social structure.[16] If an individual were to perform poorly at work and receive a negative evaluation, behave in an embarrassing manner, or have a stigmatized illness such as cancer, the individual would lose face. However, even more important, the reputation of one's entire family and social network and social standing would be denigrated.

Although these culture specific constructs may have a strong effect on health behavior, currently these beliefs are used somewhat simplistically to predict responses to cancer and are applied homogeneously to individuals with low acculturation to Western society. This approach takes the concept out of context and uses it within an Euro-American framework of beliefs and behaviors.[17] The concepts are perceived as barriers that must be supplanted through education. Their adaptive function is not recognized. Thus, the results of comparative studies of ethnic group differences often show either little effect of "culture" or may not indicate the most efficient points of intervention to change behavior.

The color-coding of behavior, or response of members of a society to each other based on skin color (i.e., the racialization of interactions in our society) often is an overlooked or avoided factor that has significant impact on health outcomes for ethnic minority populations.[18–20] One recent study documented the differential treatment of patients by gender and skin color. Schulman et al.[21] provided case-controlled scenarios to physicians to investigate referral patterns for invasive cardiac procedures. These scenarios controlled for the clinical indicators of the patients' presenting symptoms. The quality of care rendered ranged from optimal to suboptimal by skin color and gender: white men, black men, white women, and last, black women. Similar studies document that the issues surrounding disparities in health outcomes are far more complex and insidious than merely variations by socioeconomic status and health insurance coverage.[22]

To accomplish the goal of increasing the quality of life and decreasing the cancer burden for all Americans, cancer researchers must develop clearer conceptualizations and operationalizations of the concepts of race, ethnicity, and culture to increase the scientific basis for the study of cultural differences. The remainder of this paper outlines the major factors that must be clarified to identify relevant mutable points of intervention to target and to positively modify or promote healthier behaviors in diverse populations and improve cancer outcomes.

Race, Culture, and Ethnicity

The terms "race," "culture," and "ethnicity" usually are used erroneously. These terms are used interchangeably and too simplistically for accurate measurement and reflection of the complexity of these concepts. Because culture and ethnic factors are poorly measured, socioeconomic indicators loom more salient. Clear conceptualization and measurement of these concepts would provide a basis on which to develop more sensitive and accurate research designs and measurement tools to gauge their effect on the continuum of cancer care. For this discussion, the following definitions have been developed.

"Race" is a scientific myth. This concept was created in the 1800s when the belief existed that there were subspecies of *Homo sapiens.* These subspecies were categorized on the assumption that phenotype, or skin color, reflected genotype, and more important, innate behaviors, moral character, and intellectual ability.[23,24] The scientific fallacy in this thinking was demonstrated definitively > 50 years ago, and the word "race" should be deleted from our vocabulary. Greater than 99% of our genetic codes are identical, and greater genetic variation exists within phenotypic group than these purported among racial groups. Population groups or clines is the more accurate term for environmentally designated groups of people who have adapted to their ecologic niches with some biologic variations, such as sickle cell or G6-PD traits. Both of these biologic variations are evolutionarily adaptive. They afford their carriers resistance to diseases endemic in the areas in which this variation is prevalent.[25]

What differentiates population groupings is culture: the collection of malleable, adaptive strategies that groups of people have developed to survive in their ecologic niche. These behavioral, psychologic, and cognitive strategies constitute a coherent, dynamic, integrated system of beliefs, values, life-styles, and ecologic and technical resources that ensure its members' survival and a sense of well-being. Culture also provides its members a purpose in life. However, it is interesting to note that not all members identify with or adhere to their cultural group behaviors nor any single group to the same degree.[17]

"Ethnicity" is defined as self-identified membership in a subculture that exists within a power structure of a multicultural society. Individuals within the subculture identify themselves as part of the group, and nonmembers identify themselves as outsiders to the subculture. The power structure creates the opportunity for an imbalance of resource availability and access. For example, prior to the Civil Rights Act of 1964, covenants existed in property deeds that excluded Japanese-Americans from owning property in California (including Japanese-Americans who were U.S. citizens). In many parts of the country, separate hospitals or wings of hospitals segregated black from white patients. Until the mid-1980s, private social clubs still were able to disallow membership to Jews and people of color. These practices now are illegal, and much less an overt social force, but the intent still exists in many areas of social and civil venues. Ethnic and racial discrimination still exists in our society, and the power structures that implicitly support such attitudes (even if unconsciously and unintentionally) affect health care practice today. One of the major points of this article is to identify how we need to address the effect of these forces on cancer care.

"Acculturation" refers to the facility the individual has to function comfortably in other cultures.[26] Acculturation is not the same as assimilation. Just as language fluency allows multilingual individuals to function easily in other cultures without giving up their native language, individuals who acculturate to the host culture are able to maintain the beliefs, values, and practices of their native culture. These individuals switch from one set of cultural practices to the other (or within multiple frameworks) as appropriate. Assimilation means to give up one's native culture for that of the host. Although some individuals do, the majority acculturate. Therefore, it is important to measure the degree to which one is able to switch and be comfortable in doing so.

Although race is not a scientific or real concept, racism, or racialization of interactions as it affects health outcomes, is.[27–29] Racism is the assertion of power, ego fulfillment, and status at the expense of others based on skin color (color-coded groups). Thus color-coded groups in a multicultural society are disadvantaged socially and are aware of their hierarchical status.[30] Table 1 enumerates many of the factors that are included in the measurement of ethnicity. Rather than the dichotomous variable usually used in statistical analyses, the concept of ethnicity encompasses most demographic indicators used in health studies and places them into the context of the lives of ethnically identified individuals and requires that the variables be integrated within an expanded framework.

TABLE 1
Operationalizing Elements of Ethnicity[a]

- Socioeconomic status
  - Income
  - Wealth
  - Education
  - Class
- Access to health care
  - Direct cost
  - Insurance/copayment
  - Sick leave/vacation
  - Time
  - Proximity
  - Transportation
  - Language capability of provider
- Neighborhood (by circumstances or by choice)
  - Ethnic composition
  - Aesthetics
  - Economic level/consonance with personal resources
  - Level of crime/type
  - Stability
  - Degree of interaction with neighbors
- Specific ethnic group
  - Generation
  - Level of acculturation
  - Language
  - Beliefs and practices
  - Degree of personal identification and public identity
  - Number of identity groups and degree of overlap
  - Size and cohesiveness of group in geographic area
  - Degree of comfort with other ethnic groups
- Reasons for immigration
  - Voluntary
  - Refugee
- Religion/spirituality
  - Beliefs and practices
  - Internal/external locus of control
  - "Fatalism"
- Alternative/complementary health practices
  - Healers
  - Parallel/synergistic systems
- Parental heritage
  - Degree of intergenerational conflict
- Diet
  - Choices
  - Availability
  - Quality
- Social choices
  - By circumstances or by choice for social activities and support
- Family structure/support system
  - Composition
  - Age
  - Responsibilities to extended family

[a] Ethnicity constitutes one's total way of being-intrapsychically, behaviorally, and interpersonally. However, one's ethnic identity also is situational in a multicultural society. Thus, any measure must take into account the plasticity of the observable and conscious with the implicit core of identity and how and when it affects one's choices in behavior (e.g., health).

Effects of Culture, Ethnicity, and Racism on Cancer Outcomes

Through life-styles, cultural beliefs and practices influence risk factors for cancer and shape the existential and experiential meaning of cancer. Culture affects how individuals weigh the costs and benefits of screening, early detection, treatment, and rehabilitation. Therefore, the assessment of risk as well as the meaning of cancer must be incorporated into the study of ethnic differences in incidence and mortality rates. This information should be integrated into efforts to enhance the quality of care at each stage of the care continuum, such as prevention or early detection and screening or end-of-life care. We also must begin to assess why and where breakdowns occur along the entire continuum of care. Figure 2 shows the nested relation among the variables that should be incorporated into an analysis of health care behavior.

In addition, the majority of studies of ethnic differences in cancer outcomes have focused on low income ethnic minority groups. Poverty is a powerful risk factor, but it also is a proxy for more proximal variables such as environmental exposure and diet.[31] Greater investigation of the spectrum of socioeconomic levels within each ethnic minority population must be conducted to identify more accurately what the cultural component of ethnic behaviors may be, and what role socioeconomic factors play.[32]

Blackhall et al. conducted a study with elderly Mexican-Americans, Korean-Americans, African-Americans, and Euro-Americans to determine their feelings concerning telling the truth about a poor prognosis.[33] They asked individuals if the patient should be told his or her poor prognosis and/or diagnosis, and who should be the primary person to make the decisions regarding end-of-life care. Significant differences were found among the groups that seriously call into question the cross-cultural applicability of ethical parameters around end-of-life decisions such as advance directives or the assumption of a patient's rights and informed consent. Such variations will affect practitio-

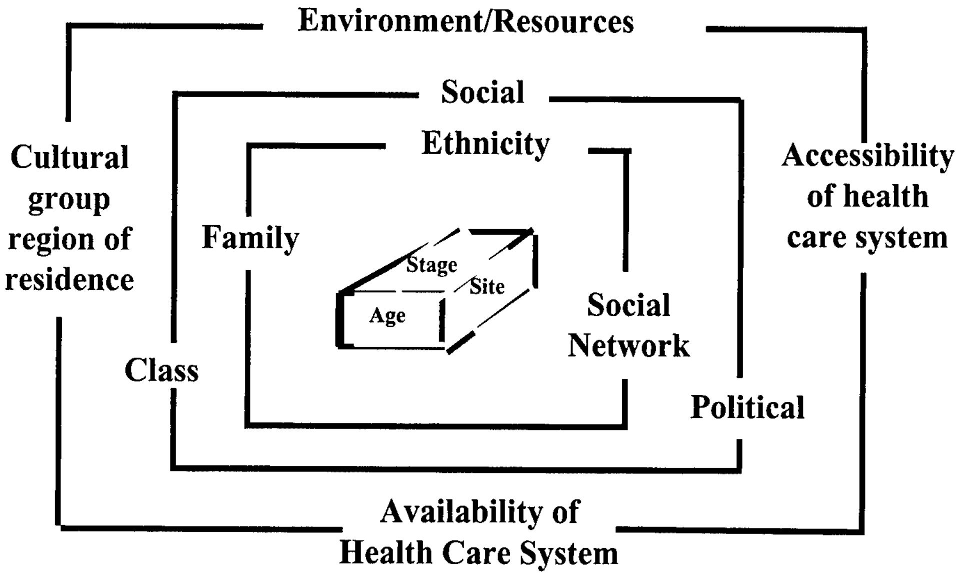

FIGURE 2. Ecologic determinants of illness response.

ner/patient communication and health care utilization and adherence to prescribed treatment regimens.

Every culture also has traditional healing techniques and practitioners, and many individuals use Western biomedicine in conjunction with their traditional therapies. Complementary and alternative practices are used widely by many individuals in the U.S., and biomedical practitioners must acknowledge their use as well if health promotion efforts are to be measured accurately.[21,34,35]

Prior experience with the health care system influences how individuals make decisions to seek care, choose treatment, and adhere to treatment protocols. However, we must also investigate the effects of the practitioners on the interaction, because patient and family choice may not be made strictly on the basis of "objectively" provided information. As noted, many studies have shown that racism, be it conscious or unconscious, has a strong impact on a patient's sense of trust and safety.[21,22] To our knowledge the effects of differential treatment based on skin color has been addressed in a few studies regarding breast and prostate carcinoma among African-Americans, but we believe they also should focus on other groups and other disease stages along the continuum of care.

Psychosocial Responses

Cross-cultural differences in the psychosocial responses to cancer also exist, and add to the burden of cancer for all patients and their families.[36,37] To our knowledge very little work has been done in this area in medical care to even describe such differences, but cross-cultural mental health studies have documented these differences well.[38–40] One study explored the prevalence of depression and anxiety among African-American and Euro-American subjects in the Epidemiologic Cachement Area Study (ECA).[41] The intent of this study was to document the incidence rate and prevalence of psychologic distress/psychopathology in the population. Huertin-Roberts et al.[41] found that the ECA noted only 32 emotional and behavioral indicators for depression and anxiety compared with the 70 indicators found in the ethnographic literature regarding African-Americans. They concluded that use of the ECA data would be problematic for program and policy development in the area of mental health for African-Americans because there would be potential undercounting or misdiagnoses of these disorders. With regard to psychosocial oncology, accurate treatment would be compromised and programmatic need would be unrecognized. Potentially, patient satisfaction with care and adherence to prescribed treatments may be compromised.

Implications for Future Directions in Cancer Control

More sophisticated understanding of cultural differences is required to move the science of cancer control forward. Several changes must occur to identify which cultural differences make a difference in cancer control efforts. We must identify what is universal about the cancer experience and what is culture specific.[42] We also must be open to discovering what is culturally protective.

Various cultural worldviews have equal validity and utility. Research efforts to study the differential adaptive value of cultural worldviews and practices in partnership with the communities of focus would be highly productive.[43,44] Research efforts directed toward studying why certain rates are significantly lower in particular groups could increase our knowledge of protective practices that could be disseminated to all groups. The reference group of comparative studies then would vary according to the research question rather than the assumption that the Euro-American population is the scientific norm.

Better data regarding what constitutes self-identified subgroups within the large OMB ethnic categories are needed to identify ethnic group differences. Lastly, intragroup variation must be documented before generalizations are made concerning the beliefs, values, and practices of population groups.

With the changing demographics in the U.S., minority groups will constitute approximately 50% of Americans by the year 2050. The goals of the American Cancer Society can be achieved only when all ethnic minority populations are included in cancer control efforts. Increased focus on the behavioral as well as the genetic aspects of oncogenesis and treatment would accelerate cancer control. Such a programmatic focus requires attending to cultural differences that make a difference.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Factors That Influence African-Americans' Willingness to Participate in Medical Research Studies

Vickie L. Shavers, Ph.D.[1]
Charles F. Lynch, M.D., Ph.D.[2]
Leon F. Burmeister, Ph.D.[3]

[1] Department of Epidemiology, Johns Hopkins University, School of Hygiene and Public Health, Baltimore, Maryland.

[2] Department of Epidemiology, College of Public Health, The University of Iowa, Iowa City, Iowa.

[3] Department of Biostatistics, College of Public Health, The University of Iowa, Iowa City, Iowa.

BACKGROUND. The underrepresentation of African-Americans among medical research participants is receiving considerable attention because of recent government mandates for the inclusion of all racial/ethnic groups in human subject research. Therefore, there is a need to determine factors that influence minority enrollment in medical research studies.

METHODS. Between 1998–1999, 91 African-American residents of the Detroit Primary Metropolitan Statistical Area participated in a mail and telephone survey designed to examine impediments to participation in medical research studies. Chi-square tests and multiple logistic regression analyses were used to examine the association between race, issues related to trust in medical researchers, and the willingness to participate in medical research studies.

RESULTS. African-American respondents were somewhat less willing to participate if they attributed high importance to the race of the physician when seeking routine medical care, believed that minorities or the poor bear most of the risks of medical research, and, most especially, their knowledge of the Tuskegee Study resulted in less trust in medical researchers.

CONCLUSIONS. These data reiterate the need for medical researchers to build trusting relations with African-Americans and to conduct research in an ethical manner. This includes maximizing benefits, reducing risks, and assuring distributive justice to *all* medical research study participants. ***Cancer*** **2001;91:233–6.**

The underrepresentation of African-Americans among medical research participants is receiving considerable attention because of recent government mandates for the inclusion of all racial/ethnic groups in human subject research. To our knowledge there has been a paucity of African-American subjects in human immunodeficiency virus treatment trials,[1-4] occupational cancer studies,[5] and cancer prevention studies.[6] Conversely, African-American representation in cancer treatment trials is proportional to their representation among cancer patients.[7-9] Although several investigators have proffered reasons for the relative absence of African-Americans among medical research participants,[10-18] to our knowledge few are based on empiric research. Thus there is a need to determine firsthand those factors that influence the willingness of African-American individuals to participate in medical research studies.

Between 1998–1999, we conducted a cross-sectional survey of the Detroit Primary Metropolitan Statistical Area (PMSA) to determine self-reported barriers to medical research participation. The Detroit PMSA encompasses Wayne, Oakland, and Macomb counties in Michigan. The current study examines factors that influence the willingness of African-Americans to participate in medical research studies.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Supported by Grant R03 HS09597-01 from the Agency for Health Care Policy and Research and Grants 1 F31 CA 72125-01A1 and T 32 CA09314-19 from the National Cancer Institute, National Institutes of Health.

Address for reprints: Vickie L. Shavers, Ph.D., National Cancer Institute, Health Services and Economics Branch, Applied Research Program, Division of Cancer Control and Population Sciences, EPN-4005, Bethesda, MD 20892-7344; Fax (301) 435-3710; E-mail: shaversv@mail.nih.gov

Received April 1, 2000; accepted August 31, 2000.

MATERIALS AND METHODS

Eligible households were located in randomly selected occupied housing units in the Detroit PMSA. Eligible respondents were age $\geq$ 18 years and were current residents of a selected household. Housing units were excluded if there were no eligible respondents (i.e., no respondent who was at least age 18 years, vacant housing units, or the respondent was too sick to participate). Households were selected using a stratified multistage area probability sampling design. This methodology has been described elsewhere.[19]

The main study instrument was a mail survey containing 24 questions (long version). There also was a short version of the mail survey, which contained seven questions that addressed the main study objectives and collected demographic data (i.e., age and race). The third instrument was a telephone survey that contained all the questions from the short mail survey and collected additional demographic data (i.e., education, income, and name).

Statistical Methods

The Survey Data Analysis Program (Version 7.5) (SUDAAN)[20] was used to analyze all weighted data. SUDAAN produced statistics adjusted for the effect of clustering. Chi-square tests were performed to assess differences in the distribution of proportions between study groups. Univariate and multiple logistic regression analyses were used to model factors associated with the willingness to participate in a medical research study. A significance level of 0.05 was used for all analyses.

Completing either a mail questionnaire or a telephone interview was deemed consent to participate in this study. The institutional review board of the University of Iowa (Committee A) approved the study protocol.

RESULTS

Participant Demographics

A total of 198 individuals participated in this survey. Ninety-one study participants (46%) were African-American and 88 study participants (44%) were white. Fourteen participants (7%) were from other racial/ethnic groups (8 Hispanics, 4 Asian/Pacific Islanders, and 2 Native Americans) and 5 participants (3%) refused to identify their racial/ethnic group. The current study includes data regarding African-Americans only.

Females had a higher representation among study participants than males (62% vs. 39%). The mean age of the respondents was 41.9 years. Approximately 73% of respondents had attended college. Approximately 44% of respondents had a total household income of \$50,000 and 38% had a total household income of < \$30,000 (Table 1).

Willingness to Participate

Fifty-six percent of respondents indicated that they would be willing to participate in a medical research study if asked in the future. Study participants did not significantly differ in their willingness to participate when stratified by gender, educational attainment, age group, or income (Table 2).

Race of the Physician When Seeking Routine Medical Care and the Subjects' Willingness to Participate

Nearly 22% of participants reported that, when seeking medical care, the race of the physician was very important, 30% regarded it as somewhat important, and 48% did not consider the race of the physician to be important. Participants who indicated that the race of the physician was very important were less willing to participate in medical research in the future than those who indicated it was somewhat important or not important; however, these differences were not statistically significant (Table 2).

Beliefs about Which Racial/Ethnic Group Bears the Most Medical Research Risks

Sixty-four percent of the participants indicated that they did not believe that all racial/ethnic groups share the risks of medical research equally. Of these, 45% indicated that minorities bear the most risk, 15% indicated that other racial/ethnic groups bear the most risk, and 40% did not specify which group they believed bore most of the risk of medical research. Participants who believed that minorities bear the most risk of medical research indicated a willingness to participate in a medical research study less frequently than those who indicated other racial/ethnic groups bear the most risk (odds ratio [OR], 0.4; 95% confidence interval [95% CI], 0.1–1.3); however, the difference was not statistically significant.

Changes in Trust as a Result of the Tuskegee Study

Eighty-one percent of participants had prior knowledge of the Tuskegee study. Of these, 51% responded that their knowledge of the Tuskegee study resulted in them having less trust in medical researchers, 48% reported that their trust had not changed, and 1% reported that they had more trust. Participants whose knowledge of the Tuskegee study resulted in less trust in medical researchers were significantly less willing to participate in a medical research study if asked in the future (OR, 0.2; 95% CI, 0.04–0.8). Approximately 50% of participants indicated that their knowledge of the Tuskegee study would affect their future decisions regarding participating in medical research. Of these, 49% indicated that they would not be willing to participate in a medical research study in the future.

In multivariate logistic regression analyses, factors that predicted the willingness of African-Americans to participate in medical research included knowledge of the Tuskegee study and changes in their trust of medical researchers due to this knowledge. After adjusting for changes in trust resulting from knowledge of the Tuskegee study, African-Americans who knew about the Tuskegee study were significantly more likely to participate in a medical research study in the future compared with those who did not know about the study (OR, 464.4; 95% CI, 44.4–4864.4). The willingness to participate in a research study was lower if knowledge of the Tuskegee study resulted in a reduction in the level of trust in medical researchers (OR, 0.21; 95% CI, 0.04–0.98) when compared with no change in trust or an increased level of trust.

Motivating Factors

Among respondents who were willing to participate in a medical research study, 83% would be willing to participate to help a friend or relative, 78% if it would benefit them directly, 69% to benefit society, 60% to learn more about their disease/condition, 56% to find a cure for diabetes, 53% to get better medical care, 51% to find a cure for cancer, 49% to find a cure for heart disease, and 38% to find a cure for the acquired immunodeficiency syndrome. To be able to participate in a medical research study, 79% of participants indicated that they would need payment for expenses, 64% payment for time and effort, 23% transportation, and 18% child care.

