AGENDA FOR RESEARCH ON WOMEN'S HEALTH FOR THE 21ST CENTURY

A Report of the Task Force on the
NIH Women's Health Research Agenda
for the 21st Century

DIFFERENCES AMONG POPULATIONS OF WOMEN

Scientific Meeting and Public Hearing
Santa Fe, New Mexico
July 1997

6 VOLUME

NATIONAL INSTITUTES
OF HEALTH
Office of the Director

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Hosted by:
University of New Mexico School of Medicine
University of Iowa College of Pharmacy

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PREFACE

In September 1991, the Office of Research on Women's Health (ORWH) of the National Institutes of Health (NIH) convened a meeting in Hunt Valley, Maryland, to assess the state of the science and to develop an agenda to guide women's health research in the coming decade. The report generated by that meeting, *Report of the National Institutes of Health: Opportunities for Research on Women's Health*, set forth the research recommendations developed by working groups focused on the major divisions of a woman's life span and on scientific issues, diseases, and conditions that affect women's health. That report has served as the broad blueprint for women's health research at the National Institutes of Health.

Now, several years later, science has continued to expand the parameters of knowledge, generating additional questions and pursuits. New public health issues and challenges emerging in the field of women's health have demonstrated a need to re-examine and update the national agenda for women's health research. To advance this concept, ORWH began a process to identify continuing or emerging gaps in knowledge and to provide research-based strategies that will result in improved health status for all women. This process included holding a series of public hearings and scientific workshops sponsored by ORWH.

The first regional conference was hosted by the University of Pennsylvania School of Medicine and Allegheny University of the Health Sciences in Philadelphia in September 1996. It focused on sex and gender issues and their impact on research in women's health; gaps in knowledge about women's heath; and successful models for the recruitment, retention, re-entry, and advancement of women in biomedical careers. The second regional meeting — hosted by Tulane University Medical Center, Xavier University of Louisiana, and Meharry Medical College — was held in New Orleans in June 1997. The New Orleans meeting focused on sex and gender perspectives for women's health research. The third in the series was held in Santa Fe, New Mexico in July 1997, and was hosted by the University of New Mexico School of Medicine and the University of Iowa College of Pharmacy. The Santa Fe meeting focused on differences among populations of women, factors that contribute to differences in their health status and health outcomes, and career issues for special populations of women. The final, national meeting, convened in Bethesda, Maryland in November 1997, and subtitled “Putting It All Together: The Agenda for Research on Women's Health for the 21st Century,” reviewed the deliberations and recommendations from the three regional public hearings and scientific workshops and developed the recommendations and priorities for updating the women's health research agenda. All the meetings included an opportunity for public testimony as well as formal scientific sessions. Practitioners interested in women's health; representatives from scientific, professional, and women's health organizations; and women's health advocates have participated in the process and continue to provide guidance and expertise to ORWH.

The information presented in this volume represents the outcome of the Santa Fe regional meeting — the scientific workshops, the plenary presentations, and the public testimony by individuals representing themselves or organizations with an interest in biomedical and behavioral research on women's health, within the mandate of the National Institutes of Health. Additional volumes in this series consist of scientific workshop reports, presentations by distinguished scientists, and public testimony presented at the regional meetings in Philadelphia, Pennsylvania, and New Orleans, Louisiana, and at the national meeting in Bethesda, Maryland.

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ACKNOWLEDGMENTS

The Office of Research on Women's Health wishes to acknowledge the contributions of many individuals in planning this regional public hearing and scientific workshop held in Santa Fe, and for their assistance in bringing this meeting to fruition.

This regional workshop would not have been possible without the leadership and efforts of our regional hosts, the University of New Mexico School of Medicine and the University of Iowa College of Pharmacy. We are grateful to them for their efforts on our behalf to facilitate the participation of so many of you in this process.

Our regional cochairs are Dr. Gloria Sarto, Professor of Obstetrics and Gynecology at the University of New Mexico, and immediate past chair of that department. She was a charter member of the Advisory Committee on Research on Women's Health at NIH. In addition to her wide range of expertise, she is also currently the President of the Society for the Advancement of Women's Health Research.