Eighty-one percent of respondents who were not willing to participate in a medical research study reported that not wanting to be experimented on was a reason. In addition, 48% cited fear of not receiving the treatment that was best for them, 43% cited a lack of trust in medical researchers, 43% cited not having time to participate, 17% cited lack of trust in physicians, and 10% cited not having medical insurance as reasons they would not be willing to participate in a medical research study.

DISCUSSION

Approximately 50% of participants indicated that there were some situations/conditions under which they would be willing to participate in a medical research study in the future. Among those indicating a willingness to participate in medical research, the most frequently cited reasons were if it would help a friend or relative and if it would be of direct benefit to the participant. A reduction in the level of trust in medical research as a result of knowledge of the Tuskegee study was associated significantly with the unwillingness to participate in medical research.

African-American distrust of medical researchers is likely exacerbated by U.S. social history. Race and ethnicity have been the major determinants of individual and group experiences and unfortunately, racial discrimination largely has characterized the experience of African-Americans. As a result, a disproportionate number of African-Americans are unemployed, impoverished, and have limited access to health care, and therefore prematurely die from chronic conditions. The suspicion and distrust resulting from racial discrimination more than likely contribute to the distrust that impedes African-American participation in medical research studies. Therefore trust-building with African-Americans will be dependent on reducing the repeated occurrences of experiences and conditions that cause distrust.

In the interim, researchers should establish trusting relations with minority communities built on mutual respect. Researchers can begin building trust by encouraging open dialogue on the past misuse of minority participants that has generated the overall distrust of researchers. It should be noted that the presence of institutional review boards has done little to alleviate fear and suspicion of research among racial/ethnic minorities[21,22]; therefore, acknowledging institutional review board approval for a project will not be sufficient. Individual researchers should state their commitment to ethical research conduct and describe provisions that they have made to protect participants in their particular studies. Researchers also should provide frank explanations for studies and initiatives that specifically target racial/ethnic minorities or that are likely to result in the disproportionate representation of racial/ethnic minorities among study participants. Most important, researchers must adhere to ethical rules for research conduct. This includes maximizing benefits, reducing risks, and assuring distributive justice to *all* medical research study participants.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Statewide Tuskegee Alliance for Clinical Trials

A Community Coalition to Enhance Minority Participation in Medical Research

Mona N. Fouad, M.D.[1]
Edward Partridge, M.D.[1]
Theresa Wynn, Ph.D.[1]
B. Lee Green, Ph.D.[1]
Connie Kohler, M.D.[1]
Steve Nagy, Ph.D.[2]

[1] University of Alabama at Birmingham, Birmingham, Alabama.

[2] The University of Alabama.

BACKGROUND. Cancer mortality rates for all sites are nearly 2.5 times greater for African-Americans compared with whites. In addition, there are data implying that cancer treatment outcomes for minorities are unfavorable compared with whites. Whether this is due to poor access to health care or a biologic property of malignancies occurring in specific populations remains to be determined. Because of these unknown factors, targeting minorities for clinical trials may contribute toward the reduction of the overall morbidity and mortality associated with specific cancers.

METHODS. The current study describes the establishment of a genuine collaborative partnership between the targeted minority community and clinical investigators at the University of Alabama at Birmingham. This partnership was formed for the purpose of identifying strategies that would enhance the accrual and retention of minority participants into current and future cancer prevention and control trials. Focus groups and key informant interviews were conducted to ascertain the community's perception of participating in clinical trials.

RESULTS. The majority of focus group participants were unclear regarding the nature of clinical trials. Participants indicated that they would participate in research studies if they received adequate information regarding the purpose and benefits of the study, and if the charge came from a pastor or physician. Barriers to participation included time commitments, family obligations, whether blood was involved, and past experiences. The majority of the participants indicated that their knowledge of the Tuskegee Syphilis Study did not influence their decision to participate in research. A major outcome of the conference was the formation of the Statewide Tuskegee Alliance Coalition. The planning coalition decided to continue their efforts to work with communities and promote cancer awareness among minorities. After the conference, the coalition conducted several meetings and in July 1998, 1 year after the conference, the coalition selected a chair, co-chair, and a formal name for the organized group.

CONCLUSIONS. The planning, development, and implementation of this conference provided a valuable experience for researchers and community members. It was discovered that community involvement in the early phase of this project contributed to its success. Furthermore, the partnership that developed between researchers (academic institutions) and communities successfully provided an infrastructure that supported the interest of both groups. ***Cancer*** **2001;91:237–41.** *© 2001 American Cancer Society.*

KEYWORDS: clinical trials, minority, participation, community involvement, coalition.

Cancer mortality rates for all anatomic sites are nearly 2.5 times greater for African-Americans than for whites.[1,2] In addition, there are data implying that treatment outcomes for minorities diagnosed

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

This publication was based on a National Cancer Institute funded grant (CA74447-01) entitled "Recruitment of Minorities into Cancer Clinical Trials."

Address for reprints: Mona N. Fouad, M.D., M.P.H., University of Alabama at Birmingham, 1530 3rd Avenue So., Medical Towers #728, Birmingham, AL 35294-4410; Fax: (205) 934-7959; E-mail: mfouad@dopm.uab.edu

Received April 1, 2000; accepted August 31, 2000.

with some of the most common malignancies, such as carcinomas of the breast, cervix, and prostate, are unfavorable compared with whites. Whether this is due to poor access to health care, presentation at later stages of disease, or a biologic property of the malignancies occurring in specific populations, the causative factor has yet to be determined. Because of these unknown factors, it stands to reason that targeting minorities for cancer prevention and control trials may contribute to the reduction of the overall morbidity and mortality associated with specific tumors.

Recent analyses support the assertion that there is proportional representation of minorities in treatment clinical trials.[3,4] However, minority accrual and retention in several large-scale National Cancer Institute (NCI) cancer prevention trials has been lower than desired.[5,6] Although to our knowledge academic institutions have not been able to provide similar enrollment into cancer prevention and control clinical trials, it stands to reason that the dynamics of recruitment and willingness to participate are quite different for treatment versus prevention cancer trials.[3,7] Given the racial differences in the prevalence of certain tumors and response to medical intervention, heterogeneity in clinical trials ensures that subset analysis will yield meaningful data and provide broader applicability of research outcomes.

Recruitment Barriers Related to the Community:

Despite overall positive feelings regarding research institutions,[7,8] Arean and Gallagher-Thompson[9] reported that attempting to recruit African-Americans without the involvement of trusted community representatives possibly may result in feelings of mistrust and alienation. The members of these organizations (e.g., churches and social groups) tend to perceive that they do not have a sense of ownership in the programs that affect the health of their members. Although these barriers often are systematic in nature, the impact frequently is felt on a personal level.[7] Information related to health often is technical and leaders in minority communities, especially health care providers, could play a pivotal role in the process of alerting members of the community to health issues.

Recruitment Barriers Related to Health Care Providers

It has been hypothesized that patients participating in clinical trials receive state-of-the-art cancer management, and through community participation in clinical trial research, programs such as the Community Clinical Oncology Program could increase information dissemination and access to improved cancer care.[10] Despite these strengths, physician involvement in clinical trial research is limited. To our knowledge to date, little research exists to evaluate and address these barriers. One study conducted by Taylor et al.[11] identified six main obstacles that prevented greater physician referral activity. These were: the physician-patient relation (i.e., individualized decision-making, potentially compromising the physician's authority, jeopardized rapport, lowered moral due to indecision from trial), informed consent (i.e., legality, difficulty in obtaining it), discussing uncertainty (i.e., physicians feeling uncomfortable telling a patient that they did not actually know which procedure would be better), clinician versus scientist (i.e., belief in their own intuitive judgment, a priori knowledge), practical difficulties in trial (i.e., additional time required to conduct follow-up), and personal responsibility (i.e., fear of personal responsibility should one treatment prove more effective than another).

In 1996, The University of Alabama at Birmingham (UAB), The University of Alabama, and Tuskegee University collaborated and responded to a request for applications from the NCI and received support for a regional conference whose aim was to share current information and strategies pertaining to minority participation and recruitment in clinical trials. On August 14 and 15, 1997, at the campus of Tuskegee University in Tuskegee, Alabama, the conference entitled "Minorities in Clinical Trials: Sowing the Seeds for a New Beginning" was implemented. The Tuskegee campus was selected for its symbolism, but, more important, to provide the backdrop for mutual collaboration with the rural African-American community in Alabama. The objective of the conference was to establish and maintain a genuine, collaborative partnership between the targeted minority community and clinical investigators in Alabama with the intent of sharing information and identifying strategies that would enhance the accrual and retention of minority participants into current and future cancer prevention and control trials. The current study describes the conference planning phase, which included the establishment of a partnership (coalition) between UAB and the community to plan the conference. During this phase, focus groups and key informant interviews were conducted to ascertain the community's perception of participating in clinical trials. The conference implementation phase currently is being published elsewhere.[12]

MATERIALS AND METHODS

Formative Evaluation Phase

The primary objective of the formative evaluation was to gather information concerning the perceptions of members of the African-American community regarding their participation in clinical research.

Focus Group and Key Informant Interviews

Ten Alabama counties were identified as target areas for conducting focus groups. Eight focus groups were conducted in eight rural counties and two were conducted in urban areas. Focus group interviews included questions regarding knowledge of research, level of trust in the health care system, barriers to participation in clinical research, and the impact the Tuskegee Syphilis Study may have had on each individual's decision to participate in clinical research. Detailed information describing focus group methodology has been published elsewhere.[13]

Key informant interviews were conducted by trained staff with identified health care providers and community leaders in the targeted counties. The interviews included general questions regarding the willingness of community members to participate in clinical trials.

Conference Planning Phase

Coalition building

After the Formative Evaluation Phase, a coalition of representatives from African-American communities (community leaders, ministers, and lay individuals) and African-American health care providers was formed. The purpose of this coalition was to encourage individuals with an interest in promoting the health of their communities to take part in the development, planning, and implementation of this conference. The formation of this coalition was based on the notion that before community members will address particular goals introduced from the outside, they first must organize and build capacity to address their own concerns and goals as described by the Community Development Theory.[14]

Study investigators contacted community organizations and African-American churches in rural counties, visited with ministers, and identified and contacted African-American physicians who were providing health care to minority patients in the targeted counties. During these visits and contacts, the investigators presented the proposed NCI conference mission to each identified individual, and asked them to assist in the formation of a partnership between the community and academic institution. The goals of the partnership were to review the information gathered from the formative evaluation and to assess the community's perception of participating in clinical trials. Based on this information, the partnership then was to develop an agenda for the conference. Those who agreed to participate and become a member of this coalition were invited to a 1-day meeting that took place at the Tuskegee University to discuss the planning phase of the conference further. After this meeting, each member received a summary of the focus group and the Key Informant interview results. A second meeting was held at Tuskegee University to finalize the conference agenda and select topics and speakers.

RESULTS

Summary of Focus Group Interviews

Ten focus groups were conducted in rural and urban counties in Alabama. All focus group participants were African-American; 32 were men and 71 were women. General attitudes regarding the health care system were positive. The majority of focus group participants were unclear regarding the nature of clinical trials. There was an apparent level of mistrust and fear of clinical trial procedures, especially if it involved taking drugs or drawing blood. Whether the fear of taking drugs or drawing blood stemmed from personal experiences with invasive protocols, fear of being a "guinea pig," or lingering effects of the Tuskegee Syphilis Study has yet to be determined.

However, participants indicated that they would participate in research studies if they received adequate information regarding the purpose of the study. Recommended solutions to increase the number of African-Americans participating in clinical trials included informational workshops on clinical trials and community education utilizing churches, fraternities, and sororities in recruitment efforts. Finally, it ultimately was necessary for the research institution to build trust within the community by being honest with community representatives and clear about the research agenda.

Summary of Key Informant Interviews

Informant interviews

Two physicians and two nurses were interviewed. They varied with regard to years of professional practice as health care providers and three of the four were involved in primary care. They believed that African-Americans in the South suffered more from cancer primarily because of a lack of education and preventive behavior. They suggested the following solutions: distributing educational materials and programs for community physicians and involving primary care providers, especially in prevention trials.

Nine community leaders were interviewed from Jefferson and other outlying counties. The years that these individuals had lived in their communities ranged from 13 years to an entire lifetime. The communities had minority populations ranging from 30–90% of the total population (mean, 65%). Approximately 50% were not familiar or only slightly familiar with clinical trials. In general, community leaders were reluctant to recruit minorities to participate in clinical trials. However, community leaders suggested that making the information regarding clinical trials available in an easy format; having flexible schedules; involving minority staff; and providing free meals, transportation, and child care were ways to increase minority accrual and retention.

Coalition building

Two ministers, 17 health-related professionals, 1 political representative, 10 lay persons, and 3 individuals from community-based organizations agreed to serve as coalition members and review the results of the above formative evaluation phase. Based on information from the formative evaluations, they made the following decisions:

- The conference should serve as a forum for discussion between researchers and community members so each group can present their perspective regarding minority participation in clinical trials.
- The conference theme should focus on providing solutions, not only discussing barriers. However, the scientific community should acknowledge the past mistakes of researchers, and commit to working with communities to correct these negative experiences. Based on this suggestion, the coalition members decided to name the conference "Minorities in Clinical Trials: Sowing the Seeds for a New Beginning."
- To ensure the participation of individuals who represent minority communities (leaders, ministers, physicians, and lay people), the coalition members decided to actively recruit participants for this conference. The formed coalition should be maintained after the completion of the conference to evaluate the conference's immediate and long term effects on accomplishing its mission.
- The conference agenda included individual presentations from a community leader, a church leader, and a researcher. In addition, workshops that were designed specifically to address cultural barriers and solutions, church barriers and solutions, health care barriers and solutions, and trial design barriers and solutions were scheduled during the first and second days of the conference.
- A total of 140 people attended the 2-day conference in Tuskegee, Alabama. Specifically, representation was from civic organizations, sororities and fraternities, nonprofit grassroots organizations (38.57%), community nurses (11.43%), community physicians (5.71%), professionals (32.14%), students (6.43%), and clergy (5.71%). A detailed report on the conference results and evaluation will be published elsewhere.[12]
- A major outcome of the conference was the formation of the Statewide Tuskegee Alliance Coalition. The planning coalition decided to continue their efforts to work with communities and promote cancer awareness among minorities. The coalition conducted several meetings and in July 1998, 1 year after the conference, the coalition selected a chair, co-chair, and a formal name for the organized group.

DISCUSSION

The conference was guided by theoretic principles derived from community development theory. In addition, Roger's diffusion theory and Friere's empowerment theory[16] provided direction for selecting and recruiting a broad-based coalition membership. In an attempt to increase knowledge in early adopters and persuade the late majority, we used constructs taken from diffusion theory. The diffusion process is comprised of five distinct phases: knowledge, persuasion, decision, implementation, and confirmation.[15]

According to the National Association of Planning Councils[16] and Greene,[17] the primary purpose of community participation is to promote positive responses to an initiative by systematically involving the targeted audience. The main strength of this conference was the active involvement of the community in the planning and implementation process. However, there is no clear pathway to follow when attempting to motivate and encourage community participation. Research[18] has shown that approaches that emphasize the community's central role in defining needs, identifying strategies, implementing methods, and actively encouraging and supporting local ownership and empowerment[19] were effective in reaching the community. Furthermore, strategies that included minority representatives in outreach planning (e.g., forming advisory groups representative of the minority population of interest or building coalitions of community organizations and institutions similar to the one we developed for this conference) provided a basis for common organizational methods and have been characterized descriptively as "constituency-based" models.[20,21] Realizing the importance of having community participation and representation present throughout the conference planning and implementation phases, the project investigators provided the support necessary to bring all interested parties together for the purposes of building relations and developing a plan of action to accomplish the NCI goals of this conference successfully.

Another strength of this conference was the information gathered from the formative evaluations. The use of focus groups and key informant interviews provided the project investigators with a valuable picture of needs and barriers identified by the community. Furthermore, a unique quality of these evaluations allowed community members to propose solutions to the barriers they identified, thus enabling investigators to develop a tailored conference agenda. In addition, having an open dialogue format was the greatest strength of this conference.

The planning, development, and implementation of this conference provided a valuable experience for researchers and community members. During our collaborative efforts, we discovered that community involvement in the early phase of this project contributed to its success. Furthermore, the partnership that developed between researchers (academic institutions) and communities successfully provided an infrastructure that supported the interest of both groups. We believe this conference could be used as a model for developing partnerships for future projects.

With regard to limitations, the development of coalitions between researchers and communities is a time-consuming process and requires additional resources that usually are not provided by funding agencies. In addition, to our knowledge little has been reported regarding methods with which to maintain these coalitions once they are formed. To be successful, funding agencies must address these barriers. Moreover, any researcher attempting to develop a coalition within a community must keep in mind that coalition development is a process and not an event. Our coalition found that patience and continual encouragement were the ingredients necessary to ensure a meaningful partnership between researchers and communities. Although this conference coalition included members who were very eager to serve their communities and to work with researchers to enhance the participation of minorities in clinical trials, there is a need for funding institutions to provide resources specifically designated to form and maintain community and academic coalitions and partnerships.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Cancer Surveillance

A Problem for Native Americans and Appalachian Populations

James W. Hampton, M.D.[1]
Gilbert H. Friedell, M.D.[2]

[1] University of Oklahoma College of Medicine and Troy and Dollie Smith Cancer Center, Integris Baptist Medical Center, Oklahoma City, Oklahoma.

[2] Markey Cancer Center, University of Kentucky, Lexington, Kentucky.

Cancer mortality rates appear to be declining for the population of the United States as a whole.[1] However, two specific populations—Native Americans and rural white Americans living in Appalachia—appear to have a disproportionate burden of cancer.[2] Although some groups of American Indians living in the Southwest have a lower incidence of cancer than the general white population, their cancer survival rate is significantly lower.[3] Alaska Natives, according to the National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) Program, have a higher incidence of certain cancers than the total population of the United States as well as the same lower cancer survival rate as the Southwest Indians.[4] According to Indian Health Service (IHS) statistics, American Indians living in the Northern Plains have higher cancer mortality than the white population taken as a whole.[5] For the eight states participating in the NCI-funded Appalachia Cancer Network (Pennsylvania, New York, Maryland, West Virginia, Ohio, Kentucky, Tennessee, and Virginia), their Appalachian counties, with rural, poor, predominantly white populations, have a higher "all cancer" mortality rate than the overall U.S. rate; five of them have lung and cervical cancer mortality rates higher than the U.S. rates; and six of them have colorectal cancer mortality rates above the U.S. rate.

Assessing the cancer burden borne by the U.S. population depends on using an accurate and comprehensive data base on cancer incidence, mortality, and survival. Currently, data from SEER provide the best approximation of a national data base, although the SEER data cover only approximately 14% of the U.S. population. However, as recognized by the SEER Program itself and as pointed out recently in the Institute of Medicine (IOM) Report, entitled *The Unequal Burden of Cancer* (1999), to be comprehensively representative of the United States, more data representation is needed. The limitations of the SEER data include 1) the limited racial and ethnic coverage by SEER of the multicultural American Indian populations through out the United States, 2) the misclassification of American Indians in national and state tumor registry data and the consequent underestimation of cancer incidence and mortality in this population, and 3) the disparity of cancer burden in incidence, mortality, and/or survival in the lower income or poverty level population, including whites, particularly those living in rural areas such as Appalachia, rural African Americans, Hispanics of different national origins, and both reservation and urban American Indians. The level of progress in the fight against cancer in these populations is virtually unknown due to the lack of data. It would be easy to conjecture that these disparities

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Address for reprints: James W. Hampton, M.D., Cancer Care Associates, 11100 Hefner Pointe Drive, Oklahoma City, OK 73120; Fax: (405) 749-6843; E-mail: james.hampton@usoncology.com

Received April 1, 2000; accepted August 31, 2000.

are contributing to unfavorable cancer treatment and outcomes for these people outside of mainstream America.

The IOM Report points out that "four facts are consistently found in studies examining cancer among American Indian populations." These four facts are 1) cancer is the second leading cause of death; 2) American Indians have the lowest 5-year survival rate for all cancers compared with other populations; 3) American Indians have the highest percentage of disseminated and ill-defined cancers; and 4) very little is known about prevention and treatment patterns for cancer in American Indians. SEER data on cancer incidence and survival of Native Americans are available only for American Indians living in New Mexico and for Alaska Natives. The IHS reports cancer mortality on the American Indians whom they serve. There are no comparable data for the remaining 500+ American Indian tribes that represent more than 2 million people currently recognized by states, the federal government, or both. The SEER data on the Southwest Indians and Alaska Natives are quite discrepant from each other and, thus, cannot be extrapolated to all American Indian populations.[5] As noted in the IOM Report and also in the more recent article by Burhanssitipanov et al.[6] on cancer surveillance issues in American Indians, state cancer registries frequently underreport Indian race and ethnicity. Hence, a child may be born American Indian and die from cancer and be reported as "white" on the death certificate. Over half of American Indians reside in urban areas, whereas fewer than 40% reside exclusively on federal reservations. In the Southwest and in Texas and California, many American Indians have Hispanic-sounding surnames and frequently are misclassified as "white" for this reason. Until there are better data from state cancer registries as well as from national data bases assessing cancer incidence, mortality, and survival in American Indians, misclassification will continue to be a largely unsolved problem. The tribal health boards and medical directors endorse this need for more accurate data, but the national data bases must pay attention to this population.

Another major source of cancer data concerning American Indians comes from patient records of the IHS. Although it often is thought of as the agency responsible for total medical care for American Indians, IHS involvement is mostly limited to the 33 "reservation states."[6] Cancer detection and treatment suffer from a lower expenditure from the IHS budget for comprehensive urban Indian health care programs in which individuals are referred for cancer treatment. IHS data and SEER report a high incidence of lung cancer among Alaska Native men and a high incidence of colorectal cancer among Alaska Native women plus IHS reports a high incidence of lung cancer seen in American Indian men and a high mortality of breast cancer in American Indian women of the Northern Plains service areas.[5,7]

The report by Valway (1990)[5] showed that mortality statistics drawn from one region on American Indians could not be extrapolated adequately to cancer mortality for all of them. Mortality for American Indians in the Southwest was lower than for those living in the Northern Plains (North and South Dakota, Wisconsin, Michigan, Minnesota, and Montana). That study also described the increasing cancer mortality rates of American Indians from 1968 to 1987, a trend that also was observed by Mahoney et al. (1998)[8] from 1973 to 1993.

A report by Nutting et al. (1993)[9] using hospital discharge data from the IHS illustrated the high degree of variation in cancer burden between 1980 and 1987 among American Indians in the 11 IHS regions. The incidence of lung cancer among American Indian men in the Montana area "was nine times higher" than that among American Indian men in the Phoenix area (56.4 per 100,000 population compared with 6.3 per 100,000 population, respectively). Cancer can vary from region to region for a number of reasons, "including ethnicity, genetic stock, geography, and cultural and behavioral factors." Breast cancer occurrence in American Indian women also varied widely according to ethnic origin and geographic region. In the Tohono O'odham/Pima, it was 18.5 per 100,000 population compared with 50.7 per 100,000 population for Eskimo women and 57.9 per 100,000 for Sioux women. Cancers of the gallbladder and uterine cervix were noted to be elevated consistently across a broader range of IHS areas and tribal groups and exceeded rates in the white U.S. population. The quality of the data for California and Oklahoma is always in doubt due to the racial and ethnic misclassification of American Indians. Those two states have the largest American Indian populations.

In some studies, an attempt has been made to correct the racial and ethnic misclassification of American Indians. A comparison study between IHS data and the Washington State Cancer Registry resulted in a change of the age-adjusted cancer incidence among American Indians in that registry from 153.5 per 100,000 population to 267.5 per 100,000 after record linkage.[10] "More than one-quarter of American Indians classified as full heritage (100% blood quantum) were not coded as American Indians in the tumor registry, again proving that true misclassification frequently occurs." Frost et al.[11] observed that the lower cancer incidence in the Pacific Northwest Indians was attributable in part to the racial misclassification in the Seattle SEER registry. The under-reporting of cancer in American Indians can only lead to a lower priority than it deserves as a health problem and reduces the funding priority for cancer prevention and control in this population.

To address the problem of obtaining better cancer data for the American Indian and Alaska Native populations, the NCI has provided developmental funds for a cancer registry for the Cherokee Nation in Oklahoma, one of the largest Indian Nations in the United States. The NCI also is working in collaboration with the IHS and area tribal health councils to continue the financial support of the Alaska Native Tumor Registry, which formally joined SEER in 1999. As part of their expansion efforts, NCI funds were provided for enhancement of the Northwest Portland Tribal Registry linkage with cancer registries in Washington, Oregon, and Idaho to improve accuracy and completeness of reporting incidence rates for American Indians in these areas.

Poverty has long been recognized as contributing to poor cancer outcomes regardless of race or ethnicity. Individuals living in poverty often do not have access to quality health care, including cancer prevention, diagnosis, and treatment, because services are not available, accessible, or utilized. Behavioral risk factors, such as tobacco use, poor nutrition, obesity, and underutilization of cancer screening examinations, are more evident in impoverished populations. The social environment in which poor people live also prevents the development of healthy behaviors. Freeman[12] pointed out that poverty "is a proxy for other elements of living, including lack of education, unemployment, substandard housing, poor nutrition, risk-promoting lifestyles and behaviors, and diminished access to health care," all of which affect an individual's chances of developing cancer and surviving it. However, until cancer surveillance incorporates socioeconomic status (SES) into its data base, the public, and especially Congress and other federal funding agencies, will remain ignorant of this information.

Unfortunately, for many years, race and ethnicity have been used as surrogates for poverty, leaving unrecognized the correlation between poverty and cancer in the poor white population and particularly in the rural, low-income or poverty-level white population. It was noted in the IOM Report that, although, in 1996, some 30% of the African-American population, 26% of the Hispanic population, and 31% of the American Indian population were living below the poverty line compared with 10.0% of the white population, when these percentages are converted into actual numbers of individuals living below the poverty line, the vast majority are white.

TABLE 1
Cancer Incidence Rates in Kentucky, 1992–1996[a]

Disease site	1992	1993	1994	1995	1996
All cases	385.71	390.54	403.74	415.69	420.2
Males	471.62	473.41	477.91	488.27	493.4
Females[b]	330.27	335.83	357.89	367.83	373.5
Lung	75.24	77.97	84.55	86.70	83.5
Males	112.51	113.20	124.38	124.64	120.2
Females	47.25	51.24	55.45	58.38	55.9
Breast (Females)	103.05	102.99	109.82	109.67	113.0
Colorectal	49.08	47.30	48.40	50.07	49.5
Males	58.22	55.29	57.63	60.87	59.1
Females	42.20	41.21	41.67	42.03	42.1
Cervix[b,c]	11.26	10.49	11.37	12.21	10.8

[a] All rates were age adjusted to the 1970 U.S. standard population using the direct method.

[b] Excluding in situ uterine cervical cancers.

[c] Invasive.

Data concerning income or other elements of SES generally are not collected by either hospital or population-based cancer registries. It is therefore difficult to identify individuals whose income is below the poverty line. In Appalachia, however, and specifically in the defined geographic area of Central Appalachia (i.e., West Virginia and parts of Kentucky, Tennessee, Virginia, and Ohio), a high proportion of the almost entirely white, largely rural population is poor.[13]

There are currently no SEER registries in Appalachia, a region that includes 22 million people in 404 counties in 13 states between Southwestern New York and Mississippi. Approximately 65% of these counties in Appalachia are rural: Forty-two percent of the region's residents live in these counties, and many of these rural counties are categorized as economically distressed by the Appalachian Regional Commission.

In the absence of a SEER registry in the region, the Kentucky Cancer Registry has become the source of cancer data from a state that is largely rural, relatively poor, and predominantly white. The reporting provides complete and accurate incidence data for the 3.8 million people in the state, including the 1.1 million people living in Appalachian Kentucky. For the state as a whole, cancer incidence has not declined in the past 4 years compared with the decrease in incidence reported for the population covered by the SEER Program (Tables 1 and 2). The burden of cancer in Kentucky and in eastern Kentucky has remained at the same level or has increased slightly compared with the decrease in incidence reported for the state population.[14]

Data from the Kentucky Cancer Registry on cervi-

TABLE 2
Surveillence, Epidemiology and End Results Cancer Incidence Rates, 1992–1996[a]

Disease site	1992	1993	1994	1995	1996
All cases	426.2	412.5	403.4	392.0	388.6
Males	536.8	510.4	482.4	460.1	454.6
Females[a]	350.0	343.7	348.0	344.3	342.0
Lung	59.8	58.0	57.2	55.9	54.2
Males	81.9	78.8	75.6	73.4	70.0
Females	43.3	42.4	43.4	42.6	42.3
Breast (females)	111.4	109.1	110.9	111.3	110.7
Colorectal	46.4	45.4	44.5	42.7	42.7
Males	56.4	54.6	53.3	50.3	51.1
Females	39.0	38.3	37.7	36.9	36.2
Cervix[c]	8.2	7.9	7.4	8.0	7.7

[a] All rates were age-adjusted to the 1970 U.S. standard population using the direct method. Data for the Surveillence, Epidemiology, and End Results (SEER) rates were obtained from the SEER Cancer Statistics Review 1973–1996 (National Cancer Institute, Bethesda, MD).

[b] Excluding in situ uterine cervical cancer.

[c] Invasive cervical cancer.

TABLE 3
1995–1997 Age-Adjusted Cancer Incidence Rates[a]

	Kentucky			
Disease site	Overall	White	Black	Appalachian ADDS
Lung	85.03	84.35	97.18	98.25
Invasive cervical	10.99	10.82	13.76	13.34

ADDS: Area Development Districts: Big Sandy, Kentucky River, and Cumberland.

[a] Rates are per 100,000 population.

cal cancer and lung cancer (Table 3) reveal that the incidence of these two cancers in the low-income, 99% white population in eastern Kentucky is similar to that of the predominantly urban Kentucky, African-American population and is higher than the incidence of lung cancer and cervical cancer in the overall Kentucky population and in the population covered by the SEER Program. In this region, the level of high school completion is much lower than in the rest of the state. The rate of adult cigarette smoking in eastern Kentucky is the highest in the country, a phenomenon related to both the high lung cancer incidence and mortality rates.[15]

Defining the SES for specific populations diagnosed with cancer is a major problem. One means of doing so is to use the home address of cancer patients to identify the census tracts in which they reside, and then attribute to these individuals the average income level ascribed to that census tract or administrative unit, such as a county or service area. In the same way, education and other determinants of SES can be correlated with cancer incidence and mortality. This approach obviously cannot address the potential wide variation in income, education, etc., among residents living in some census tracts, particularly in rural areas; however, currently, this may be the most practical way to relate SES data with cancer incidence and mortality rates.

Selecting appropriate criteria for the determination of SES on an individual basis, however, currently is quite difficult. In addition to income, information about occupation and education would help to determine SES. However, these data generally are not readily available in the medical records of cancer patients for use by cancer registrars. Moreover, to have meaningful, population-based data for the purposes of comparison, this information would necessarily have to be a part of the medical record for all patients at both in-patient and ambulatory facilities.

Currently, most providers indicate in the medical record, e.g., on the front sheet of hospital charts, the type of health insurance (or its lack) when an individual is first seen. Today, this also is true for screening facilities as well as other ambulatory care facilities. This would be a part of the SES data base, although, in some instances, it may provide us with relatively little information about the actual SES of the individual, e.g., if Medicare was the only type of insurance listed. In such instances, with the majority of cancers occurring in patients age > 65 years, all of whom presumably have Medicare coverage, other data elements, such as secondary insurance coverage, would be needed to determine SES more precisely.

If most recent or "usual" occupations were routinely reported in patient records, even though many occupations would be reported as "retired" or "housewife," then this information would be of value. Information concerning income level would be helpful; however, currently, there is no agreement on what question to ask (i.e., "current income," "average income," or "past income,"), nor is there agreement on whom the responsibility should fall to collect this information. At this time, the level of formal education achieved (e.g., "highest grade level completed,") may be the most useful, least intrusive, and most reliable surrogate for SES. Perhaps some of these data elements, in addition to the type of health insurance, could be collected when individuals first register at any health care facility, just as data are collected at the time of hospital admission.

Another mechanism would be to have these and other data concerning SES collected by the health care professional who is taking a "family and social history" as part of the overall medical history. An alternative way to collect this information about the highest level of formal education achieved would be to collect it as part of the initial "nursing assessment" mandated by the Joint Commission on the Accreditation of Health Organizations. In any event, if there is to be a standardized method of assessing individual SES by cancer registries from medical records kept by different facilities, the items and the means of collection must be agreed upon if we are to have population-based data drawn from individual records.

Having information about the SES of cancer patients is essential as we try to separate cancer and health care issues related to poverty for all disparate populations from those related to race or ethnicity. At the same time, better coverage of American Indians and issues of misclassification in health data systems must be recognized and dealt with if we are to develop accurate statistics about cancer in these populations. Until we resolve these and related problems for minorities and the underserved, we will be unable to develop a meaningful cancer data set for the entire population of the United States.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Tobacco Wars:

The Successes, the Challenges, and Some Failures

Dileep G. Bal, M.D.
Thomas J. Glynn, Ph.D.
Gerald L. Woolam, M.D.

American Cancer Society, Atlanta, Georgia.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Presented as *Tobacco use—an Asian strategy for its prevention and control* at the 15th Asia Pacific Cancer Conference, Chennai, India, December 14, 1999 [this paper and presentation were adapted from that presentation].

Dileep G. Bal, M.D. is the President-Elect of the American Cancer Society; Thomas J. Glynn, Ph.D., is the Director, Cancer Science and Trends, American Cancer Society; and Gerald L. Woolam, M.D., is the President of the American Cancer Society.

Received April 1, 2000; accepted August 31, 2000.

Tobacco use and its health and economic consequences are global problems. Although the origins of tobacco use lie in the world's high-income nations, in the new millennium, tobacco use is swiftly becoming a major public health problem in middle- and low-income nations as well. Consider the following: 1) In the majority of the world's high-income nations, tobacco use is the primary cause of preventable death, primarily from heart and atherosclerotic disease, cancers, and chronic obstructive lung diseases. In the United States, for example, more than 430,000 deaths per year are directly attributable to tobacco use. In the middle- and low-income nations, deaths from tobacco use are becoming more prevalent, and, although patterns of tobacco-related mortality may differ in these nations (e.g., in China, tobacco-related lung diseases and cancers account for substantially more deaths than tobacco-related heart disease), these increases are expected to accelerate in the new century.

2) Tobacco kills more of the U.S. population each year than alcohol, cocaine, heroin, homicide, suicide, car accidents, fires, and acquired immunodeficiency syndrome *combined.* Although the death toll from tobacco use in the world's middle- and low-income nations has not yet reached these epidemic proportions, it is expected that this will be the case before the end of the third decade of the new century.

3) Worldwide, during the 1990s, tobacco killed the equivalent of every man, woman, and child in the cities of Perth, Australia; Lagos, Nigeria; Montreal, Canada; Xi'an, China; Sofia, Bulgaria; Manchester, England; Kuala Lumpur, Malaysia; Cape Town, South Africa; Brasilia, Brazil; Riga, Latvia; Kyoto, Japan; Wellington, New Zealand; San Diego, California; and Jaipur, India—more than 30 million people.

4) In the first year of the new millennium, it is estimated that tobacco will kill approximately 2 million people in the developed nations and an equal number in the developing nations. By the year 2030, however, estimates are that 3 million per year will die from tobacco use in the developed nations and *more than 7 million people per year* will die from tobacco use in the developing world.

5) In all nations of the world, nearly 1 in 10 people—or more than 500 million human beings—who are now alive will die from a tobacco-related disease. Given these data and the enormous amount of evidence that tobacco use is one of the major causes of premature mortality throughout the world, consideration must be given to the reasons why the use of tobacco persists and is even spreading.

Addictive Nature of Tobacco Use

Tobacco contains the alkaloid nicotine, which has been demonstrated in numerous studies to be a highly addictive substance. Most tobacco products deliver nicotine to the brain very rapidly and effectively, thus, bringing on rapid onset and maintenance of addiction. The resulting physiologic need for tobacco, as well as the accompanying psychological and behavioral needs related to tobacco use, provide ample explanation for continuing use of this substance despite the well known dangers.

Evidence of the dependence-producing properties of tobacco has been accumulating for some time, but it is only relatively recently that these properties have been broadly recognized. In 1987, the American Psychiatric Association first classified "nicotine dependence" as a psychoactive substance dependence disorder.[1] This was followed by the landmark U.S. Surgeon General's Report in 1988,[2] which reached three key conclusions about dependence on tobacco use: 1) Cigarettes and other forms of tobacco are addictive, 2) nicotine is the drug in tobacco that causes addiction, and 3) the pharmacologic and behavioral processes that determine tobacco addiction are similar to those that determine addiction to such drugs as heroin and cocaine.

Those reports, as well as others throughout the world, demonstrated that tobacco use (and, specifically, nicotine) fulfills the established criteria for identification of addictive substances, i.e., 1) it is psychoactive; 2) it creates dependence and leads to compulsive use; 3) it causes emotional and physical distress—withdrawal symptoms, such as headache, drowsiness, irritability, stomach upset—when quitting is abrupt; and 4) it is associated with a strong tendency for relapse to regular use. Nevertheless, despite the addictive properties of tobacco use that foster its continued use in the face of known morbidity and mortality, quitting is possible, as discussed below.

Tobacco Use Prevention and Control

Numerous studies, commissions, and blue ribbon panels have developed specific suggestions for methods and strategies of effective tobacco control.[3,4] Although a compilation of the most effective of these suggestions is provided in this article in a section below, there also are several broad strategies or principles for disease control on a regional or national scale that should be recognized first. These principles have been derived from many sources, most notably, from the successful global effort to eradicate smallpox.

Principles of national tobacco control efforts

The experience of those involved in regional and national disease control efforts, and particularly those involved in smallpox eradication, have identified four core principles that translate well to the context of tobacco control. These principles are as follows:

Political commitment. Although the principle of political commitment may seem out of place when discussing control of an addictive disease, tobacco control—because of its long history, significant economic costs and benefits, enormous health consequences, and the power and political influence of the tobacco industry—requires strong political commitment as an essential element of its efforts. Without political commitment to providing treatment and prevention resources, increasing tobacco taxes, foregoing the short term benefits promised by the tobacco industry, and taking the necessary regulatory steps to control tobacco, the efforts of the public health community will be considerably more difficult, if not impossible.

Partnerships. No individual or group involved in tobacco control, no matter how eloquent or powerful, can match the multinational tobacco industry in resources or commitment to their cause. What is required for success in national tobacco control efforts are partnerships and coalitions of groups—e.g., medical societies, voluntary health organizations, politicians, professional organizations, etc.—that are willing to put aside any differences they may have and focus instead on the single goal of controlling and/or eliminating tobacco use as a social, economic, and health problem in their country.

Resources. The need for resources may seem obvious; however, it must be stated as a principle to make it as clear as possible that the goal of tobacco control cannot be met without the dedication of significant resources to the effort. Experience has demonstrated that the tobacco industry has enormous resources at hand to counter tobacco control efforts, and the political commitment and partnerships described above must be in place to secure the necessary resources to address this issue.

Surveillance. Without knowledge of the extent and nature of the tobacco problem in a given region or nation, it is not possible to design an effective tobacco control program. It is equally true that, without knowledge of where and how tobacco control efforts have succeeded or failed, it will not be possible to continue or modify programs to make them more effective.

Knowledge of the tobacco problem and of the success of efforts to control it cannot be obtained without the existence of strong, science-based surveillance systems. Once these principles are established in a given region or nation, it is then possible to move the tobacco control effort to a more specific stage—implementing effective strategies.

Specific strategies for national tobacco control efforts

Although many strategies have been suggested as useful in the effort to control tobacco use, there are now a number of these strategies around which consensus attesting to their effectiveness is beginning to develop. They include the following.

Increase tobacco taxes. Although this is an exceptionally complicated issue the application of which will differ from nation to nation, the basic principle on which both data and tobacco control experts agree is that increasing tobacco prices through taxation, sharply and on a regular basis, will reduce tobacco consumption.

Reduce exposure to secondhand smoke. Reducing exposure to the smoke from other people's cigarettes is both a health issue and a social issue. Although the tobacco industry will oppose measures to curtail smoking in public places and other clean-air measures involving tobacco smoke, this is an area of increasing success due to the strength of the health data surrounding secondhand smoke and the desire of nonsmokers to avoid exposure to the smoke of others.

Reduce youth access to tobacco. Measures to reduce youth access to tobacco—minimum age purchase laws, restriction of single cigarette sales, increased taxes, elimination of vending machines, etc.—provide evidence of the commitment to controlling tobacco use as well as a reasonably effective measure of curtailing tobacco use among youth.[5]

Increase tobacco counter advertising. Although the tobacco industry has enormous advertising resources, there is ample evidence to suggest that counter advertising, even if it is modest in scale compared with protobacco advertising, can negatively influence attitudes and behavior toward tobacco use.

Increase legal challenges. Legal challenges to the tobacco industry—ranging from the defense of clear indoor air legislation to recovery of health care costs related to tobacco-induced disease—have proven to be an effective method of raising funds for tobacco control and increasing awareness of the breadth of social, economic, and health problems caused by tobacco use.

Increase health care provider involvement. In nearly all countries where tobacco use prevalence has begun to recede, significant reductions in use were measured first among health care providers. Health care providers, especially physicians, serve as opinion leaders and role models in health-related matters, and their involvement in tobacco control efforts are an essential element of successful national programs.

Increase opportunities for treatment of nicotine dependence. In high-income nations, as many as 75% of all tobacco users say that they want to stop. Effective treatment regimens, access to pharmaceutical aids, and trained health care providers often are lacking, however, and those who might stop if treatment opportunities were more readily available are not able to do so. Increased opportunities for nicotine dependence treatment are an integral part of any national tobacco control program.

California Tobacco Control Initiative

The most prominent example of a large scale tobacco control effort that has incorporated many of the principles outlined above is the State of California's tobacco control campaign in the United States.[6,7] A brief summary of that effort follows with a particular emphasis on the origins and development of the California program, which may serve as a broad model.

In the late 1980s, the power and influence of the tobacco industry in California was well established, and the industry was able to defeat virtually every threat—whether driven by grassroots coalitions or legislation. In the 1970s and 1980s, the federal government had been able to make some inroads with warning labels and advertising restrictions; however, in California, the tobacco industry was able to defeat every proposal that negatively affected its interests.

The turning point for tobacco control in California came in 1988, when, after several years of coalition building and grassroots organizing, the citizens of California voted in favor of what became known as Proposition 99—a tax increase of $0.25 (from $0.10 to $0.35) on every pack of cigarettes sold in the State. The key to this success was putting the tobacco issue in the hands of the voters, the citizens of the state, rather than depending on legislative initiatives to combat the tobacco industry.

An equally important decision on the part of the supporters of Proposition 99 —both at the grassroots level and at the level of those legislators who were not tainted by their acceptance of tobacco industry campaign funds—was to allocate 20% of the resulting revenues—nearly $100 million per year—for tobacco education and 5% for tobacco-related research. Seventy percent was allocated for health care costs, and 5% was allocated for environmental issues.