Dr. Mary Berg is the first woman to attain the position of full Professor at the University of Iowa College of Pharmacy, and also a charter member of the NIH Advisory Committee on Women's Health Research. She has served as cochair of the program and prepared the proceedings for the "International Leadership Symposium: The Role of Women in Pharmacy," and currently serves as Secretary-General of the Group Leadership International: Women for Pharmacy.

Sarah Kovner, Special Assistant to Donna Shalala, the Secretary of the Department of Health and Human Services (DHHS), is a welcome guest. Under Dr. Shalala's leadership and her own special interest in and support of women's health in the department, we, along with all of the agencies, have enjoyed her exceptional leadership and voice in our issues.

Our office at NIH enjoys a very warm and special collegial relationship with other Offices of Women's Health across DHHS, and we are honored to have with us the heads of some of these offices: Dr. Wanda Jones and Audrey Sheppard.

This workshop was planned with the assistance of a great number of other individuals, only a few of whom I am able to acknowledge at this time.

Of our ORWH office staff, let me first acknowledge Ms. Joyce Rudick, who is the Acting Deputy Director of our office, and who has tirelessly devoted her leadership to the development and implementation of these meetings to revise our research agenda. She has provided the day to day, and often minute to moment, energy and leadership to make our regional meetings a reality, and to her we owe a special appreciation. Other members of the ORWH staff who are present are available to assist in any way possible to make this meeting a beneficial and pleasant experience for you.

I would also like to acknowledge Dr. Loretta Finnegan, Director of the Women's Health Initiative, one of the largest prevention studies ever conducted, which is examining the role of hormone replacement therapy, dietary modification, vitamin D and calcium supplementation, and behavioral modification in the prevention of the major causes of death and frailty in postmenopausal women (i.e., cardiovascular disease, cancer, and osteoporotic fractures). We are delighted that Dr. Finnegan will soon be dividing her time between WHI and ORWH, where we shall welcome her many areas of clinical and scientific expertise.

We also wish to thank the following individuals for their assistance in planning and implementing this meeting.

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ELDERLY AND FRAIL ELDERLY YEARS

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CAREER ISSUES FOR SPECIAL POPULATIONS OF WOMEN SCIENTISTS

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INTRODUCTION

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This was the third in a series of workshops and scientific meetings sponsored by the Office of Research on Women's Health (ORWH) of the National Institutes of Health (NIH) to develop the Women's Health Research Agenda for the 21st Century.

The public testimony and the recommendations developed by the working groups assisted us in assessing our existing priorities and scientific directives for a science-driven agenda for women's health research.

Our efforts to revisit our research agenda were led by our Task Force on the NIH Women's Health Research Agenda for the 21st Century and the Advisory Committee for Research on Women's Health. We were fortunate to have members of the NIH scientific community, as well as women's health advocates, scientists, and health professionals from across the country serving as members of these important bodies.

OVERVIEW: THE OFFICE OF RESEARCH ON WOMEN'S HEALTH

The major charge during this workshop was to help determine future directions for the women's health scientific research agenda, with a special emphasis on factors that result in differences between the health status and health outcomes of different populations of women. There is no question that research is central to providing the scientific foundation for change, and that new knowledge resulting from research can provide the basis for the improved health of girls and women. If research on and about women is to change with the times and respond to continuing and emerging gaps in knowledge, we must involve all segments of the scientific and health care communities, federal agencies, women's health advocacy groups, and, most importantly, women themselves, and their families and communities. History has demonstrated that the efforts of these groups, in harmony and with concerted effort, have brought about significant change.

We owe much of these changes to many individuals, groups and organizations dedicated to improving the health of women, which have been in existence for some time, such as the Boston Women's Health Book Collective, the National Women's Health Network, the National Black Women's Health Network, The Society for the Advancement of Women's Health Research, and many others, including those who provided testimony during our public hearing. They have been working in the "trenches," so to speak, to call attention to the need to focus our attention on women's health.

But, it is only recently that the efforts of the Federal Government have recognized women's health as a real issue requiring a real remedy, and because of the efforts of advocates and scientists of the past and future, we are beginning to make progress.