Although the resulting California Tobacco Control Initiative has faced a number of challenges in the nearly 12 years since it began—including legislative delay, sequestering of funds, and tobacco industry attacks—perseverance and a focus on exposing the malfeasance of the tobacco industry has made it a great success. By taking on the tobacco industry directly and, at the same time, incorporating the specific tobacco control tactics outlined above, there has been a 50% decline in tobacco consumption in California during the 1990s.

The tobacco industry has bought influence in California, the United States, and throughout the world by buying government officials, influencing the press and media, threatening lawsuits, and the political process at every level and branch of government. The one enduring legacy of tobacco use prevention in the United States in general, and California in particular, is exposing the tobacco industry's tactics and diminishing their attendant influence as a discreet tobacco control strategy.

The major strategies in California include efforts to eliminate exposure to secondhand smoke (especially the California smoke free indoor workplace law), counter protobacco influences, reduce the availability of tobacco to youth, raising tobacco taxes, and cessation-focused programs. A judicious mix of statewide programs (especially media) and aggressive local programs in the public and private sectors have worked wonders.

To summarize the successes and failures of California's Tobacco Control Program, it is fair to say that the biggest success is that, in the 9 years immediately following 1988, there was a dramatic 45% decline in the adult per capita tobacco consumption rate. Let us compare the annual adult tobacco use consumption rate between California and the rest of the United States: In 1989, California was approximately 22% below the rest of the United States, whereas, in 1999, California was more than 50% below the rest of the United States in terms of the adult tobacco use consumption rate. During the same 9 years, there was a 32% reduction in the annual adult tobacco use prevalence rate in California compared with a 19 % reduction in the annual adult tobacco use prevalence rate in the United States at large. Thus, California has not only had significant declines in absolute terms over the period of a decade but has actually had a much accelerated decline compared with the rest of the country. This is especially significant given the fact that California's rates were among the lowest of all other states 10 years ago. The most dramatic failure is seen in the youth prevalence rate, which has remained dramatically unchanged over this decade-long period. All of the process measures have been uniformly positive in terms of impact. Many fewer stores are selling tobacco to kids; tobacco sponsorship and promotion of sports, social events, and cultural events has plummeted; protection from environmental tobacco smoke in the workplace and home has increased dramatically; and even the restaurants and bars in California are all smoke free.

CONCLUSIONS

We are indeed at a crossroads in our antitobacco wars in the United States and the world. The tobacco industry's settlement with the Attorneys General in the United States has created the mistaken impression that this issue is now being solved and that the tobacco industry is now being reasonable and accommodating. This is an impression that the tobacco industry is promoting carefully with the use of its immense public relations resources. Nothing could be further from the truth: Tobacco uptake in youth is not declining, and tobacco control programs are undergoing a whiplash effect nurtured by these orchestrated tobacco industry efforts aimed at characterizing them as extremists and even as "health Nazis." The United States and worldwide health burden of tobacco use is expected to increase geometrically unless there is some dramatic action. Smoking presently kills 1 in 10 adults worldwide. By 2030, this proportion will be 1 in 6, or 10 million deaths per year—more than any other single cause. By 2020, 7 of every 10 people killed by tobacco will be in low- or middle-income nations. To that end, we propose a concerted national effort in the United States by dramatically increasing the funding of the Office on Smoking and Health of the Centers for Disease Control and Prevention and the funding in all of the states for aggressive and targeted tobacco control programs. The National Cancer Institute also needs funding for research, especially for research focusing on program translation and the minority groups at maximal risk. Simultaneously, we propose to vigorously support the worldwide efforts of the World Health Organization by supporting the Framework Convention on Tobacco Control and providing support for its implementation.

The California Tobacco Control Program has sought to change the broad social norms around using tobacco, i.e., denormalize tobacco use and smoking through judiciously engaging nonsmokers and smokers. To be successful, such an effort must be both comprehensive and well funded, as it was in California. The model tobacco control programs of California, Massachusetts, and Florida have become examples for the rest of the United States and the world.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Liver Carcinoma Prevention among Asian Pacific Islanders

Getting Hepatitis B Shots into Arms

Christopher N. H. Jenkins, M.A., M.P.H.[1]
Chau Buu, M.D., M.P.H.[2]
Wendy Berger, M.P.H.[3]
Do T. Son, M.D.[4]

[1] "Suc Khoe La Vang (Health Is Gold)", Vietnamese Community Health Promotion Project, Division of General Internal Medicine, University of California, San Francisco, California.

[2] Harris County Health Department, Houston, Texas.

[3] Los Angeles County Immunization Program, Los Angeles, California.

[4] Dallas, Texas.

BACKGROUND. For the past 20 years, the hepatitis B virus (HBV) has infected at least 250,000 persons annually in the United States. Persons with chronic HBV infection are at increased risk for liver carcinoma. Among immigrants to the United States from countries with high HBV endemicity, high rates of chronic HBV infection account in large part for their high incidence rates of liver carcinoma. Among those who have not been infected, hepatitis B and hepatitis B–related liver carcinoma can be prevented through hepatitis B vaccine immunizations. In this article, the authors examine hepatitis B vaccine coverage rates from surveys of Asian and Pacific Islander children in Houston, Texas and Los Angeles County, California.

METHODS. In Houston, the authors surveyed the parents of 300 students aged 10 to 18 years at a Vietnamese-language school. In Los Angeles County, they surveyed parents of 471 fourth grade students from 6 different Asian and Pacific Islander ethnic groups in 8 public elementary schools.

RESULTS. In Houston, 55% of responding parents submitted immunization records indicating that their child had had 3 hepatitis B shots; 3% reported that their child had had no shots. In Los Angeles County, 37% (Filipino) to 67% (Japanese) had had 3 shots; proportions of children having had no shots ranged from 5% to 15%.

CONCLUSIONS. Under current immunization practices, the authors estimate that nearly 13,000 Asian and Pacific Islander children living in the United States today will become infected with HBV in the future, resulting in more than 600 liver carcinoma deaths. It is essential that cancer control agencies in the United States take leadership in raising awareness about the role of HBV in the etiology of liver carcinoma and that of the hepatitis B vaccine in preventing it. ***Cancer* 2001;91: 252–6.** *© 2001 American Cancer Society.*

KEYWORDS: Asian Pacific Islanders, hepatitis B, liver carcinoma, prevention.

For the past 20 years, the hepatitis B virus (HBV) has infected at least 250,000 persons annually in the United States.[1] Although most who become infected with HBV recover, between 6% and 10% do not.[2] They become chronically infected and can transmit the virus to others. Persons with chronic HBV infection are at increased risk of liver carcinoma and other hepatitis B–related sequelae.[3] Epidemiologic studies have shown that persons with chronic HBV infection have a risk of developing liver carcinoma more than 200 times greater than those not infected.[4] During the past 2 decades, overall liver carcinoma incidence rates in the United States increased from 1.4 per 100,000 to 2.4 per 100,000, reaching 7.4 per 100,000 among those in

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Supported by grants from the National Task Force on Hepatitis B Immunization: Focus on Asians and Pacific Islanders.

Address for reprints: Christopher N. H. Jenkins, M.A., M.P.H., "Suc Khoe La Vang (Health Is Gold)," Vietnamese Community Health Promotion Project, Division of General Internal Medicine, University of California, San Francisco, 44 Page St., Suite 500, San Francisco, CA 94102; (415) 476-0557; chrisj@itsa.ucsf.edu

Received April 1, 2000; accepted August 31, 2000.

the nonwhite, nonblack group (Asian Pacific Islanders [API], Hispanics, and Native Americans).[5]

Hepatitis B is highly endemic in most countries of Asia, most Pacific Island Groups, Sub-Saharan Africa, most of the Middle East, and the Amazon Basin of South America, where greater than 60% of the population become infected during their lifetime.[1] High rates of chronic HBV infection among immigrants to the United States who were born in these countries account in large part for their high incidence rates of liver carcinoma. For example, Vietnamese males have the highest liver carcinoma incidence rate of any race/ethnic group in the United States (41.8 per 100,000)—greater than 11 times higher than the rate among white males (3.7 per 100,000).[6] Liver carcinoma incidence rates among the Chinese, Filipinos, Japanese, Koreans, African Americans, and Hispanics in the United States exceed the rate for whites.[6] In addition, reflecting the differential rates of HBV infection, there are considerable disparities in liver carcinoma mortality among racial and ethnic groups. For the period 1990–1995, the liver carcinoma mortality rate for whites was 2.9 per 100,000 whereas the rate among African Americans was 4.6, among Hispanics was 4.7, and among API was 9.0.[7]

Among those who have not been infected, hepatitis B and hepatitis B–related liver carcinoma can be prevented by the administration of three doses of hepatitis B vaccine. In Taiwan, a nationwide hepatitis B vaccination program started in 1984 has resulted in significant reductions in hepatitis B infections and liver carcinoma incidence among children.[8,9] In the United States, the full implementation of universal infant hepatitis B vaccination could eventually eliminate vertical (mother to infant) HBV transmission and, ultimately, horizontal (person to person) transmission as well.

The Centers for Disease Control and Prevention, the American Academy of Pediatrics, and the American Academy of Family Physicians recommend that all children from birth to 18 years old and selected high risk adults should be immunized with the hepatitis B vaccine. Currently, however, many states limit their immunization efforts primarily to infants and adolescents entering middle school. To determine if nontargeted age groups of API children may remain unvaccinated and at risk of HBV infection, we examined hepatitis B vaccine coverage rates from surveys of API children in Houston, Texas and Los Angeles County, California.

METHODS

In Houston, we surveyed the parents of 300 students aged 10 to 18 at a Vietnamese-language school. A letter was sent to parents requesting them to provide their child's immunization record. As an incentive to complete the survey, parents who participated in the record audit received a free T-shirt with the school logo for their child and a statement encouraging hepatitis B vaccination. Hepatitis B immunization information was abstracted from the records furnished by parents.

In Los Angeles County, in the fall of 1999, we distributed a self-administered questionnaire to all parents of 1034 fourth grade students in the 8 public elementary schools with a high percentage of APIs. The questionnaire was translated into Cambodian, Chinese, Korean, and Vietnamese. Filipino and Japanese parents also were surveyed using the English-language questionnaire. We asked parents to refer to their child's immunization record, record their child's hepatitis B immunization dates, and return completed questionnaires to their child's teacher. Parents who did not have immunization records were asked to obtain the information from their child's health care provider. As incentives, students who returned questionnaires were offered coupons redeemable for free meals at a popular fast food restaurant chain and classroom teachers were offered coupons for free coffee at a popular coffeehouse chain. In both Houston and Los Angeles County, we obtained oral informed consent.

RESULTS

In Houston, we received responses from 179 (60%) of 300 parents. Among these respondents, 99 (55%) supplied immunization records indicating that their child had had 3 hepatitis B shots; an additional 25 (14%) had had 1 or 2 shots. Six (3%) parents submitted immunization records indicating that their child had had no hepatitis B shots, and 39 (22%) parents were unable to find their child's immunization records. Three (2%) parents refused to supply immunization records. Finally, the records of 7 (4%) children indicated that their serology tests confirmed prior infection with HBV; for these children, no shots were necessary. The immunization status of the children of the remaining 121 parents who did not respond could not be determined.

In Los Angeles County, 803 of 1034 (78%) parents of fourth-graders returned surveys; 471 parents were APIs. Rates of having had 3 hepatitis B shots ranged from 37% (Filipino) to 64% (Japanese; Table 1). Rates

TABLE 1
Hepatitis B Coverage Proportions among Asian Pacific Islander Fourth-Graders in Los Angeles County, 1999

No. of shots	Chinese (n = 209) (%)	Korean (n = 108) (%)	Filipino (n = 67) (%)	Vietnamese (n = 30) (%)	Japanese (n = 14) (%)	Other API[a] (n = 43) (%)	Total (n = 471) (%)
3 shots	55	54	37	43	64	53	52
1-2 shots	13	9	26	10	15	17	14
no shots	15	10	7	7	14	5	11
No response	17	27	30	40	7	25	23

API: Asian Pacific Islander.
[a] Did not specify ethnicity.

of having had no shots ranged from 5% ("other," that is, API respondents who did not specify an ethnic group) to 15% (Chinese).

DISCUSSION

The data presented here demonstrate that although substantial numbers of API children have been immunized against the HBV, some of these children (3% in Houston, 5–15% in Los Angeles County) remain unvaccinated and at risk of HBV infection. An additional 14% in Houston and 9–26% in Los Angeles County remain incompletely vaccinated. Many of those who are unvaccinated may be vaccinated at middle school entry, as required by law in California (September 1999) and Texas (August 2000). Unvaccinated children who were too old when these laws were implemented, however, will remain unprotected against HBV infection.

In Houston, the high nonresponse rates and the high numbers of parents who could not find their child's immunization records raise concerns that the rates of unvaccinated children may be higher than indicated by these survey results. In Los Angeles County, the lack of physician-verified data may mean that immunization rates there were actually lower than the rates reported by parents. For example, in a 1998 San Diego telephone survey of parents of fifth- and sixth-graders in which results were verified by provider or parent-held immunization records, the proportion of children who had had no hepatitis B shots was considerably higher (58%) than the rates reported here.[10] In addition, data from 1998 surveys of API children born between 1984 and 1993 in 6 cities in which responses were verified by provider records, parent-held records, or school records again showed higher rates of no hepatitis B vaccine immunizations that ranged from 20% (Hmong in St. Paul) to 74% (Vietnamese in Houston).[11]

Under current immunization practices, we estimate that nearly 13,000 API children living in the United States today will become infected with HBV in the future, resulting in more than 3000 deaths, including more than 600 liver carcinoma deaths (Table 2). Conducting "catch-up" hepatitis B vaccination programs among these older age groups (born before 1994) could prevent many of these unnecessary deaths.

It is essential that cancer control agencies in the United States, such as the National Cancer Institute, the Centers for Disease Control and Prevention, and the American Cancer Society, take leadership in raising awareness about the role of HBV in the etiology of liver carcinoma and that of the hepatitis B vaccine in preventing it. Historically, HBV control has not been thought of as a cancer control issue. In the United States, HBV has been viewed largely as an infectious disease. HBV control efforts, for example, are housed primarily in the National Immunization Program and National Center for Infectious Diseases of the Centers for Disease Control and Prevention together with other vaccine-preventable disease and infectious disease control programs. It is time to recognize, however, that the hepatitis B vaccine is our first cancer prevention vaccine.

Cancer control agencies should do the following: 1) strongly endorse and promote recommendations that all children from birth to 18 years old be immunized with the hepatitis B vaccine; 2) recommend HBV serologic screening of all adults who were born in countries of high HBV endemicity and immunization of all of them who are HBV susceptible with the hepatitis B vaccine; 3) provide health education to chronic HBV-infected persons about prevention of HBV transmission; 4) recommend referral of chronic HBV-infected persons to medical specialists for routine follow-up, and, as appropriate, lamivudine or interferon treatment, liver transplantation, and potential new drug therapies as they become available; 5) integrate information about HBV and liver

TABLE 2
Projected No. of Chronic HBV Infections and HBV-Related Deaths among Unvaccinated API Children in 12 States with the Largest Populations of APIs in 2000

State	Start date of kindergarten/ 1st grade entry law requiring hepatitis B immunization[a]	Start date of middle school entry law requiring hepatitis B immunization[b]	Ages of children not covered by state hepatitis B school entry laws, 2000 (yrs)	Estimated API population 2000[c]
CA	1997	1999	15–18	4,289,000
NY	1998	No law	10–18	1,028,000
HI	1998	No law	10–18	796,000
TX	1998	2000	13–18	562,000
NJ	No law	No law	8–18	475,000
IL	1998	1998	16–18	423,000
WA	1997	No law	11–18	358,000
FL	1998	1997	17–18	267,000
VA	1999	No law	9–18	267,000
MA	1996	1999	15–18	246,000
MD	2001	2006	8–18	223,000
PA	1997	No law	11–18	218,000
Total				9,152,000

State	No. of API children not covered by state hepatitis B school entry laws,[d] 2000	Projected no. of chronic HBV infections[e]	Projected number of HBV-related deaths[f]	Projected number of HBV-related liver cancer deaths[g]
CA	386,010	4169	1042	208
NY	187,100	2021	505	101
HI	144,872	1565	391	78
TX	72,214	780	195	39
NJ	104,025	1123	281	56
IL	28,764	311	78	15
WA	65,156	704	176	35
FL	18,156	196	49	10
VA	53,400	576	144	29
MA	22,140	239	60	12
MD	48,837	527	132	26
PA	35,752	386	97	19
Total	1,166,426	12,597	3150	628

HBV: hepatitis B virus; API: Asian Pacific Islander.

[a] Immunization Action Coalition.[12]

[b] Assumes children in kindergarten/1st grade are aged 6–7 yrs at entry and middle school children are aged 12–13 yrs at entry.

[c] Population estimates from U.S. Census Bureau.[13]

[d] Numbers were calculated using the following factors as proportions of each state's total estimated API population: for age 8–18, 0.219; age 9–18, 0.200; age 10–18, 0.182; age 11–18, 0.164; age 13–18, 0.128; age 15–18, 0.090; age 16–18, 0.068. Factors reflect age distribution for Vietnamese population in 1990 according to the U.S. Census.

[e] Numbers were calculated first using a factor of 0.90 times the number of API children not covered, assuming that 10% of these children already have been infected and have become immune. This number then was multiplied by 0.15 (assuming that over the next 30 years, 0.50% will become infected per year, or 15% at the end of 30 years). This number then was multiplied by 0.08, assuming that, on average, 8% of infected adults develop chronic infection.

[f] Numbers were calculated using a factor of 0.25 times the number of anticipated chronic HBV infections, based on the assumption that 25% of those chronically infected die of HBV-related liver disease.

[g] Numbers were calculated using a factor of 0.20 times the number of anticipated HBV-related deaths (assuming that 20% of deaths due to chronic HBV infection are due to liver carcinoma).

carcinoma prevention into their patient education and professional education programs; and, finally, 6) provide funding to support programs and research to identify barriers to and effective models to promote hepatitis B vaccine immunization in high risk communities in the United States.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Receipt of Cancer Screening Procedures among Hispanic and Non-Hispanic Health Maintenance Organization Members

Elizabeth A. Jacobs, M.D.[1]
Diane S. Lauderdale, Ph.D.[2]

[1] Collaborative Research Unit, Department of Medicine, Cook County Hospital, Chicago, Illinois.

[2] Department of Health Studies, University of Chicago, Chicago, Illinois.

BACKGROUND. Hispanic Americans have been shown to receive fewer cancer screening procedures than nonminority populations. Although lack of insurance or a regular source of care appear to be important determinants, cultural factors also have been suggested. This study examines whether Hispanic patients receive cancer screening at the same rate as the non-Hispanic population when both groups have equivalent insurance and a regular source of care.

METHODS. Receipt of five cancer screening procedures (mammography, Pap test, fecal occult blood testing, breast examination, and rectal examination) was determined for adult health maintenance organization (HMO) members who met appropriate age and gender criteria. Rates of receipt were compared for 2 cohorts over a 2-year period: Hispanic members identified by surname and a comparison group, a 10% random sample of the non-Spanish surnamed members. Only members with at least one HMO contact over the study period were included. Logistic regression was used to test whether being in the Hispanic group was associated with decreased likelihood of receiving the procedure at least once over the 2 years, adjusting for potential confounders.

RESULTS. Among the comparison group, a high proportion received each recommended procedure at least once (0.70–0.86). The proportions were very similar for the Hispanic group (0.67–0.84). None of the rates differed statistically for the two groups.

CONCLUSIONS. Hispanic HMO members received cancer screening at the same high rate as non-Hispanics, suggesting that insurance coverage and continuity of care are more important than cultural factors in determining rates of cancer screening receipt. ***Cancer*** **2001;91:257–61.** *© 2001 American Cancer Society.*

KEYWORDS: cancer, prevention and control, screening, Hispanic Americans, health maintenance organization (HMO), disparities.

Large disparities in cancer incidence, mortality, treatment and prevention persist between minority and nonminority populations in the United States.[1] Disparity between the rapidly growing Hispanic population and the non-Hispanic white population in receipt of cancer screening procedures has been a focus of concern. Population-based studies using self-reported (rather than medical record) data have found that Hispanic populations receive cancer screening procedures such as mammograms, Pap tests, fecal occult blood testing, and rectal exams at lower rates than non-Hispanic white populations living in the same geographic areas.[2–6]

Both cultural factors and access barriers have been examined as determinants of lower rates of cancer screening among Hispanics.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Elizabeth A. Jacobs, M.D. was supported by a Robert Wood Johnson Clinical Scholar Fellowship at the time she completed this work.

The authors thank Jeanette Shorey, M.D. for her help in obtaining this data and Paul Rathouz, Ph.D. for his statistical support and thoughtful review of the manuscript.

Address for reprints: Elizabeth A. Jacobs, M.D., Collaborative Research Unit, Department of Medicine, Cook County Hospital, 1900 W Polk Street, 16th Floor, Chicago, IL 60612; fax: (312) 633-6783; E-mail: ejacobs@rush.edu.

Received April 1, 2000; accepted August 31, 2000.

Cultural factors include low levels of acculturation, specific health beliefs such as that once a person has cancer nothing can be done about it (fatalism), language barriers, and lack of knowledge of the benefits of preventive health measures.[4,5,7–9] Access barriers include low socioeconomic status, measured by income and education, lack of insurance or underinsurance, and lack of continuity of care or a regular source of care.[10–14]

To further understand the importance of the independent contribution of cultural factors to receipt of cancer screening procedures for Hispanic persons, this study examines whether rates of cancer screening vary among Hispanic members of an health maintenance organization (HMO), all of whom have equal access to health care and a continuous source of care.

METHODS

Study Setting and Data Sources

The study was conducted at 4 of the 14 staff-model health centers of Harvard Pilgrim Health Care (HPHC), the largest managed care organization in New England. These health centers were chosen because they served relatively larger populations of Hispanic patients than the other 10 centers. All had fully automated medical record data files that contain demographic and clinical data, including documented completion of recommended cancer screening services. Data files include service use and billing throughout the entire health plan regardless of site of delivery. The human studies committee of HCHP approved the use of these records for this study.

Study Population and Sample

Harvard Pilgrim Health Care members were eligible for the study if they were adults at least 18 years of age at the beginning of the study, were continuously enrolled from June 1, 1995 through June 1, 1997, and had accessed care at least once during the study period. Hispanic members were identified by surname because HPHC did not routinely collect Hispanic ethnicity information from its members during the study period. A Spanish surname list developed by the Census Bureau was matched to the member enrollment file.[15] Portuguese members also were identified using a surname list specifically developed for HPHC by the Latino Health Institute (Boston, MA) based on the Massachusetts population. Because of the substantial number of persons of Portuguese and Cape Verdean descent in Eastern Massachusetts, and because some surnames are common to both Hispanic and Portuguese populations, all members whose surnames matched the Spanish surname list but not the Portuguese list formed the Hispanic group (HG) in this study. A 10% random sample of all other eligible members, whose surname did not match the Spanish or Portuguese lists, were included in the comparison group (CG).

TABLE 1
Baseline Participant Characteristics

Characteristic	Hispanic group (n = 1718)	Comparison group (n = 3944)	*P* value
Mean age, yrs (SD)	40 (13)	43 (13)	< 0.01
No. of females (%)	945 (55)	2,203 (56)	0.55
Mean prior enrollment, yrs (SD)	1.44 (1.10)	1.58 (1.11)	< 0.01
Median zip code income[a] (SD)	$36,495 (14,051)	$40,772 (15,261)	< 0.01

SD: standard deviation.
[a] From 1990 census.

Study Measures

Demographic characteristics available in the database included age, gender, date of enrollment, and zip code of residence. Each member's zip code of residence was linked to zip code level data from the 1990 Census to determine median household income. The cancer screening procedures were mammograms (for women aged 50 years or older), breast examinations (all adult women), Pap tests (all adult women), fecal occult blood testing (persons aged 50 years and older), and rectal exams (men aged 40 years and older). Screenings dependent on patient age or gender were assessed only on patients for whom the procedure is recommended. Although HPHC recommends these procedures be performed annually, screening was measured over 2 years in this study because the same starting date was used for each person regardless of how recently they previously had been screened.

Statistical Analyses

Cancer screening count data was converted into binary indicators for receipt of one (or more) versus none of each cancer screening service over the 2 years of the study. We determined the 2-year rate of cancer screening service delivery in the HG and CG and tested whether the rates differed for each screening procedure between the two groups by using logistic regression, adjusting for the demographic variables. All data analyses were performed using STATA 6 (STATA Corp, College Station, TX).

RESULTS

One thousand seven hundred eighteen members were eligible to be in the HG, and 3944 made up the 10% random sample of remaining eligible members included in the CG. Table 1 compares the baseline char-

TABLE 2
Rates of Preventive Service over 2 Years among Persons for Whom the Procedure Is Recommended

Procedure	Sample size[a]	Hispanic group	Comparison group
Mammogram	724	0.84	0.86
Breast exam	3148	0.73	0.74
Pap test	3148	0.84	0.82
FOBT	1351	0.67	0.70
Rectal exam	1345	0.73	0.78

FOBT: fecal occult blood testing.

[a] Sample size of age and gender appropriate sample.

TABLE 3
Logistic Regression Odds Ratios for Cancer Preventive Service Receipt over 2 Years for the Hispanic Group versus the Comparison Group, Adjusted for Age, Gender, and Zip Code Mean Household Income

Test	Odds ratio	95% CI
Mammogram	0.87	0.55–1.38
Breast exam	0.99	0.83–1.18
Pap test	1.08	0.88–1.34
FOBT	0.83	0.63–1.10
Rectal exam	1.11	0.79–1.55

CI: confidence interval; FOBT: fecal occult blood testing.

acteristics of the two: the HG participants were on average 3 years younger, had been enrolled in the HMO for an average of 1.7 fewer months before the study, and lived in zip codes where the 1990 median household income was more than $4000 lower than in the CG.

The rates of delivery of each cancer screening service over 2 years are presented in Table 2. Rates of procedure receipt range from a low of 0.67 for fecal occult blood testing in the HG to a high of 0.86 for mammography in the CG. Overall, rates for the HG are slightly lower for 4 of the 5 procedures, but 2% higher for Pap test screening. There were no significant differences in rates between the two groups.

The results of the logistic regression of preventive service receipt in the HG versus the CG are summarized in Table 3. Results are reported as the odds ratio of receiving each preventive service if an individual is in the HG versus the CG, adjusted for age, gender (when both genders are included), total years of HMO enrollment, and median zip code household income. All of the odds ratios are close to 1, ranging from 0.83 (95% confidence interval [CI], 0.63–1.10) for receipt of fecal occult blood testing to 1.11 (95% CI, 0.79–1.55) for rectal exams. None of the odds ratios was significantly different from 1, and the confidence intervals were consistent with the findings of a lack of association between Hispanic ethnicity and receipt of cancer screening.

DISCUSSION

Within an HMO-insured population, we found no significant differences in receipt of cancer screening and preventive services between surname-identified Hispanic members and non-Hispanic members, among those continuously enrolled for at least 2 years and with documented HMO contact. These data suggest that access measured by health insurance and continuity of care is relatively more important than cultural factors in explaining the low rates of cancer screening reported by Hispanics in other studies.

This finding is generally consistent with several previous studies that have concurrently assessed the relative importance of cultural and access barriers in population-based samples. Examining the importance of financial versus nonfinancial determinants of health care use in 1893 Hispanic adults surveyed in the 1987 National Medical Expenditure Survey, Schur et al. found that financial factors were the paramount barriers to care.[14,16] Insurance status, not health beliefs about medical care or language preference, determined whether Hispanic adults had a usual source of care, their number of physician visits, and the probability of using one preventive service, blood pressure screening.[14,16] Solis et al. reported very similar findings from the Hispanic Health and Nutrition Examination Survey.[8] Regression analyses controlling for age, education, and income indicated that utilization of preventive services was predicted more strongly by access to care, measured by having a routine source of care, a regular provider, and health insurance coverage, than by acculturation assessed by ethnic identification.

We could find only one previous study that compared rates of cancer screening for Hispanic and non-Hispanic persons in a similarly insured population. Pérez-Stable et al. surveyed 844 Hispanics and 510 non-Hispanic whites who were members of Kaiser Permanente Medical Care in San Francisco and Alameda Counties.[6] Based on self-report of previous receipt of screening procedures and after adjustment for demographic factors and self-rated health, their findings show that Latinos were not significantly less likely to report having had any of 6 screening procedures over specific 2- or 3-year time frames. When participant clinical records subsequently were linked to the survey responses, adjusted odds ratios for documented receipt of each of the procedures for the Hispanic relative to non-Hispanic members were close to 1.[17] The Hispanic population in northern California is primarily Mexican and Central American. In contrast, the Hispanic population in Eastern Massachusetts is primarily from Puerto Rico and the Caribbean. Yet, the findings of these two studies based on clinic records are very similar.

The primary concern in this study is the determination of Hispanic ethnicity. No method of Hispanic identification is ideal, even the apparent "gold standard," self-identification, is not completely reliable: up to 10% of people inconsistently identify themselves as Hispanic.[15,18] Identifying Hispanics by surname will result in some misclassification. The two main sources of misclassification for surname identification are names common to both Hispanic and other ethnic groups, which reduces specificity, and marriage outside the ethnic group with concomitant name change for women, which could reduce both specificity and sensitivity for women. The magnitude of the first problem—ethnic specificity—depends on the prevalence of the other ethnic population with similar surnames. In California, for example, the Filipino population is very large, approximately 50% of the entire Filipino population in the United States, and consequently a significant minority of persons identified as Hispanic by surname in California are Filipino. In Massachusetts, however, the Filipino population is very small, and it is Portuguese surnames that are a potential source of misclassification. In this study, we have minimized that source of reduced specificity by removing persons from the HG who have Portuguese surnames. The diminished sensitivity and specificity of surname identification for women does not appear to be a major problem in this study for two reasons. First, our findings are very similar for the female and male screening procedures, and, second, our findings are very similar to those for the Kaiser Permanente study that confirmed surname identification with ethnic self-identification.

Another limitation of this study is that we could not assess cultural factors such as primary language spoken at home, country of ancestry, or health beliefs. It may be that this Hispanic HMO population had rates of cancer screening similar to the non-Hispanic population because they also faced fewer cultural barriers than most Hispanics. However, the HMO Hispanic population studied did differ from the comparison group in ways that mirror the general Hispanic population, with a younger average age and lower mean zip code income than the comparison population.

More research is needed to confirm that access to continuous primary care is the dominant determinant of receipt of preventive services among Hispanics. Both this study and the one reported by Pérez-Stable were conducted at large staff model HMOs in urban areas. Hispanics may not fare as well if they live in rural areas, receive health care via different insurance mechanisms, or belong to less inclusive health care systems. The role of culture also deserves more exploration. Insured Hispanics are likely to be more acculturated than those who are uninsured. Future research should focus on how a change in access to and/or continuity of health care for Hispanics at different stages of acculturation affects preventive cancer screening rates, stage at diagnosis, and cancer mortality rates.

In conclusion, we found that with the support of health insurance and contact with a regular source of care, a surname-identified Hispanic population received cancer screening at a rate commensurate with a high rate among the non-Hispanic population. Given that 30% of Hispanics in the United States are uninsured and the number of uninsured Hispanics is growing,[19,20] the policy implication of this study is that efforts to improve insurance coverage and access would have a greater impact on reducing screening disparities than interventions addressed at the cultural factors. Although the incidence and mortality is lower for several cancers in the Hispanic population (although higher for cervical carcinoma), a greater proportion of cancers of the cervix, breast, colon, and prostate are diagnosed with distant metastases in Hispanics than in non-Hispanic whites.[21] These later stage and less treatable cancers could be reduced by appropriate cancer screening, further reducing the mortality rate in this ethnic group.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Beliefs and Attitudes of Samoan Women toward Early Detection of Breast Cancer and Mammography Utilization

Dianne N. Ishida, Ph.D.[1]
Tusitala F. Toomata-Mayer, B.S.[2]
Nafanua S. Braginsky, B.S.[3]

[1] University of Hawaìi at Manoa, School of Nursing and Dental Hygiene, Honolulu, Hawaìi.

[2] Queen's Medical Center, Honolulu, Hawaìi.

[3] Queen's Medical Center, Honolulu, Hawaìi.

BACKGROUND. Among Pacific Islanders in Hawaìi, the breast has been the foremost cancer site. Among Samoans, it is a leading cancer site along with sites for respiratory cancers. A recent study reported that cancer has been diagnosed at relatively advanced stages in younger Samoans.

METHODS. An exploratory, qualitative design was used with a semi-structured, open ended, talk story interview with Samoan women aged 40 years and older who spoke English and who had no personal history of breast cancer. The coding of interviews was validated with a faculty member unrelated to the study. Interviews were stopped at 15 participants once thematic patterns were saturated. Content analysis was performed. Triangulation to validate results was performed with research assistants and one participant.

RESULTS . Participants ranged from 40–73 years of age, had lived in the U.S. 3–40 years, and most were married, born in Samoa or American Samoa, and had health insurance. Their education ranged from ninth grade to some college. Their health promotion activities included eating right, exercising, immunizing their children, and visiting their physician for an annual examination. Most had had positive or neutral experiences with western health care. Most reported that they would use Samoan medicine if available. Priorities reported were health, family, and education. Women considered the care and health of their families their responsibility. All had negative perceptions of cancer. Most had had mammograms. Reported major barriers to mammography were fear, not a priority, and pain. Reported major motivators were physician recommendation, prevention, and fear. Over half of the women reported concern over their breasts being touched either by themselves or by others.

CONCLUSIONS. The study participants had strong beliefs that cancer meant death and, therefore, no cure. Samoan women emphasized the health and education of their families and their role in family health care. Therefore, health care providers should promote health and breast screening by emphasizing that family health care also means caring for oneself. Although Samoan women reported that they used western health care, most women also were willing to use traditional Samoan medicine if it was available. Their understanding the causes of cancer included currently accepted explanations and uncommonly accepted views of causation. Correcting misinformation, teaching, addressing fears (motivators as well as barriers), using female health providers for screening, conveying respect for privacy and person, reinforcing that examination of the breast is not sexual, and gently handling breasts during examinations are important considerations for the prevention of breast cancer in Samoan women. ***Cancer*** **2001;91:262–6.**

KEYWORDS: breast cancer, women, Samoans, mammography, beliefs and attitudes, screening, Polynesian, Pacific Islanders.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000

This research was funded by the University of Hawaìi Research Council.

The authors acknowledge the contributions of Yoshiko Shimamoto, Ph.D., to this research.

Address for reprints: Dianne N. Ishida, Ph.D., University of Hawaìi at Manoa, 2528 McCarthy Mall, Honolulu, Hawaii 96822; fax: (808) 956-5296; E-mail: dianne@hawaii.edu

Received April 1, 2000; accepted August 31, 2000.

The need to reduce disparities in health care among all ethnic minorities compared with the white majority has been gaining attention in the United States.[1,2] The disparities have been unequal access to screening, diagnosis, and treatment, and, thus, to health care outcomes of the poor, medically underserved, and minorities. The need for cancer prevention and control among Pacific and Asian Islanders was highlighted by Chen and Koh.[3] They noted that cancer deaths among these groups in the United States increased faster than in any other ethnic or racial group to approximately twice the percentage increase in the general population. The Pacific and Asian Islander designations encompass heterogeneous cultural groups including Pacific Islanders such as Hawaiians, Samoans, Guamanians, and Fijians; and Asians such as Chinese, Japanese, Filipino, Koreans, and Southeast Asians. With their varied histories, countries of origin, languages, and degrees of acculturation, the health needs of Pacific and Asian Islander groups are diverse and generally not considered when they are merged into one ethnic category. For example, Native Hawaiians in Hawai̇i have a lower incidence when all cancers are combined than whites, but a higher mortality,[4,5] and Vietnamese women have the highest cervical cancer incidence rate of any racial or ethnic group in the United States.[6]

Among Pacific Islanders in Hawai̇i, the breast is the most frequent cancer site. Data from the 1996 Hawai̇i Tumor Registry and a recent study suggest that among Samoans, breast and respiratory tract cancers are the most frequently occurring. [7,] Although the availability of statistical data on cancer rates among Samoans is relatively new, a recently completed study on cancer among Samoans living in Los Angeles, Hawai̇i, and American Samoa reported that cancer is being diagnosed at relatively late stages in Samoans at younger ages.[8] When the same authors compared their data with data on Hawaiians, another Polynesian group that has high cancer mortality rates, the Samoan data appeared comparatively worse. Further, the study indicated that there was a wide variation in the Samoan understanding of cancer risk factors, and that Samoans had a very limited or no knowledge of screening and early detection examinations for breast, cervical, prostate, and colorectal cancers.

According to the United States 1990 census,[9] Samoans are the second largest Pacific Islander group after Hawaiians. They have the largest number of persons per family, the youngest median age, the highest poverty rate, and one of the lowest fluency rates for English when they are compared with other Pacific Islanders. The provision of health education, early detection programs, and treatment strategies that are culturally appropriate to this unique group is important to the reduction of their unequal burden of cancer.

MATERIALS AND METHODS

For the purpose of determining culturally appropriate interventions, the current study explored the health beliefs and attitudes of Samoan women toward early detection of breast cancer and use of mammography. The study used an explorative, qualitative design with a semi-structured, open ended, talk story approach with Samoan women living in Hawai̇i. Participants who were 40 years of age and older, spoke English, and who had no personal history of breast cancer were enlisted from various Samoan churches on Oahu, Hawai̇i. An instrument guide designed by the principal investigator directed the audiotaped interviews. The interviews explored what women did to stay healthy and promote health. Women's roles and their life priorities also were explored. Women were asked to report their illness experiences, their attitudes toward western health care, and their use of western and traditional health care. The interviewer asked the women to report their cancer experiences and beliefs about cancer, particularly breast cancer, and their attitudes toward breast self-examination and mammography. The taped conversations were played to the participants to verify their recorded statements and to allow elaboration and change. To validate the coding, an interview that was coded separately by the principal investigator and a retired nurse faculty member who was familiar with the Samoan culture was compared for consistency. Interviews were ended by the principal investigator and Samoan research assistants once thematic patterns were saturated. A convenience sample size of 15 women was obtained. Content analysis of the data was performed within the large topic areas of the interview guide noted above. Triangulation to validate the research findings was performed by the research assistants and one participant in the study. Major themes were identified.

RESULTS

Demographics

The 15 Samoan women ranged from 40–73 years of age with a median of 54.7 years. Eleven of the participants were married and had lived in United States from 3–40 years with an average of 25 years. All participants except one were born in Samoa (formerly Western Samoa) or American Samoa. The participants' education ranged from ninth grade to graduate education. Four had trained as nurses, and over half had some college education. All except one had some form of health insurance, although all had access to health care either through their private physicians or a free clinic.

Health Promotion Activities

All the women indicated that their children were immunized. With the exception of two, all saw their physicians at least annually. These visits to health care professionals can be opportunities for nurses and physicians to teach, correct misinformation, and make referrals for routine screening until early detection practices become a habit for these women. Thirteen of the participants conveyed the importance of diet by mentioning eating properly, watching what one eats, eating more fresh foods, vegetables, Samoan food, fish and chicken, or decreasing fats and meats as health promoting practices. Nine women mentioned the importance of exercise in promoting health. Some mentioned the need to exercise more consistently. One mentioned walking often to the plantation in Samoa and that it was too easy to "slack off" in Hawai̇i. Over a fourth of the participants also mentioned the importance of hygiene at home in maintaining health, and emphasized clean kitchen utensils. One participant noted, "Samoan women are generally clean freaks. In Samoa the women's committees take care of the health and welfare of the people." The women's committees that promoted sanitation and health care were the backbone of public health programs at the village level in Samoa.[10] Participants also mentioned that decreasing stress, getting enough sleep, taking needed medicines, praying, and family problem solving promoted health.

Women's Roles

The Samoan women reported that they felt responsible for the health of their families and that what they did affected family well-being. This responsibility included making decisions affecting the nutritional health of the family through the types of food served, approaching health care systems for health promotion and early detection and treatment of disease, providing health care, and making health care decisions. The family caregiver role of the women was reflected strongly in their responses. Study participants noted the importance of placing the health of family members above their own, exhibiting model exercise, dietary, hygienic and grooming behaviors, and assuming leadership over matters of family health. Thus, the Samoan women's beliefs and attitudes have an impact on the health of the family and health care professionals need to work with them in a concerted way.

LIFE PRIORITIES

The most frequently mentioned priorities in order of importance were health, family, and education. One participant mentioned that lack of health care was the reason that she did not return to American Samoa, although her husband wanted to return. A 66 year old participant mentioned, "Education for the kids (is) why (we) came here and stayed." Two participants noted that health was a priority because of a need to care for themselves so that they could perform their caretaker role in the family.

Western and Traditional Health Care Experiences

Thirteen participants had positive or neutral experiences with western health care. One participant mentioned having had a negative experience with the hospital on her native island. She trusted western medicine despite relating that a Hawai̇i physician did not detect her mother's cancer until it was at an advanced stage. Fourteen women noted that they felt comfortable using Samoan medicine and would use traditional Samoan medicine if it were available. Some participants were pragmatic in their choices and used what worked best and was available. This might have involved use of both western and Samoan medicine, following the premise that if one medicine worked, then two would increase the chances for a positive result. One participant related that she was told she had stomach cancer by a physician in Hawai̇i. She returned to American Samoan and tried Samoan medicine. Later she returned to Hawai̇i and had surgery, but no cancer was found. She trusted Samoan medicine but used both. Another woman noted that with breast cancer her recommendation was to "Better go to Samoan medicine first; keep up with that, then go to the (western) doctor." She further related that her niece, who was 30 years old when diagnosed with breast cancer, had a mastectomy but the cancer spread.

Cancer Experiences and the Meaning of Cancer

All participants except one had known someone with cancer, either family or friends. Those experiences generally were negative and ended in death. Participant comments indicated that they thought cancer was a terrible, painful disease that caused suffering and death to many. From the participants' perspective, this was the meaning of cancer. Several said there was no cure for cancer or that it was fatal. One participant commented, "It's some illness which the doctor cannot find out for sure so they call it cancer," and another noted that she thought cancer was chronic and, therefore, could not be prevented. One participant stated that cancer meant a long-lasting sickness, useless to treat, and expressed in Samoan as, "ùi, we're ùi." "Kalofai, so sad, too bad," commented another. More than one fourth of the participants expressed a passive acceptance of cancer as a part of life by saying, "If it happens, it happens," or "It's God's will."

Causes of Cancer

Seven women mentioned that the causes of cancer are diet and heredity. Women noted that they ate too much processed food, fast food, sodas, sweets, and greasy foods. One woman commented that Samoans had become an obese society and a fried food culture. Concern about frozen food by another respondent was related to her past experiences. She stated that the food she used to eat was from the land and from the sea and that, at that time, there were no frozen foods.

The next frequently believed causes of cancer were trauma and environment (three study participants each). One woman noted that not wearing a bra could cause breast cancer, whereas another noted that if a man hits his wife on her breast, cancer could result. Causes of cancer attributed to the environment included chemicals in the water, the environment, and the air. Other participants listed causes of cancer as lifestyle, infection, stress, smoking, and contagion. The latter response was from a woman caring for her mother who had cancer. She noted, "I didn't protect myself. I didn't know if cancer gets transferred to one another." Participants frequently listed both currently accepted causes and risk factors and less accepted risk factors and causes for breast cancer.