As we meet to talk about future directions for women's health research at NIH, as a government agency, and in particular the research agenda for the Office of Research on Women's Health, let us reflect for a moment on what has brought us to this point.

THE PHS TASK FORCE AND THE ESTABLISHMENT OF ORWH

In 1983, the Assistant Secretary for Health, Dr. Edward N. Brandt, established the Public Health Service (PHS) Task Force on Women's Health Issues to examine the role of the Department of Health and Human Services in addressing women's health. This Task Force made a number of recommendations on a broad array of women's health issues across the entire life span of women in a report published in 1985. Among the most pertinent recommendations of the Task Force report was one that stated:

> *Biomedical and behavioral research should be expanded to ensure emphasis on conditions and diseases unique to, or more prevalent in, women in all age groups.*

NIH has responded to this recommendation, and today's workshop is but one example of this commitment.

History of Inclusion Policies at the National Institutes of Health

The establishment and implementation of policies for the inclusion of women and minorities in clinical research funded by NIH has its origins in the women's health movement. Following the issuance of the report of the PHS Task Force on Women's Health in 1985, NIH established a policy for the inclusion of women in clinical research. This policy, which *urged* the inclusion of women, was first published in the *NIH Guide to Grants and Contracts* in 1987. In a later 1987 version of the NIH Guide, a policy *encouraging* the inclusion of minorities in clinical studies was first published.

Now comes the real action that initiated the surge of activities that have brought us to our meeting agenda today! The Congressional Caucus for Women's Issues requested the General Accounting Office (GAO) investigation of the implementation by NIH of the guidelines for the inclusion of women in 1990. The GAO report stated that implementation of the policy for the inclusion of women was lacking, that implementation was slow and not well communicated, that gender analysis was not implemented, and that one could not determine the impact of policy.[2]

In September 1990, just 3 months after the release of the GAO report, subsequent media coverage and public reaction catalyzed the establishment of the Office of Research on Women's Health (ORWH) at the National Institutes of Health (NIH). The Office was established to serve as the focal point for women's health research at NIH, in a collaborative partnership with the institutes and centers. ORWH was given a threefold mandate:

- First, to strengthen, develop, and increase research into diseases, disorders, and conditions that affect women, determining gaps in knowledge about such conditions and diseases, and then establish a research agenda for NIH for future directions in women's health research.
- Second, to ensure that women are appropriately represented in biomedical and biobehavioral research studies, especially clinical trials, that are supported by NIH; and
- Third, to create direct initiatives to increase the number of women in biomedical careers and to facilitate their advancement and promotion.

In 1993, ORWH was legislatively mandated in the NIH Revitalization Act. It was this congressional language that also mandated that we establish a Coordinating Committee on Research on Women's Health, to be composed of the Directors of the NIH Institutes and Centers, and an Advisory Committee on Research on Women's Health, to be composed of non-federal employees who are experts on women's health.

Over the past 6 1/2 years, our responsibilities and major program efforts have increased, and although there is still much to be accomplished, we have made some progress.

The NIH Mandate for the Inclusion of Women and Minorities in Clinical Research

ORWH has assumed leadership in implementing policies requiring the inclusion of women and minorities in human subject research. Wanting to assure that the policies for inclusion were firmly implemented by NIH, the Congress made what had previously been policy into Public Law, through a section in the NIH Revitalization Act of 1993, entitled, “Women and Minorities as Subjects in Clinical Research.”

The NIH Revitalization Act of 1993 essentially put forth the existing NIH policies but with four major differences:

- that NIH ensure that women and minorities and their subpopulations be included in all human subject research;
- that women and minorities and their subpopulations be included in Phase III clinical trials in numbers adequate to allow for valid analyses of differences in intervention effect;
- that cost is not allowed as an acceptable reason for excluding these groups; and,
- that NIH initiate programs and support for outreach efforts to recruit and retain women and minorities and their subpopulations as volunteers in clinical studies.

The guidelines for inclusion developed in response to this law were published in the *Federal Register* in March 1994,[3] and have been fully implemented. We have established a tracking system to monitor inclusion. For the first time, we are able to determine the numbers of women and minorities in clinical trials, and, as we now begin to analyze data from studies active in FY 1995, establish trends in inclusion and determine better ways to examine this data.