Breast Self Examination and Touching of the Breast

Although twelve of the participants noted that they knew about breast self examination (BSE), their frequency of examination was highly variable ranging from twice daily, to once a day, when they showered, weekly, monthly, or once in awhile. Most of the women reported that they performed BSE more frequently than the American Cancer Society recommendation of once a month.[11] Two participants noted that their physicians checked their breasts, and, thus, they did not examine themselves because they did not want to "find something" or because they felt it was unnecessary. Eight of the participants commented that they and others should not touch their breasts. A 45 year old participant noted, "I don't think our girls are comfortable with. . .what may seemingly appear as fondling," and "You know how anything to do with the breast, the genitals, you know, the naked body seems to have been regarded as taboo." "It feel[s] funny-. . .[be]cause you never, to me, touch yourself like that," noted a 47 year old participant. Two study participants, aged 66 years and 50 years, said that they did not want anyone to touch their breasts.

Mammography Utilization

Thirteen of the 15 women in the current study had had at least one mammogram. More than one third of these study participants (5) had had a mammogram at least yearly. Of these, most had had a family history of cancer or were older than 60 years of age. A 59 year old participant reported that she had had a mammogram every 6 months, although she gave no indication of a family history of breast cancer or other health problems. The two study participants that had never had a mammogram were aged 73 and 50 years. The 73 year old had never heard of mammography, whereas the 50 year old, who had no health insurance responded that she had not had time and that she did not want to know if she had cancer.

Barriers to having a mammogram that the participants reported were fear (eight participants), lack of importance (seven), pain (seven), a desire not to know (five), a feeling of intrusion (four), a male technician (three), embarrassment (three), the expense or lack of insurance (three), "feeling okay" (two), and a belief that after menopause a mammagram is unneccessary (one). Fear of discovering cancer as a result of mammography was the most frequently reported barrier. This can be expected given their generally negative past experiences with cancer. Some of the women who deemed health to be a low priority responded that they were busy, did not want to take the time when they were "well," or that they did not care (about getting a mammogram). In regard to pain, a 66-year-old participant noted, "It felt like my breast was going to be taken out of my body," and a 42 year old Samoan woman stated, "I think a man invented (it) to torture us women." Another 66 year old woman felt that a mammogram was an intrusion and an insult to dignity because of the way the breasts were handled. Similarly, a 59 year old participant noted that the mammography technicians picked up the breast as if it were a piece of meat. One woman felt menopausal women did not need to have mammograms and that they were for younger women.

Motivators to having a mammogram were physician recommendation (five participants), a desire to prevent breast cancer (five), fear of the disease (four), encouragement by other Samoan women (four), women physicians or technicians (four), availability (three), and ease of accomplishment (one). A 45 year old participant noted the need for a structured, collective effort to encourage women to have mammograms. Using the women's group in a church may prove to be an effective way for health care providers to mobilize women because Samoan women believe that health care falls within their role.

DISCUSSION

While the participants in the current study were relatively highly educated, a strong cultural influence was reflected in their willingness to use Samoan medicine if available. Support of traditional medicine or healers also was found in an earlier study that reported over 30% of Samoan women in Hawaìi used Samoan medicine and a higher percentage would use it for cancer than their American Samoan counterparts.[8] Samoans tend to be pragmatic in their use of health care. Therefore, as part of their regular assessment, health care providers should assume that their clients are using Samoan medicine and ask them what traditional remedies are being used. Health care providers should familiarize themselves with Samoan medicine and health and illness beliefs. The traditional Samoan view that sickness is something unavoidable, inevitable, and not preventable[12] was mentioned by some participants.

Emphasizing the relationship between early detection and better health outcomes is important to Samoans whose cancer experiences with family and friends generally have been negative. The ground for this negative view was supported by a study that found Samoan men and women were being diagnosed with cancer at younger ages and at more advanced stages compared with whites and Hawaiians.[8] It is not surprising that this has resulted in more negative health outcomes, reinforcing the negative view of cancer. This cycle needs to be stopped. Providing health education to the women through the women's groups in the churches, especially with the support and aid of key Samoan women, such as the pastor's wife or respected elders,[13] is needed to help correct misinformation and lack of knowledge and to promote early detection and effective treatment. Health care providers also need to address fears of the Samoan client, since fear can be a motivator as well as a barrier. Checking breasts twice a day or even daily out of fear is wasted time and energy that can be better spent on exercising or cooking healthy foods. Although most of the participants had mammograms, it is important for health care providers to minimize embarrassment and discomfort for the women by informing the women to schedule examinations at the time in their cycle when their breasts are least sensitive, by telling them generally what to expect, by informing them that touching of the breasts for examination is not sexual, and by alerting the women before touching of the breasts during the examination. Providing for privacy and gentle handling of the breasts also would help to make the breast examination and mammogram less traumatic. Telling the women that the mammogram can be uncomfortable, but that it will be over quickly may make it more tolerable. Efforts should be made to have female health care providers available to this population for any screening that involves examination of the more private parts of the body.[13]

In conclusion, health care providers have a responsibility to understand Samoan women's unique needs, fears, and concerns related to their health and life priorities. Capitalizing on Samoan women's priorities of health, family, and education to promote understanding of early detection and screening is timely and appropriate. Caring for oneself in order to care for one's family needs to be emphasized.

Limitations of Study

The selection criteria of English fluency limited the representativeness of the current study sample, and accounts for a fairly educated study population. This also may account for a lack of mention of other traditional beliefs concerning causation of illness, such as spirit possession,[12] as a cause of cancer. This sample also probably had a higher than expected use of mammography and awareness of other health promotion activities. Also, the age groups of the participants were unevenly distributed with few 50 year olds and only one 70 year old.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

Promoting Early Detection of Breast Cancer among Vietnamese-American Women

Results of a Controlled Trial

Thoa Nguyen
Phuong H. Vo, M.S.
Stephen J. McPhee, M.D.
Christopher N. H. Jenkins, M.A., M.P.H.

"Suc Khoe La Vang (Health Is Gold)," Vietnamese Community Health Promotion Project, Division of General Internal Medicine, Department of Medicine, University of California, San Francisco, California.

BACKGROUND. Although breast cancer is the second most common cancer among Vietnamese-American women, previous research has shown that they are less likely to have ever had, and to be more often overdue for, clinical breast examinations (CBE) and mammograms than women in the general population.

METHODS. Over a 2.5-year period, the following intervention activities were targeted at both Vietnamese women and physicians in Alameda County, California: neighborhood-based educational activities; dissemination of health education materials; a media campaign; and continuing medical education seminars for physicians. Women in Los Angeles and Orange Counties served as controls. Preintervention telephone interviews were conducted with 384 randomly selected Vietnamese women in the intervention community and 404 women in the control community in 1996, and post-test intervention interviews were conducted with 405 and 402 women, respectively, in 1998.

RESULTS. Multiple logistic regression analyses of postintervention surveys showed the intervention community women at posttest were no more likely to recognize, receive, plan, or be up-to-date for CBE or mammograms than women in the control community. However, women who reported greater exposure to the various intervention elements were significantly more likely to have heard of, have had, and to plan CBE and mammograms than women with less exposure.

CONCLUSIONS. Although the effect on the women in the intervention group was not significant, the intervention did have a modest positive impact on women who had more exposure to it. ***Cancer*** **2001;91:267–73.** *© 2001 American Cancer Society.*

KEYWORDS: breast carcinoma, screening, Vietnamese women.

Although Vietnamese women are approximately one-third as likely to develop breast cancer compared with women of other racial and ethnic groups in the United States, it is still the second most common cancer occurring among them.[1] Data from the Ho Chi Minh City Cancer Registry also indicate that breast carcinoma is the second most common cancer occurring among women there.[2] It is the leading cancer among women in Hanoi.[3] Unfortunately, Vietnamese women are less likely to have heard of recommended breast cancer screening tests and less likely to report ever having had them than other women in the United States.[4–8] In general, Asian women with breast carcinoma are also more likely to receive a diagnosis at a later stage and have larger tumors at diagnosis than U.S. non-Hispanic white women.[9] Data from the California Cancer Registry has shown that more Vietnamese women (31%) with breast carcinoma received a diagnosis with regional spread compared with women in the general

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Supported by funds from the California Breast Cancer Research Program of the University of California, Grant 1RB-0343. Additional funds were provided by San Francisco Women and Cancer Walk, The San Jose Mercury News, Oakland Kaiser Permanente, Bay Area Komen Foundation, Macy's, and Summit Medical Center.

The authors thank the Women's Advisory Committee, Karen R. Rezai, Susan Sheehan, Tram Quynh LeNguyen, Alice Nguyen, and Betty Shen for their help with the research project, and Yifei Ma for data analysis.

Address for reprints: Thoa Nguyen, Vietnamese Community Health Promotion Project, Division of General Internal Medicine, Department of Medicine, University of California, San Francisco, 44 Page Street, Suite 500, San Francisco, CA 94102; fax: (415) 431-7700; E-mail: thoa@itsa.ucsf.edu

Received April 1, 2000; accepted August 31, 2000.

California population (27.4%). In addition, 5.6% of Vietnamese women received a diagnosis with distant metastases compared with 4.3% of women in the general California population.[10]

Numerous studies have shown the effectiveness of screening tests in the reduction of breast carcinoma morbidity and mortality. Our previous research showed that interventions among Vietnamese women can effectively increase their knowledge, intentions, and behaviors toward early breast cancer detection. For example, a media-led intervention was successful in promoting recognition of and intention to have breast cancer screening tests.[11] In a second study involving trained lay health workers, Vietnamese women's recognition, receipt, and maintenance of breast cancer screening were significantly improved.[12]

These studies also showed that although most Vietnamese women reported having a Vietnamese physician, this was a significant negative predictor of undergoing screening.[11–14] Most of the Vietnamese women surveyed reported that their physicians had not recommended breast cancer screening tests. Elsewhere, reminder interventions targeting physicians in the general population have been shown to increase breast screening rates.[15] However, such interventions targeting Vietnamese physicians were unsuccessful in increasing breast screening rates in one small pilot study.[16]

To continue to improve breast cancer screening services among Vietnamese women, an intervention was developed and tested. The intervention consisted of a media-led informational and educational campaign combined with a set of neighborhood-based activities. In addition to targeting Vietnamese consumers, the intervention also targeted Vietnamese physicians. The primary hypothesis of this research project was that rates of ever having had a clinical breast examination (CBE) and mammogram would be significantly greater among consumers in the intervention community than consumers in the control community. The secondary hypothesis tested differences among the two groups of consumers in screening knowledge, attitudes, and intentions. This article reports pre- and postintervention survey results from Vietnamese women in California's Alameda County (the intervention community) and Los Angeles and Orange Counties (the control community) and presents bivariate and multivariate analyses of the intervention effects.

METHODS

Subjects

The subjects of the intervention were Vietnamese women aged 18 years or older in Alameda County; the control population was Vietnamese women of similar age in Los Angeles and Orange Counties. According to the 1990 Census, 13,374 Vietnamese lived in Alameda County, and 134,416 Vietnamese lived in Los Angeles and Orange Counties.[17]

Intervention Strategies

To reduce cultural and economic barriers to breast screening services for Vietnamese women, the 2.5-year project's intervention activities targeted both Vietnamese women and physicians. There were four types of intervention activities: neighborhood-based interventions; dissemination of health education materials; a media campaign; and continuing medical education seminars for Vietnamese physicians.

Neighborhood-based interventions

The core of this intervention involved establishing a Vietnamese Women's Center in a storefront in the East Oakland neighborhood of the City of Oakland, the residential heart of the Vietnamese community in northern Alameda County. A bilingual, bicultural project coordinator (T.N.) staffed the Women's Center. The project coordinator recruited young professionals and high school, undergraduate, and graduate students to assist her with the intervention activities. The storefront operation enabled staff and volunteers to conduct the following outreach activities regarding breast cancer screening: counseling, appointment-making assistance, and referrals to free breast cancer screening services; a Vietnamese-language breast health telephone "warm" line; participation in community coalitions and health fairs; presentations about breast cancer and screening to small groups; and contests with prizes to promote knowledge of breast cancer early detection methods.

A 14-member Vietnamese Women's Advisory Board was formed of women aged 45–65 years old. The women were mostly community college students, English-as-a-second language students, homemakers, caregivers, and grandmothers. They helped recruit women to attend small-group educational sessions, distributed breast cancer educational materials, participated in health fairs, provided ideas for prize incentives for participants in educational contests, and graded contest entries. There were three breast cancer survivors on the advisory board who provided support for Vietnamese patients with newly diagnosed breast carcinoma.

During the intervention period, 12 health fairs were sponsored in various settings, ranging from a farmer's market, a museum, a middle school, and the Lunar New Year's Festivals in San Jose, a city 45 miles south of Oakland. Project staff collaborated with 10 community coalitions to advocate for improved access to breast cancer screening and follow-up services. Thirty presentations about breast carcinoma and screening were made at community meetings. Sixty small-group educational sessions were conducted at various sites including our storefront Health Center; WIC (Women and Infant's Care) offices; English-as-a-second-language and citizenship classes; Vietnamese community associations, beauty schools, and salons; and Vietnamese senior centers and women's homes. The project coordinator and volunteers conducted these sessions in the Vietnamese language by using culturally sensitive health education materials. During these sessions, Vietnamese women were counseled about their need for breast cancer screening, taught the screening techniques and frequencies appropriate for their age, and were told where such screening could be obtained. Women were given the locations of free breast cancer screening services provided through the Breast and Cervical Cancer Control Program and the Breast Cancer Early Detection Program, which cover screening fees for all age-eligible, low-income California women. Women also were given a written guide, developed by our staff, to help them navigate the health care system. The guide provided locations of clinics and hospitals where translation and specific screening services were offered and their eligibility guidelines.

Two educational contests were organized to promote knowledge about breast cancer early detection methods. Prizes were funded by contributions from two local hospitals, a newspaper, a department store, and the San Francisco Women and Cancer Walk. The contest entry forms were printed in five Vietnamese newspapers and magazines and 10,000 contest forms were distributed through various community-based organizations, markets, churches, pagodas, English-as-a-second-language classes, hospitals, clinics, health fairs, flea markets, and farmer's markets. Participants who submitted entry forms with all answers correct were eligible for the prize drawing (cookware sets and $100 department store gift certificates) by members of our advisory board. Two contests were conducted during the intervention period. Three hundred fifty women and 129 men participated. Their ages ranged from 16 to 80 years. Ninety-five participants had all answers correct; 77 participants received prizes.

Dissemination of health education materials

Culturally sensitive pamphlets, booklets, and calendars were developed in the Vietnamese language. They were distributed at health fairs, small group educational sessions, local physicians' offices, neighborhood stores and agencies, and other community sites. The project coordinator and volunteers distributed 10,500 pamphlets about breast carcinoma and Vietnamese women, 10,000 pamphlets about the health center, 2500 20-page breast cancer booklets, and 5700 traditional New Year's calendars with breast cancer screening reminders.

Media campaign

Ten news articles about breast carcinoma and screening and about the project were printed in 4 Vietnamese-language newspapers resulting in an estimated 159,000 print media exposures. In addition, five news articles about the project appeared in local English-language newspapers. Newspaper advertisements regarding breast carcinoma checkups, 1 featuring a photograph of a member of our advisory board and the other featuring a line drawing of 6 Vietnamese women of 3 generations, were printed many times in 4 newspapers resulting in an estimated 1,508,000 exposures. Twenty-two advertisements about breast carcinoma and early detection methods were aired on 3 Vietnamese-language television stations and 2 Vietnamese-language radio stations. The project coordinator was interviewed on two of these television stations and one of the radio stations about breast carcinoma and access to screening services. The reach of the media campaign covered the entire intervention area of Alameda County.

Vietnamese physicians intervention

Three continuing medical education seminars were conducted for Vietnamese physicians in family practice, general medicine, and surgery. Each seminar focused on a different theme: 1) "Breast Cancer Screening of Vietnamese Women: Breast Self-Examination, Clinical Examination and Mammography;" 2) "Access to and Follow-Up of Screening Mammography for Vietnamese Women;" and 3) "Breast Cancer Treatment." Five to 7 of the 10 Alameda County Vietnamese physicians and their spouses attended each seminar. In addition, Vietnamese-language breast health education materials were placed in Vietnamese physicians' offices. Posters and calendars were hung in their waiting rooms.

Survey Methods

To evaluate the effect of the intervention, we used a pretest/post-test control group design.[18] Computer-assisted telephone interview surveys were conducted of independent random samples of Vietnamese women aged 40 years and older in both intervention and control communities at pre- and postintervention. Cross-sectional samples were selected randomly from sampling frames compiled from published telephone listings associated with 23 Vietnamese family names that as we have shown previously account for 99% of Vietnamese.[11]

Measures

The survey instrument was developed in Vietnamese, translated into English, and backtranslated into Vietnamese to ensure linguistic equivalence and pilot-tested and revised. The instrument contained 108 items. Items included: sociodemographics; health insurance; source of health care; utilization of preventive care services; and knowledge, attitudes, and beliefs regarding cancer. Our outcome variables included measures of self-reported CBE and mammography and consumer knowledge, attitudes, intentions, and behaviors regarding CBE and mammography (ever screened and last tested). Indicators of knowledge and attitudes (e.g., "Do you think that having cancer in the family might cause cancer?") and indicators of intentions and behaviors (e.g., "Are you planning to have a clinical breast exam during the next 12 months?") were measured on a dichotomous (yes/no) scale.

At postintervention, other survey items were added that assessed respondents' exposure to the different intervention elements by assessing self-reported recall of the different intervention elements. Indicators of exposure to intervention activities (e.g., "Have you ever seen the 22-page, multi-colored, Vietnamese-language booklet about breast cancer screening tests?") were measured on a dichotomous (yes/no) scale.

Data Analysis

Chi-square tests of differences of proportions were used in preliminary analyses to examine differences between the intervention and control communities in sociodemographic characteristics and screening behaviors. Multiple logistic regression analyses were used to assess the impact of the intervention at post-test and to identify other variables significantly associated with the outcomes. First, all independent variable models were entered into full models. To develop parsimonious models, we deleted nonsignificant variables from the initial full models, retaining the control variables of time, site, and age. To enable comparisons between the models, we kept all variables that appeared significant in at least one full model in all final models. Each final model included time, site, time x, site, age, year of immigration, cancer knowledge, having a male physician, having a Vietnamese physician, educational status, marital status, health insurance status, and Intervention Exposure Index Score. Two log likelihood of fit tests were conducted to assess the adequacy of the models. The SAS statistical package was used to perform all analyses.[19]

Exposure index scores were calculated by adding the number of intervention elements recalled by each respondent. Scores could range from zero to seven.

RESULTS

Survey Response Rates

Response rates were calculated conservatively by dividing the number of eligible persons who completed the interviews by the number of eligible persons who completed interviews plus those eligible who refused and all potentially eligible unanswered calls. Call attempts that reached businesses, disconnected numbers, answering machines or fax/modems, telephones that were not in service, households with no eligible persons, and persons who were ill or hard of hearing were excluded and were not available at the time of the study. At the 1996 preintervention survey, the response rates were 41.9% for the intervention area and 38.6% for the control area. At the 1998 postintervention survey, the response rates were 54.6% for the intervention area and 36.5% for the control area. All respondents elected to be interviewed in the Vietnamese language.

Sociodemographic Characteristics

Table 1 shows the sociodemographic characteristics of respondents at pre- and post-test intervention surveys. At pretest, respondents in the control community were more likely to have fluent/good English proficiency, be employed, have health insurance, have a male physician, and have a Vietnamese physician, whereas respondents in the intervention community were more likely to have less than 12 years of education and income below the poverty level. At post-test, control community respondents were more likely to have a male physician, a Vietnamese physician, and employment whereas intervention community respondents were more likely to have less than 12 years of education. Regardless of residential area, significantly more respondents interviewed at post-test in 1998 were employed compared with those interviewed at pretest in 1996.