We have found a high compliance with the inclusion policy. Analysis of FY 1994 NIH enrollment data shows that substantial numbers of both women and minorities have been included as research subjects.

The goal of NIH policy is not to satisfy any quotas for proportional representation, but rather to conduct biomedical and behavioral research in such a manner that the scientific knowledge acquired will be generalizable to the entire population.

We also funded the Institute of Medicine study of *Women in Health Research,* which is an excellent report on the legal and ethical issues related to women, especially women of childbearing age, in human subject research. However, as we have moved from being cognizant of regulations put in place to protect women and minorities and other populations from being exploited in research, and to respond to the tragedies witnessed in the Tuskegee syphilis study, the effects of those exposed to DES and to thalidomide in utero, we still must grapple with the very important issues of women of childbearing age in clinical research and the issues of protection of women and their potential offspring as the risks versus benefits of participation in clinical studies are weighed.

We firmly believe that the implementation of the NIH policy for the inclusion of women and minorities in human subject research requires the increased participation of women and minority physicians and scientists in the design, implementation, and interpretation of such studies.

WOMEN IN BIOMEDICAL CAREERS

With expanding horizons in biotechnology and science, there is a need for more women to participate in investigations that will open new frontiers of knowledge about health, disease, and scientific technology. While exact figures are not available for those who are participating in research careers, it is recognized that there is a need to increase not only the numbers of women who are biomedical and behavioral investigators, but also the numbers of women who are in policymaking positions who can influence or determine the direction of research initiatives and well as those who participate in the conduct of that research.

To determine best directions to increase opportunities for women in biomedical research careers, we held a public hearing and workshop on the recruitment, retention, advancement and re-entry of women in biomedical careers to determine barriers to women's success and how to overcome these barriers. A number of barriers were identified in the report from our Task Force on Women in Biomedical Careers, for which the cochairs were Drs. Carola Eisenberg and Shirley Malcolm.

From nearly 70 testimonies, nine general issues that serve as barriers emerged that are common to women biomedical professionals regardless of racial, ethnic, cultural, or specialty backgrounds. These are:

1. Recruiting women to biomedical sciences,
2. Visibility, role models, and mentors,
3. Career paths and rewards,
4. Re-entry into a biomedical career,
5. Family responsibilities,
6. Sexual discrimination and sexual harassment,
7. Research initiatives on women's health,
8. Sensitizing men about special career concerns of women, and
9. Minorities and racial discrimination.

From this report we have established a number of programs, including our re-entry program to address the loss of women whose dual roles as care givers had led to an interruption of their research careers. We have also put into place a number of other initiatives to develop the careers of women and men scientists in research on women's health, including workshops on how to speak and write about science.

ORWH supports ongoing projects and has initiated specific training projects that include opportunities for high school students, college faculty and students, and minority students to obtain research experience or exposure to current scientific concepts through NIH.

ORWH has also developed and supported a number of programs for the advancement of girls and women in science through collaboration with the NIH Office of Science Education. To increase the number of women in biomedical careers, it is necessary to "Target Women" — and girls — at the time when they must make the critical choices to start on the science track. Likewise, support and encouragement must be provided for those young women who have already decided to enter the biomedical professions.

The seven programs are:

1. *Outreach on the World Wide Web:* Outreach portions of the NIH electronic bulletin board have been transferred to the user-friendly World Wide Web.
2. *ORWH/OSE Speakers Bureau:* A program to increase visibility of a diverse group of women scientists in the NIH community has been developed to provide both role models and information about careers in research.
3. *Writing about Science:* Four 3-hour sessions to teach young scientists to write about science effectively were developed. In FY 1996, 48 people successfully completed the course. This course will continue in FY 1997 because of the demand by women and men scientists for this type of instruction.
4. *Talking about Science:* Five 3-hour workshops to teach young scientists how to present scientific data effectively were also implemented. In FY 1996, 61 people successfully completed the course. This course will continue in FY 1997, again because of the widespread interest in this instruction.
5. *"Women in Science" Poster Series:* A set of colorful posters for middle school students that feature contemporary women scientists and their contributions is being developed for distribution to provide role models and incentives for girls to consider scientific careers.

6. *"Young Women's Network" Brown Bag Series:* A program for the young scientists who come to campus for a summer internship was sponsored to provide a forum for discussion of family and career concerns that can affect their professional and personal lives.

7. *Career Development Workshops:* A series of workshops to support the successful career development of young post doctoral intramural researchers was conducted to provide mentoring and counseling.

ORWH and the Office of Science Education are planning ways to make many of these efforts adaptable by and for scientific societies as models for supporting women in research careers.

Under the leadership of Joyce Rudick, Dr. Anne Sassaman, and Dr. Julia Freeman, cochairs of the women's careers committee of our Coordinating Committee, we have evaluated the re-entry program and are now looking for ways to best expand our other initiatives. As an integral part of our regional meetings, we are focusing on recommendations to assist us with future program planning.

During our Philadelphia meeting, a Working Group on Women in Biomedical Careers emphasized that data on women in science are needed to justify new programs for women. Discussions focused on positive ways to advance women's careers through training and leadership opportunities, mentoring, and other mechanisms to increase recruitment, retention, re-entry, and advancement of women in biomedical careers. Priorities recommended for development of innovative programs for women scientists included:

- Define, train, facilitate, and reward mentoring.

- Define what work is; study different ways men and women spend their days.

- Recruit more women; increase women's visibility in the research and academic setting; provide encouragement to younger women.

- Expand NIH's leadership role in supporting women in scientific careers.

- Determine ways to partner with industry, academia, and professional societies.

- Encourage each institution to have, as part of its cultural values, assistance for women and minorities.

- Encourage institutions and professional societies to gather statistics on gender-gap issues such as salary, tenure, and percentages of women at senior levels.

During this meeting, a working group will focus its discussions on scientific careers for diverse populations of women.

The NIH National Research Agenda on Women's Health

While much remains to be done to address the many pressing issues in women's health, it is all too easy to focus only on the gaps in knowledge that remain, forgetting where we started and how far we have traveled. The NIH Office of Research on Women's Health convened this meeting, "Beyond Hunt Valley: Research on Women's Health for the 21st Century," to look ahead, but also to pause for a moment to see how far we have come.

Over the past 6 1/2 years, the national agenda on women's health research has been shaped by certain underlying principles that must continue to inform our directions for the future. The basis for our current agenda began with the Hunt Valley report, *National Institutes of Health: Opportunities for Research on Women's Health.* This agenda was formulated from a public hearing and workshop held in September 1991 in Hunt Valley, Maryland, from which the parameters of women's health have been redefined, and research has been redirected to provide better information on sex and gender differences between women and men in development, health, and disease, and to focus on populations of women that have been underrepresented in clinical research.

Our agenda recognizes the full spectrum of research from basic to clinical research and trials, epidemiologic and population studies, clinical applications, and health outcomes. We have embraced the expanded concepts of women's health and research, that is, to address the health of girls and women across the life span, recognizing that women's health encompasses more than the reproductive system, and that research does involve the entire spectrum and not just human subject research. We have also expanded our boundaries of the life span to take into account the health of women from the prenatal stage to that of the frail elderly — the divisions of the working groups which were utilized in this meeting.

The research agenda includes biomedical, behavioral, and psychosocial research. And, we have made, as an integral part of our research priorities, reaching out to populations of women and girls that have been previously excluded from scientific investigation, such as minorities, women of differing socioeconomic status and geographic locations, lesbians, and women with disabilities. In all of our efforts to implement our research agenda, we are in an active and beneficial partnership with all of the NIH institutes, divisions, and centers. And, we constantly review our research priorities to determine where the major gaps in knowledge exist.

As a part of our effort to address the implementation of women's health research and its implementation in the standards of health care practice, promoting multidisciplinary, comprehensive, and effective women's health care, we collaborated with the Health Resources and Services Administration (HRSA) and the Public Health Service Office of Women's Health to prepare a report of surveys of all osteopathic and allopathic schools of medicine to determine women's health in their curriculum. This report also contains examples of model women's health curricula. We are now working with dental, nursing, and pharmacy school representatives to initiate a similar study of their educational curricula.