Within each area, differences in sociodemographic characteristics were observed between pretest and post-test surveys. The following characteristics showed statistically significant differences between pre- and post-test surveys in the intervention community: an increased number of respondents reported having a fluent/good English proficiency, identified as Vietnamese, were employed, had income levels below the poverty level, and had health insurance. Control

TABLE 1
Demographic Characteristics of Respondents to Pre- and Postintervention Telephone Surveys in Alameda County Intervention and Los Angeles and Orange Counties (Control)

	Pretest (1996)					Post-test (1998)						
	Intervention (n = 384)		Control (n = 404)		Pretest intervention vs. pretest control	Intervention (n = 405)		Control (n = 402)		Post-test intervention vs. post-test control	Pretest intervention vs. post-test intervention	Pretest control vs. post-test control (*P* value)
Variable	n	%	n	%	(*P* value)	n	%	n	%	(*P* value)	(*P* value)	
English-language proficiency fluent/good	382	26.44	404	31.68	0.106	402	34.08	400	30.75	0.314	0.020	0.775
Vietnamese ethnicity	384	82.55	404	87.62	0.003	405	88.64	401	87.53	0.558	0.001	0.841
Mean year of immigration	370	1988	404	1985	0.000	397	1986	385	1987	0.000	0.000	0.000
Mean age	378	51.22	404	52.34	0.000	398	51.50	388	52.49	0.000	0.000	0.000
Ever married	377	81.96	403	80.40	0.949	398	85.93	393	84.48	0.554	0.745	0.484
Education < 12 yrs	382	64.92	399	56.89	0.022	400	69.25	387	62.02	0.033	0.198	0.144
Employed	379	24.02	400	33.33	0.000	385	37.14	398	40.70	0.022	0.001	0.007
Income below poverty level	249	64.66	279	54.12	0.014	284	56.34	279	51.61	0.261	0.050	0.553
Has health insurance	384	39.32	401	49.63	0.004	403	51.86	400	51.75	0.975	0.001	0.548
Physician is male	318	76.10	350	84.86	0.004	346	74.57	341	82.11	0.016	0.647	0.331
Physician is Vietnamese	324	67.28	354	79.38	0.000	350	63.43	341	86.22	0.001	0.294	0.017
Self-rated health excellent/good	382	22.51	399	27.32	0.121	402	28.36	400	25.25	0.320	0.061	0.507

TABLE 2
Results of Computer-Assisted Telephone Surveys of Adult Vietnamese Women Age ≥ 40 Years in Intervention and Control Communities at Preintervention (1996) and Postintervention (1998)

	Pretest (1996)					Post-test (1998)						
	Intervention (n = 384)		Control (n = 404)		Pretest intervention vs. pretest control	Intervention (n = 405)		Control (n = 402)		Post-test intervention vs. post-test control	Pretest intervention vs. post-test intervention	Pretest control vs. post-test control (*P* value)
Outcome variable	n	%	n	%	(*P* value)	n	%	n	%	(*P* value)	(*P* value)	
Clinical breast examination												
Had heard of	383	94.8	404	88.1	0.001	404	95.1	400	94.5	0.726	0.862	0.001
Had had	384	81.3	402	72.9	0.005	403	85.9	400	81.8	0.114	0.081	0.003
Planning to have	359	76.3	388	67.8	0.010	378	85.2	362	81.5	0.117	0.002	0.000
Last CBE within 12 mos	303	72.3	289	68.9	0.471	319	76.5	309	72.5	0.362	0.565	0.734
Mammography												
Had heard of	381	78.0	402	76.9	0.716	401	85.8	396	87.1	0.582	0.004	0.002
Had had	384	68.1	402	61.4	0.053	403	79.2	400	79.5	0.919	0.081	0.003
Planning to have	343	75.2	376	64.1	0.001	345	82.3	354	80.8	0.603	0.023	0.000
Last mammogram within 12 mos	249	64.7	246	65.0	0.869	289	68.9	297	71.0	0.460	0.027	0.054

area respondents more often said they were employed and had a Vietnamese physician on the post-test survey.

Rates of Screening Tests

Women in the intervention community had significant increases in plans to have a CBE (from 76.3% to 85.2%, *P* = 0.002) but not in recognition, receipt, or currency of CBE (Table 2). However, rates of CBE recognition, receipt, and plans increased significantly in the control community. Between pre- and post-test, women in the intervention community had significant increases in recognition, plans, and currency of mammography, but rates of mammography recognition, receipt, plans, and currency also increased in the control community.

Results of Multivariate Analysis

Multiple logistic regression analyses show that intervention community women at post-test were not more likely to recognize, receive, plan, or be up-to-date for CBE and were significantly less likely to recognize, receive, and plan mammograms than women in the control community (Table 3).

TABLE 3
Multiple Regression Results for Women in the Intervention Community at Postintervention

Outcome variable	OR (95% CI) (n = 405)
CBE	
Had heard of	0.48 (0.19–1.25)
Had had	0.63 (0.34–1.16)
Last within 12 mos	1.03 (0.57–1.87)
Planning to have	0.56 (0.30–1.07)
Mammography	
Had heard of	0.47 (0.25–0.91)
Had had	0.47 (0.27–0.80)
Last within 12 mos	0.80 (0.45–1.44)
Planning to have	0.43 (0.24–0.79)

OR: odds ratio; CI: confidence interval; CBE: clinical breast examination.

TABLE 4
Relationship between Outcomes and Exposure to the 7 Intervention Elements

Outcome variable	OR (95% CI) (n = 405)
CBE	
Had heard of	1.24 (1.05–1.47)
Had had	1.14 (1.03–1.27)
Planning to have	1.15 (1.04–1.28)
Mammography	
Had heard of	1.38 (1.23–1.55)
Had had	1.13 (1.04–1.24)
Planning to have	1.21 (1.09–1.33)

OR: odds ratio; CI: confidence interval; CBE: clinical breast examination.

Effects of Exposure to Intervention Activities

In Table 4, among intervention community women, women who reported greater exposure to the various intervention elements were significantly more likely to have heard of, to have had, and to plan a CBE and to have heard of, to have had, and to plan a mammogram than women with less exposure. Higher scores on the exposure index increased the chance that a woman would likely perform the outcome.

DISCUSSION

The results of this trial show that in general our media- and neighborhood-based intervention had little effect among Vietnamese women in the intervention community. Multiple logistic regression analyses showed that intervention community women at post-test were not more likely to recognize, receive, plan, or be up-to-date for CBE and were less likely to recognize, receive, and plan mammograms than women in the control community. However, among intervention community women, women who reported more exposure to the various intervention elements were significantly more likely to have heard of, have had, and to plan a CBE and to have heard of, have had, and to plan a mammogram than women with less exposure. Although the intervention appears not to have been effective in the intervention community at large, it seems to have had a measurable effect on those who were exposed to it.

The findings reported here are in contrast to our previous findings of relative success for a media-based intervention and greater success for a lay health worker–based intervention.[11,12] In the current project, we had hoped to harness and bring together the most effective elements of our earlier trials. One explanation for the difference in outcome from our current project in comparison to our previous research results could be that the intervention outreach from the Vietnamese Women's Center was not as intense or focused as the lay health worker intervention. In the earlier lay health worker intervention, 84 lay health workers were paid, trained intensively, and focused their work on Vietnamese women living in a few city blocks in the City of San Francisco. The current project had only the project coordinator and 31 unpaid volunteers who had to undertake outreach to a more dispersed Vietnamese population in the intervention area of Alameda County.

Failure to show an effect among women in the intervention community, thus, may be due to the lack of success of the intervention in reaching all Vietnamese women in Alameda County. Although the media components of the intervention covered all of Alameda County, many of the neighborhood-based components were necessarily concentrated around the Vietnamese Women's Center in Oakland in the northern part of the County. By surveying all Vietnamese women throughout the county, measurable effects of the intervention were diluted.

In addition, failure to show an effect may derive from our choice of survey method. Pre- and postintervention cross-sectional surveys of randomly selected women in both communities were used. Had we instead performed a longitudinal, cohort study of women in northern Alameda County who could have been exposed to all components of the intervention, we might have shown a greater effect.

Finally, our failure to show significant effects of the intervention may be due in part to the success of the unanticipated breast cancer prevention activities that were being conducted concurrently in the control community (personal communication from Christine Ta, Director of Nhan Hoa Clinic, and Rayout Sobero, Coordinator of Orange County BCEDP, February 26, 2000). These activities included Vietnamese media campaigns, a clinic-based Vietnamese physician education program, distribution of Vietnamese-language brochures, and outreach at health fairs. These unanticipated activities led to measurable effects in the control community that may have confounded our ability to show outcome differences between the intervention and control communities.

CONCLUSIONS

The results of this study indicate that our media- and neighborhood based intervention was not effective in increasing knowledge, intentions, and behaviors regarding early breast cancer detection among Vietnamese women in the intervention community at large. Nonetheless, the intervention had a measurable effect on those women who reported greater degrees of exposure to it. This finding reinforces the need for more culturally sensitive early breast cancer screening programs and more intense outreach to increase screening rates among minority, low-income, and immigrant populations such as the Vietnamese. Future research should be designed to evaluate the effectiveness of lay health workers, media, health education brochures, and provider education separately and in combination. Furthermore, evaluation methodologies should be tailored to measure outcomes among those directly exposed to each type of intervention.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

The National Marrow Donor Program

Meeting the Needs of the Medically Underserved

Dennis L. Confer, M.D.

National Marrow Donor Program, Minneapolis, Minnesota.

BACKGROUND. The National Marrow Donor Program operates the world's largest registry of volunteer unrelated stem cell donors. In recent years, the program has focused on building a large and diverse donor file. After initial recruitment, however, months or years may elapse before a potential donor is contacted on behalf of a searching patient. Here, the author begins to explore factors that influence donor availability at the confirmatory typing stage of the search process.

METHODS. Over a 1-year period from March 1, 1999 through February 29, 2000, the author evaluated donor unavailability rates at the confirmatory typing stage of the search process. Unavailability rates by donor racial/ethnic group and by donor center were evaluated. To determine the consistency within individual donor centers, the author compared donor unavailability during the first 6 months of the observation period with unavailability during the second 6 months.

RESULTS. Donor unavailability at confirmatory typing was higher among donors registered with domestic (U.S.) donor centers. The self-identified racial or ethnic group of the donor also affected the likelihood the donor will be available when requested. Between individual donor centers, there were large differences in the overall donor unavailability. Rates of donor unavailability tended to remain consistent at individual centers over time.

CONCLUSIONS. This study suggests that procedures used at individual donor centers may dramatically impact donor unavailability. Future initiatives should undertake to identify best practice models for donor recruitment, retention, and subsequent contacts. *Cancer* 2001;91:274–8. © *2001 American Cancer Society.*

KEYWORDS: National Marrow Donor Program, hematopoietic stem cell, human leukocyte antigen.

Seventy percent of people who are candidates for allogeneic hematopoietic stem cell (HSC) transplantation do not have matched-sibling donors. In 1986, the National Marrow Donor Program (NMDP) was established to create a system that would seek to provide human leukocyte antigen (HLA)–matched, volunteer unrelated donors for these people. The mission of the NMDP is the following: to facilitate successful transplants of hematopoietic stem cells from volunteer unrelated donors as lifesaving therapy for patients of all racial and socioeconomic backgrounds.

As of March 2000, more than 3.9 million potential donors were listed in the NMDP files. Donors who have been identified through the search process as appropriate matches have provided stem cell support for more than 9500 unrelated donor transplants.

Early in the NMDP's history, it became apparent that HLA phenotypes were not evenly distributed within or among various racial and ethnic groups.[1] Not only are some HLA phenotypes more com-

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

Address for reprints: Dennis L. Confer, M.D., National Marrow Donor Program, 3433 Broadway Street NE, Suite 500, Minneapolis, MN 55413; fax: 612-627-8125; E-mail: dconfer@nmdp.org

Received April 1, 2000; accepted August 31, 2000.

mon within certain racial and ethnic populations, but in addition the richness of the HLA repertoire, i.e., the number of phenotypes within the population, also varies. Recognizing these variations, the NMDP, with the support of federal funding agencies, has worked to recruit potential donors from racial and ethnic minority communities.

Here, I report our progress toward building a large and ethnically diverse donor file and identify new challenges that are emerging as the NMDP works to fulfill its mission.

METHODS

The NMDP and the NMDP Network

The NMDP is a nonprofit corporation with headquarters in Minneapolis, Minnesota. Since its inception, it has received federal funding support that has been vital to its success. Currently, the program operates the congressionally mandated National Bone Marrow Donor Registry under a contract from the Health Resources and Services Administration. In addition, the NMDP receives support under a cooperative agreement with the Office of Naval Research.

The NMDP maintains an international network of member centers. NMDP donor centers and recruitment groups recruit volunteer donors. Eleven recruitment groups, primarily focused on recruitment within specific racial and ethnic minority populations, assist the donor centers in their recruitment efforts. In addition, the donor centers, which currently number 94, are responsible for all subsequent donor contacts, including the evaluation of donors selected for stem cell donation. Seven member donor centers are located outside the United States.

NMDP Transplant Centers manage potential stem cell transplant recipients. One hundred twenty-seven transplant centers, including 28 outside the United States, are members of the NMDP network. Each transplant center's membership is reviewed annually to ensure that NMDP criteria for participation are met.

Donor Recruitment and HLA Typing

Historically, newly recruited donors were only tested for HLA-A and -B antigens. To identify an appropriately matched donor for transplantation, a second stage of typing at HLA-DR was necessary. Selection of donors for HLA-DR typing was the responsibility of the NMDP transplant centers operating on behalf of the searching patients, and this typing was typically performed using serology-based techniques. In 1991, however, in an effort to make donors more readily and rapidly available, the NMDP initiated a program of prospective HLA-DR typing. To define the HLA-DR type, the NMDP elected to use DNA-based analyses of the DRB1 gene. Currently, greater than half of the total potential donors have HLA-A, -B, and -DR (DRB1) typing completed. Greater than 95% of successful searches, i.e., those resulting in transplantation, use donors selected directly from this HLA-A, -B, and -DR typed pool.[2]

Beginning in 2000, the NMDP initiated complete HLA-A, -B, and -DRB1 typing on all newly recruited donors whose typings are funded through NMDP mechanisms. Currently, all donor HLA typing at NMDP contract laboratories is performed using DNA-based technologies. HLA typing results are stored in the NMDP Search, Tracking, and Registry (STAR) system, a computer network linking daily activities and data entry to the National Coordinating Center in Minneapolis.

Search Process

Any licensed physician can submit a patient's HLA-A, -B, and -DR typing to the NMDP. A preliminary search is run at no cost to reveal potential stem cell donors. The NMDP defines a matched donor/recipient pair as a serologic match at the HLA-A and -B loci and a DNA allele-level match at HLA-DRB1. NMDP policies allow for a single mismatch at HLA-A, -B, or -DRB1. After the preliminary search, a formal search is necessary to actually pursue a donor for stem cell transplantation. Formal searches can only be initiated through member NMDP Transplant Centers. Most often, the initial activity in the formal search is one or more requests for donor "confirmatory typing," or CT. When a prospective donor is requested for CT, the NMDP notifies the responsible NMDP donor center, which in turn contacts the donor and arranges for additional donor blood samples. At the time of CT contact, the donor also receives a medical screening interview and additional educational material about the stem cell donation processes.

Measurements of Donor Availability

If the NMDP donor center is unable to arrange for the donor to provide blood samples for CT testing, then the donor is declared "unavailable," and the donor center assigns one of four possible codes to describe the reason for donor unavailability. These codes and their definitions are: unable to contact (UC)—meaning that the donor center was not successful in locating the donor; not interested (NI)—meaning that the donor was located but is no longer interested in being considered for hematopoietic stem cell donation; donor deferred (DD)—meaning that the donor was located and potentially interested, but upon medical screening was determined to have a risk factor or medical condition that permanently eliminated the donor from further participation; and temporarily unavailable (TU)—meaning that the donor was contacted, potentially interested, but for some temporary reason was unable to proceed at this time. The last category includes donors who are temporarily medically ineligible, e.g., pregnant, high risk exposure, etc., and those who are otherwise occupied, e.g., changing jobs, moving, etc. When a donor is classified TU, the donor center also supplies a date when it is expected the donor will become available again.

We evaluated donor availability at the CT testing stage during a 1-year period from March 1, 1999 through February 29, 2000. Donor availability by racial and ethnic group was examined as well as availability at individual donor centers.

For the purpose of evaluating consistency of donor center performance, the observation period was divided into period 1 (March 1, 1999 through August 31, 1999) and period 2 (September 1, 1999 through February 29, 2000). To provide an adequate sample size, we included only domestic donor centers that had received at least 80 CT requests during the year in this portion of the analysis.

Statistical Methods

Donor unavailability rates by racial and ethnic group were compared using chi-square analysis. Unavailability rates at donor centers were compared by Spearman rank correlation test.

RESULTS

Donor Registry and Search Activity

As of March 31, 2000, the NMDP registry reflected 3,939,064 available donors. In the 12 months preceding, the registry grew by 366,495 donors, or an average of approximately 30,500 per month. This growth reflects the net of new donors recruited minus those who were removed from the active file by virtue of age, health status, etc. Among the available NMDP donors, 2,159,143 (55%) were fully typed for HLA-A, -B, and -DR. The remaining donors are typed only for HLA-A and -B.

The self-identified racial and ethnic breakdown of donors is displayed in Table 1. For each major racial and ethnic minority group, between 83% and 92% of the potential donors have had HLA-DR typing completed, which places these donors into the functionally active pool from which greater than 95% of matches are selected.[2] Forty-seven percent of white donors had had HLA-DR typing completed. Table 2 compares the current (March 31, 2000) distribution of HLA-A, -B, and -DR typed donors by racial and ethnic group with the composition of the Registry in 1996. For each racial and ethnic minority group, the numbers of fully typed potential donors have increased between 2.9- and 3.9-fold over the past 5 years. By comparison, the number of fully typed white donors has increased 2.6-fold.

For the 12 months ending February 29, 2000, the NMDP initiated 4474 formal searches under the management of NMDP Transplant Centers. In this same 12-month period, 24,198 requests for CT were issued. Of the total CT requests, 21,885 (90%) went to 87 domestic donor centers. Overall, 16,341 (68%) NMDP donors provided additional blood samples for CT testing.

TABLE 1
Self-Identified Racial and Ethnic Grouping of NMDP Donors

Racial/ethnic group	Number	Fully typed[a] (n)	Percentage fully typed[a]	Percentage among fully typed donors
Black	310,512	270,700	87.2	12.5
Asian/Pacific Islander	234,527	209,532	89.3	9.7
White	2,188,957	1,023,452	46.8	47.4
Hispanic/Latino	314,491	271,291	86.3	12.6
American Indian/ Alaska Native	52,306	43,772	83.7	2.0
Other	14,589	9993	68.5	0.5
Multiple Race	53,047	49,119	92.6	2.3
Declines	5390	3326	61.7	0.2
Unknown[b]	765,245	277,958	36.3	12.9
Total	3,939,064	2,159,143	54.8	100

NMDP: National Marrow Donor Program; HLA: human leukocyte antigen.

[a] Fully typed are donors with HLA-A, -B, and -DR typing.

[b] Most NMDP donors without race or ethnicity data are registered at international NMDP donor centers where collection of these data is restricted.

TABLE 2
HLA-A, -B, and -DR Typed Donors, by Racial and Ethnic Group April 30, 1996 vs. March 31, 2000

Racial/ethnic group	April 30, 1996 (n)	March 31, 2000 (n)	Increase 1996–2000 (%)
Black	92,015	270,700	194
Asian/Pacific Islander	58,815	209,532	256
White	395,545	1,023,452	158
Hispanic/Latino	68,805	271,291	294
American Indian/Alaska Native	14,656	43,772	198
Other	5683	9993	75
Multiple race	—[a]	49,119	N/A
Declines	1253	3326	165
Unknown[b]	124,713	277,958	123
Total	760,499	2,159,143	184

HLA: human leukocyte antigen; NMDP: National Marrow Donor Program.

[a] Multiple race classification was not recorded at this time.

[b] Most NMDP donors without race or ethnicity data are registered at international NMDP donor centers where collection of these data is restricted.

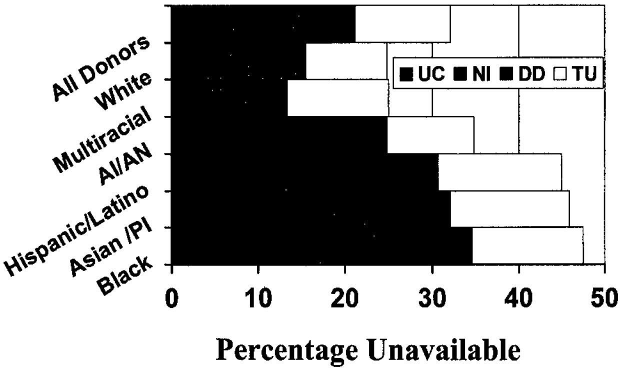

FIGURE 1. Percentage of donors unavailable at the confirmatory typing stage overall and by racial/ethnic group, March 1999 through February 2000. UC: unable to contact; NI: not interested; DD: donor (medically) deferred; TU: temporarily unavailable. AI: American Indian; AN: Alaska Native; PI: Pacific Islander.

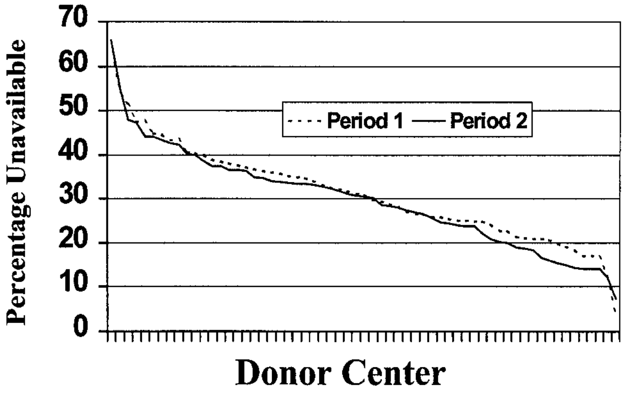

FIGURE 2. Total donor unavailability for 61 domestic donor centers receiving 80 or more CT requests. Period 1: March 1, 1999 through August 31, 1999. Period 2: September 1, 1999 through February 29, 2000. Within each period, centers are ranked along the x axis from highest rate of unavailability to lowest rate. AI: American Indian; AN: Alaska Native; PI: Pacific Islander; UC: unable to contact; NI: not interested; DD: donor (medically) deferred; TU: temporarily unavailable.

The distribution of CT requests among donor centers is highly correlated with the number of HLA-A, -B, and -DR typed donors (data not shown). During the year of observation, the number of CT requests handled by domestic donor centers ranged from 18 to 2487 with a median of 133. Seven international donor centers handled between 19 and 1441 CT requests, with a median of 169.

Donor Availability

Donors at international donor centers were more likely to provide samples than those at domestic donor centers (1929 of 2313 [83%] vs. 14,412 of 21,885 [66%], $P < 0.0001$).

Donor unavailable rates are higher among donors who identify as black, Asian/Pacific Islander, or American Indian/Alaska Native (Fig. 1). UC, NI, and TU rates are all higher among racial and ethnic minority populations ($P < 0.0001$). In contrast, the rates for donor deferral, DD, for medical reasons are similar across racial and ethnic classifications (Fig. 1).