It is now more than 6$^1/_2$ years since the Hunt Valley meeting that led to our current working research document. We believe that it is time to look "beyond Hunt Valley" and to update our agenda. We have found the model of broad participation in this process through public hearings and workshops with representative and voluntary participation, and we have thus turned again to this model to help us in the current process. This mechanism provides an opportunity for the continued collaboration between individuals and groups of women, advocates, scientists, health care practitioners and pubic health policy makers with NIH to establish our research agenda as we move forward into the 21st century.

Our research agenda has focused on sex and gender factors in the health and diseases of women, in considering such matters as normal development, disease prevention, health maintenance, response to interventions, disease prognosis, and treatment outcomes. We have also focused on factors that influence differences in health status and health outcomes among different populations of women.

Beginning in September 1996, at our first regional meeting in Philadelphia, we began our process of reexamining our research agenda to ensure that it is relevant as we move towards the next century, thus, the name of this series of meetings is "Beyond Hunt Valley: Research on Women's Health for the 21st Century." At the Philadelphia meeting, we directed attention to some of the major areas of concern for women's health.

We now look at two ways to examine knowledge about women's health: sex and gender factors *and* differences among populations of women. During the New Orleans scientific workshop, we examined aspects of the research agenda based upon sex and gender perspectives (i.e., physiological, psychosocial, and pharmacologic differences between women and men). Plenary presentations addressed whether sex and gender differences were due only to hormones, and the role of the environment and genetic information.

At this, our third and last regional meeting, we focused on factors that contribute to differences in health status and health outcome among different populations of women, including biologic, genetic, race, culture and ethnicity, psychosocial and behavioral factors, educational influences, traditional and alternative practices, environment, poverty and socioeconomic status, access to health care, and occupational.

Finally, on November 17-19, 1997, we brought together the results of all three regional meetings in a workshop in Bethesda, Maryland, to provide an opportunity for our participants to guide our Task Force in developing recommendations for the NIH research agenda for the beginning of the 21st century.

The specific objectives of this 2-day workshop were to:

- Assess differences among populations of women such as those from diverse cultures, minority populations, the elderly, rural or inner city women, those affected by poverty and low socioeconomic status, lesbians, migrant farm women, and women with disabilities;
- Examine the influence of a number of biologic and societal factors on women's health and research;
- Assess the current status of research on women's health, identify gaps in knowledge, and recommend research (and public policy) strategies to address these gaps; and
- Develop strategies for research that can result in improved health status for women, regardless of race, ethnicity, age, or other population characteristics.

We asked the working groups, to develop their reports within the following parameters:

- Identify scientific progress since the establishment of the Office of Research on Women's Health;
- Highlight successes in the advances of scientific knowledge about women's health and gender/sex information;
- Highlight programs that have advanced women's health research;
- Develop strategies for identifying continuing or emerging gaps in knowledge and how to address them;
- Generate recommendations for future research priorities and necessary consideration of the biomedical/behavioral research community;
- Provide pathways for networking and collaboration among researchers; and
- Consider effective implementation of research outcomes in public policy and health care of women, with consideration of changing parameters (e.g., advances in biotechnology, managed care, etc.).

All of the recommendations for our research agenda were based upon science-driven initiatives. The role of participants was a significant and meaningful one. Our updated agenda must reaffirm the commitment to an integration of scientific disciplines and medical specialties with advocacy and forward thinking optimism.

Our aim is to make a difference for women's health in the 21st century through an improved research agenda to yield scientific data to lessen or eliminate continuing or emerging gaps in knowledge about women's health.

Over the past 6 $^1/_2$ years, with the creation of new laws, policies, and programs, we have made tangible progress toward improving women's health, and we have gained a sure sense of our power to effect real change. With your assistance, as we enter into the 21st century, ORWH can build on that power and maximize its fruition to improve the health of women and their families. That is the vision for women's health in the United States and beyond that we are trusting you to help us ensure for the future. No single individual or group can do the job alone. The challenge — and the responsibility — must be shared by all of us.