When examined by donor center, the rates of donor unavailability again vary widely. Considering only those 61 centers receiving at least 80 CT requests during the year, total donor unavailable rates varied from 5.2% (n = 96 requests) to 56.3% (n = 80 requests) with a median of 30.1%.

The distribution of donor unavailability among donor centers was very similar in both periods 1 and 2 (Fig. 2). Within the individual donor centers, there was a strong correlation between performance in periods 1 and 2 (Fig. 3A). Most of this appears related to highly correlated rates of UC and TU donors during the two periods (Fig. 3B). Within donor centers, there is only a weak correlation in the rate of NI and DD (medically) donors between periods 1 and 2 (Fig. 3C).

DISCUSSION

The National Marrow Donor Program is the world's largest registry of volunteer unrelated stem cell donors. The HLA-A, -B, and -DR typed pool of NMDP donors, from which most donors are ultimately chosen, has surpassed 2 million. Among these, more than 850,000 (40%) are from racial and ethnic minority populations. The availability of a larger and more diverse pool of donors has increased the likelihood of a match for patients who are searching, particularly those from racial and ethnic minority groups. As the likelihood of matching has increased, however, issues concerning the availability of these preliminarily matched donors have become more concerning. Currently almost 20% of all donors are permanently deferred at the time of CT (Fig. 1). An additional 12% are temporarily unavailable when called upon at CT.

Although some factors affecting donor availability are beyond control, for example, a major change in health status, others may be remediable. Examples of the latter at the time of recruitment include: inadequate medical screening, incomplete education, failure to provide a pressure-free environment, and inadequate collection of demographic, i.e., contact information. At the time of CT request, donor availability may be influenced by the route of contact (e.g., timing of phone calls), the cultural sensitivity used (e.g., language spoken), and the effort expended.

Switzer et al. evaluated psychosocial factors influencing donor retention at the DR typing stage.[3] Do-

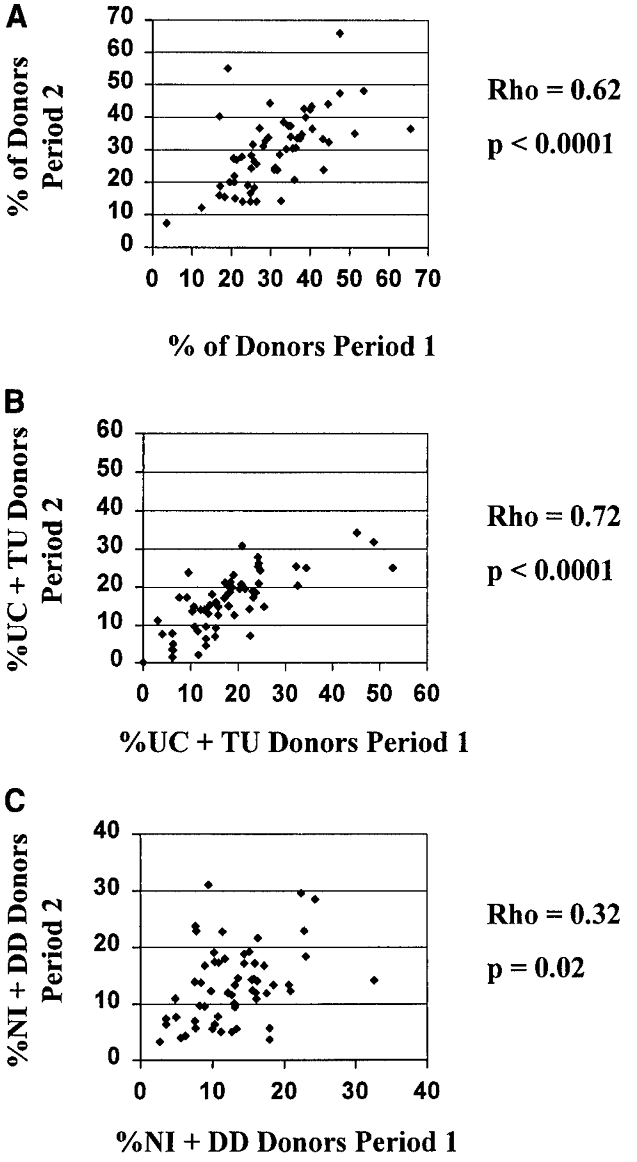

FIGURE 3. Correlation by donor center of donor unavailability rates at 61 domestic donor centers during period 1 (March 1, 1999 through August 31, 1999) and period 2 (September 1, 1999 through February 29, 2000). Rho: Spearman rank correlation coefficient. (A) Total unavailable rates (the sum of unable to contact, not interested, donor (medically) deferred, and temporarily unavailable). (B) Unavailable rates for the combined total of unable to contact and temporarily unavailable. (C) Unavailable rates for the combined total of not interested and donor deferred.

nors who had difficulty deciding to join the registry, those who were discouraged from joining by others, and those with longer residence on the registry dropped out at higher rates. Furthermore, those who indicated that their ethnicity was an important factor in the decision to join also were less likely to be available at a later date. Donor's personal concerns also played an important role in the commitment to donation. Donors who were concerned about the adverse health effects of donation and those who were concerned about missing work were more than twice as likely to drop out than were donors without these concerns.[3]

The NMDP has initiated donor retention projects based on this study and others intended to evaluate new approaches to improving donor availability. Included in these are projects to evaluate recruitment settings, scheduled donor contacts after recruitment, donor mailings, and collaborative projects between donor centers, recruitment groups, and community organizations.

The large and consistent differences in donor unavailability rates between donor centers (Fig. 2) suggest that improved and standardized process controls also may result in more donors being available at the time of CT. Each donor center's performance tended to be consistent during the two halves of the year-long observation period (Fig. 3). It appears that rates of UC and TU are highly center specific, perhaps reflecting differences in the routine practices in place at the various centers. In contrast, the availability codes that are more reflective of donor issues (NI and DD [medically]) are less correlated with the individual centers. The NMDP is undertaking to better understand the variations in center-to-center performance. The ultimate goal of these efforts is the development of best practice models for donor centers.

Over the past 13 years, the potential of successful unrelated donor hematopoietic stem cell transplantation has become a reality. Success, however, has served to emphasize that many persons who might benefit from transplantation are still unable to locate donors. In addition to efforts aimed at maximizing diversity in the donor file, it is necessary to evaluate and understand factors that influence donor availability. This study suggests that procedures used at individual donor centers may dramatically impact donor availability. Future initiatives should undertake to identify best practice models for donor recruitment, retention, and subsequent contacts, which can be implemented throughout the network of donor centers.

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7th Biennial Symposium on Minorities, the Medically Underserved and Cancer

Supplement to ***Cancer***

African-American and White Head and Neck Carcinoma Patients in a University Medical Center Setting

Are Treatments Provided and Are Outcomes Similar or Disparate?

Joan M. Murdock, Ph.D.
Jack L. Gluckman, M.D.

University of Cincinnati Medical Center, Cincinnati, Ohio.

Presented at the 7th Biennial Symposium on Minorities, the Medically Underserved and Cancer, Washington, DC, February 9–13, 2000.

The authors acknowledge Shanna Armstrong, R.N., Director of the Cancer Registry at the University of Cincinnati Medical Center, Barrett Center, who provided assistance in obtaining Cancer Registry data and patient follow-up information. The authors also acknowledge Linda Levin, Ph.D., of the University of Cincinnati Medical Center, Center of Biostatistical Services, who assisted with the interpretation and analysis of data.

Address for reprints. Joan M. Murdock, 7 Hetherington Court, Cincinnati, OH 45246; Fax: (513) 321-3341; E-mail: joancinti@fuse.net

Received April 1, 2000; accepted August 31, 2000.

Racial and ethnic disparities occur in many areas of the health care management system in the United States. These disparities include disease incidence, access to health and medical services, treatments provided, and disease outcomes. Health care delivery organizations have limited resources. Encounters between patients and providers in health care delivery organizations typically are cross-cultural. Access to care, quality of care, and equity may be affected by limited resources and cross-cultural encounters. This impacts the diagnosis, treatments provided, and outcomes, with African-American patients faring poorly compared with white patients. African Americans are 15% more likely to develop cancer than whites and are about 34% more likely to die of cancer than whites in the United States. The purpose of this study was to determine and compare the characteristics of African-American patients and white patients with carcinoma of the head and neck at the University of Cincinnati Medical Center, an equal-access facility, reporting similarities and disparities in disease stage at the time of diagnosis, treatment received, and patient outcomes. ***Cancer*** **2001;91:279–83.** *© 2001 American Cancer Society.*

KEYWORDS: head and neck carcinoma, racial differences, equal-access facility, mortality by race, sociologic factors affecting outcomes, cancer demographics.

The hospital records and tumor registry abstracts of 54 African-American patients and 52 white patients who were diagnosed and treated for carcinoma of the head and neck at the University of Cincinnati Medical Center between 1991 and 1996 were selected randomly from a larger sample and reviewed retrospectively. Forty-four of the African-American patients were men, and 33 of the white patients were men. The mean age at diagnosis was 59.8 years for African Americans (range, 44–81 years) and 59.3 years for whites (range, 39–87). Criteria for inclusion in this study required an original occurrence, a pathologic diagnosis of squamous cell carcinoma, diagnosis and treatment between 1991 and 1996, an approximately equal number of African-American and white patients, and the availability of American Joint Committee on Cancer/International Union Against Cancer classification and stage grouping of malignant tumors.[1] Follow-up records for these patients were reviewed through December 31, 1999. Nine patients were lost to follow-up.

In addition to medical, surgical, and pathologic information, nonmedical data were collected, including insurance, marital status, education, occupation, tobacco and alcohol use, and other factors.

Some of this information was not available in the records that were reviewed. Death certificate information was obtained for cause of death. Patient survival was calculated from the time of pathologic diagnosis to either death or the most recent contact.

MATERIALS AND METHODS

Cancer and Demographics

In 1999, the Institute of Medicine Committee on Cancer Research Among Minorities and the Medically Underserved published a report entitled *The Unequal Burden of Cancer: An Assessment of National Institutes of Health Research and Programs for Ethnic Minorities and the Medically Underserved.*[2] Noting that "the burden of cancer in specific populations is a critical tool in the establishment of research priorities," the report described the cancer burden experienced by many ethnic minorities in the United States. African-American men and women have the highest reported mortality rates from all cancers (except for female lung carcinoma) of all racial/ethnic populations in the United States. African-American men have the highest rates of prostate carcinoma in the world. Lung carcinoma incidence and mortality rates for African-American men are 53.5% and 45% higher, respectively, than the incidence rates for white American men. Although the incident rates for carcinoma of the colon and rectum in African Americans declined between 1990 and 1995, they are still higher than in any other racial and ethnic group. The death rates for colon and rectal carcinoma among African Americans are about 30% higher than those in other racial and ethnic groups.[3] For oral cavity and pharyngeal disease sites, the mortality rate for African Americans has been almost twice the mortality of whites (5.4 vs. 2.9) The highest cancer mortality rate was for African-American men (9.5).[4]

Tobacco Usage

There is a correlation between tobacco and alcohol use and head and neck carcinoma. Tobacco is the most preventable cause of premature death in the United States and is responsible for about 30% of all cancer deaths. Recent national data suggest that the prevalence of smoking among African-American youth has increased. From 1991 to 1997, cigarette smoking among African-American male students doubled from 14.1% to 28.2%.[5] In this study population, 100% of African American patients and 88% of white patients reported significant smoking history, and more than 80% of all patients reported alcohol use.

TABLE 1
Descriptive Statistics of 54 African-American Patients and 52 White Patients with Head and Neck Carcinoma who were Diagnosed and Treated Between 1991 and 1996

	No. (%) of patients	
Stage	African-American	White
Laryngeal carcinoma		
I	4 (15)	3 (18)
II	4 (15)	4 (23)
III	12 (44)	8 (23)
IV	7 (26)	2 (12)
Total	27 (100)	17 (100)
Pharyngeal carcinoma[a]		
I	0 (0)	4 (18)
II	3 (18)	4 (18)
III	4 (23)	9 (41)
IV	10 (59)	5 (23)
Total	17 (100)	22 (100)
Carcinoma of the oral cavity		
I	3 (30)	2 (15)
II	2 (20)	4 (31)
III	2 (20)	4 (31)
IV	3 (30)	3 (23)
Total	10 (100)	13 (100)

[a] Includes 6 patients with sinus carcinoma.

Disease Site

Each patient was assigned to one of nine head and neck carcinoma sites. There were no patients with nasopharyneal or subglottic tumors in this study group. The most common sites for African Americans were supraglottic, glottic, oropharynx, and oral cavity. For whites, the four most common sites were oropharynx, oral cavity, supraglottic, and glottic. For the purposes of analysis, the original nine sites were condensed into larynx, pharynx, sinus, and oral cavity (Tables 1 and 2).

Treatment

The management of patients with carcinoma of the head and neck is complex and may involve single-modality treatment for approximately 40% of patients who present with Stage I or II disease. Combined-modality therapy is recommended for patients with locally advanced disease.[6] In this study group, surgery was considered minimum treatment. Ninety-eight percent of all patients in the group underwent surgery. Of the African-American patients who underwent surgery, 26% underwent surgery alone, 68% underwent surgery and received radiation therapy, 4% underwent surgery and received both radiation therapy and chemotherapy, and 2% underwent surgery and received chemotherapy. Of the white patients who underwent

TABLE 2
TNM Classification by Race

	Lymph node status				
Tumor status	N0	N1	N2	N3	Total
African-American patients					
1	7	0	1	0	8
2	9	2	2	1	14
3	12	6	2	0	20
4	6	0	4	2	12
White patients					
1	9	0	2	0	11
2	13	4	0	1	18
3	15	1	4	0	20
4	2	1	0	0	3

[a] None of the patients in this study had distant metastases at the time of presentation.

TABLE 3
Number and Percent of Patients Receiving Each Type of Treatment by Race

	No. (%) of patients		
Treatment	African-Americans	Whites	Total
Surgery	14 (36)	25 (64)	39 (100)
Surgery and radiation	36 (62)	22 (38)	58 (100)
Surgery, radiation, and chemotherapy	2 (33)	4 (67)	6 (100)
Radiation	1 (100)	0	1 (100)
Surgery and chemotherapy	1 (100)	0	1 (100)
Radiation and chemotherapy	0	1	1 (100)

TABLE 4
Number and Percent of Deaths Through December 31, 1999, by Cause

	No. (%) of deaths		
Cause	African-Americans	Whites	Total
Total deaths	33 (65)	18 (35)	51
Disease specific causes	18 (75)	6 (25)	24
All causes	15 (56)	12 (44)	27

surgery, 49% underwent surgery alone, 43% underwent surgery and received radiation therapy, and 8% underwent surgery and received both radiation therapy and chemotherapy.

Disease Stage

For patients with head and neck tumors, disease stage at the time of diagnosis is the single factor that is most predictive of survival.[6] In this study group, for patients with Stage I–III disease, African-American patients and white patients were similar, with eight more cases reported for whites in these stages. African-American patients presented with Stage IV disease twice as often as white patients (20 patients vs. 10 patients, respectively). Laryngeal tumors represented 43% of all cases, pharyngeal tumors represented 36%, and oral cavity tumors represented 21%. Six sinus carcinoma patients were included in the pharyngeal carcinoma category.

RESULTS

The goal of this study was to determine whether all patients received comparable treatment regardless of their cultural background. We found that 98% of all patients received at least surgical treatment. Of the African-American patients who underwent surgery, 26% underwent surgery alone, 68% underwent surgery and radiation therapy, 4% underwent surgery and received both radiation therapy and chemotherapy, and 2% underwent surgery and received chemotherapy. Of the white patients who underwent surgery, 49% underwent surgery alone, 43% underwent surgery and received radiation therapy, and 8% underwent surgery and received both radiation therapy and chemotherapy (Table 3). Twice as many African-American patients presented with Stage IV disease. The average death rate over time was about twice as great for African-American patients. There were 51 deaths in this study group through the follow-up date, December 31, 1999: 33 African-American patients and 18 white patients. Deaths among African Americans occurred most often (75%) from disease specific causes. Among white patients, death from disease specific causes occurred 25% of the time (Table 4).

Using logistic regression, the odds ratio (OR) at 95% confidence intervals was calculated relating death to race, with adjustment for age at diagnosis, treatment site, and disease stage. The results revealed a significantly greater risk of death among African-American patients compared with white patients ($P < 0.05$), as shown in Table 5. The OR of 2.8 indicates that African-American patients have an almost threefold greater risk of death at the end of the follow-up period compared with white patients. Using the Cox proportional hazards regression model (Table 6) reveals the conditional risk ratios at 95% confidence intervals and relates the number of years to death (or outcome) to race with adjustment for age at diagnosis, treatment, tumor site, and disease stage. This analysis revealed a significantly greater rate of death for African-American patients compared with white patients ($P < 0.01$). In addition, a risk ratio of 1.5 indicates that later stage disease increases the death rate by 50% after adjustment for age at the time of diagnosis, type of treatment, tumor site, and disease stage at diagno-

TABLE 5
Odds Ratios and 95% Confidence Intervals Relating Death at the End of Follow-Up to Race with Adjustment for Age, Treatment, Tumor Site, and Disease Stage

Variable	Odds ratio	95% CI
Race (African American vs. white)	2.8[a]	1.2–6.7
Age at diagnosis (5 yrs)	1.1	0.9–1.3
Surgery vs. other treatment[b]	0.8	0.2–3.4
Surgery and radiation vs. other treatment[b]	0.8	0.2–3.3
Larynx vs. other site[c]	0.8	0.2–2.3
Pharynx vs. other site[c]	0.9	0.3–2.8
Stage (I–IV)	1.5	1.0–2.3

95% CI: 95% confidence interval.

[a] Significantly greater risk of death among African Americans compared with whites ($P < 0.05$). An odds ratio of 2.8 indicates that African Americans had an almost three-fold greater risk of death at the end of follow-up compared with whites after adjustment for age at diagnosis, type of surgery, tumor site, and disease stage at diagnosis.

[b] Other treatment means combined categories: radiation, or surgery plus radiation and chemotherapy, or surgery plus chemotherapy, or radiation plus chemotherapy.

[c] Other site means sites other than the larynx and pharynx.

TABLE 6
Conditional Risk Ratios and 95% Confidence Intervals for the Model Relating Number of Years to Death (or Censoring) to Race with Adjustment for Age, Treatment, Tumor Site, and Disease Stage

Variable	Risk ratio	95% CI
Race (African American vs. white)	2.2[a]	1.1–4.2
Age at diagnosis (1 yr)	1.0	0.9–1.0
Surgery vs. other treatment[b]	0.9	0.3–2.7
Surgery and radiation vs. other treatment[b]	0.6	0.2–1.8
Larynx vs. other site[c]	0.7	0.4–1.5
Pharynx vs. other site[c]	1.0	0.5–2.1
Stage (I–IV)	1.5[d]	1.5–2.0

95% CI: 95% confidence interval.

[a] Significantly greater rate of death during the study of African Americans compared with whites ($P < 0.01$). A risk ratio of 2.2 indicates that African Americans had an approximately two-fold greater rate of death compared with whites after adjustment for age at diagnosis, type of treatment, tumor site, and disease stage at diagnosis.

[b] Other treatment means combined categories: radiation, or surgery plus radiation and chemotherapy, or surgery plus chemotherapy, or radiation plus chemotherapy.

[c] Other site means sites other than the larynx and pharynx.

[d] A risk ratio of 1.5 indicates that later stage disease increases the death rate by 50% after adjustment for age at diagnosis, type of treatment, tumor site, and disease stage at diagnosis ($P = 0.02$).

sis ($P = 0.02$). A risk ratio of 2.2 indicates that African-American patients have an approximately two-fold greater rate of death compared with white patients in this study group. The mean survival from the time of diagnosis to death was 2.1 years for both African-American patients and white patients.

DISCUSSION

The hypothesis that, in an equal-access facility, patients with head and neck carcinoma receive equal minimum treatment was verified in this study. Ninety-eight percent of the patients received the single modality, surgery. In the combined-modality group, 60% were African-American patients, and 40% were white patients. African-American patients presented with Stage IV disease twice as often and died twice as often as white patients. The unequal burden of cancer among African Americans in this study population in relation to more advanced disease and poorer outcome has been demonstrated. What, then, may be possible sociologic factors that affect later disease stage at the time of presentation and poorer outcomes for African Americans? These may include the following: 1) Is there access to health care services? Even if services are available, is there a range of services available, are hours feasible, and is transportation available? 2) Does the patient have a primary care physician? 3) What (if any) type of insurance does the patient have? 4) Is there an awareness level regarding risk factors for head and neck cancer? 5) If there is a primary care physician, will that individual refer to secondary and tertiary resources? 6) Does cancer fatalism or fear in knowing the truth result in delay in seeking care? 7) Is there variability in how disease progresses between racial groups?

These factors need additional study and analysis and may lead to increased funding for research, health education programs, community awareness campaigns, service availability in neighborhoods, and factors that allow all citizens to utilize health care services easily. Hopefully, this study has provided information and knowledge that will lead to changes in health care policy and funding that can reduce the unequal burden of cancer among minorities and the medically underserved.

CONCLUSIONS

At the University of Cincinnati Medical Center, an equal-access medical facility, 98% of all patients in this study group underwent surgery. Sixty-one percent (65 patients) received combined-modality therapy. Of that group, 60% were African-American patients, and 40% were white patients. The higher mortality outcomes and later disease stage at the time of presentation for African Americans may be the result of sociologic factors, such as access to health care, insurance, awareness of risk factors, and variability in disease progression. Insurance information for this study group will be analyzed and reported later. Other sociologic factors warrant further study and analysis.

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