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WORKING GROUP REPORTS

PRENATAL YEARS

Cochairs

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BACKGROUND

The Office of Research on Women's Health (ORWH), created in 1991, has worked toward the identification and study of health issues as they relate to women at all stages of life. Strategies to meet these overall goals were set forth during the September 1991 conference in Hunt Valley, Maryland. The process of regional meetings serves to gather input from investigators and the public concerning progress made on the agenda of Hunt Valley and, subsequently, to provide a forum for the discussion of issues that may not have been identified at the time of the Hunt Valley meeting. The regional meetings also offer the opportunity to review and re-evaluate the areas of emphasis by ORWH and to set the agenda for future funding of and involvement by NIH in women's health research.

CONCLUSIONS FROM HUNT VALLEY

Hunt Valley identified at least 20 research questions of direct relevance to prenatal care. The following is excerpted from *Report of the National Institutes of Health: Opportunities for Research on Women's Health*, *Executive Summary.*

Fetal Development/Placental Environment and/or Mother's Health

- Differences between female and male fetuses during pregnancy.
- Effects of a mother's health and health practices on the health of the fetus, the newborn, and herself. Examples of health practices include treatment the mother is undergoing for pre-existing disease; depression and stress; ethnic characteristics; breast feeding; and alcohol, drug, and tobacco use.
- How the transfer of vital nutrients (e.g., glucose, amino acids, fatty acids) and growth-promoting hormones through the placenta can be enhanced so that newborns have appropriate birthweights.
- Factors that determine the ethnicity differences in birthweights.
- Strategies to prevent and treat habitual abortion and toxemia.
- Maternal interventions to assure the development of a healthy nervous system.
- What constitutes normal uterine behavior during pregnancy, and what induces labor at full term when the fetus matures.

Pharmacokinetics

- How to improve information about the effects of drugs on the developing fetus, so that pregnant women are not deprived of needed treatment and the fetus is not exposed to harmful substances.

Noninvasive Technology

- Development of more precise and accessible, less expensive, and risk-free methods for screening pregnant women and monitoring the fetus using noninvasive technology.

Genetics

- Whether identifying and cloning genes can lead to prevention of inherited defects such as cystic fibrosis and muscular dystrophy.
- Whether it is possible to discover new therapies for preventing and treating cancer and inherited defects through molecular genetics.
- Whether mothers and fetuses from different racial groups respond differently to environmental factors and to drug therapies in genetically determined ways.
- What occurs when the gene from the mother versus the gene from the father is inactive, and how this contributes to successful childbearing.

Preterm Labor and Delivery

- The extent to which stress, substance abuse, race, and maternal age contribute to preterm labor and premature delivery of an infant.
- The extent to which a woman can prevent premature delivery through diet, vitamins, and psychological support.
- How to prevent preterm birth and birth defects.

Fertility/Infertility

- Ways to improve infertility treatments.
- Whether fertility can be restored by stimulating follicle growth or secretion of progesterone, and whether new contraceptive techniques can be identified.
- Whether frequent pregnancy losses can be prevented by increasing progesterone hormone levels in the early weeks of gestation.

Embryo Implantation

- How to foster a successful normal embryo implantation.

Focus on Special Populations

The Hunt Valley conference established the initial parameters that formed the ORWH Research Agenda on Women's Health. Six distinct categories of subpopulations were identified as a means to attend to the immediate and pressing issues of women's health. The following subpopulations are not mutually exclusive or even exhaustive categories among women, but are essential to the continued refinement and clarification of women's health issues:

1. Race;
2. Ethnicity;
3. Culture;
4. Socioeconomic status;
5. Lesbians; and
6. Disabilities.

This report does not define these categories of women but addresses each of these groups using the terminology "diverse groups," "diverse human groups," and "subpopulations." The research recommendations contain a suggested educational initiative to address the issue of group self identification.

SCIENTIFIC PROGRESS SINCE ESTABLISHMENT OF ORWH

Several initiatives funded by NIH since Hunt Valley have addressed issues during pregnancy, including use of glucocorticoid hormones for the prevention of neonatal lung disease, prevention of preterm labor, role of nutrition in maintaining pregnancy, and motivation for birth planning. In addition, many studies related to the transmission of infections during pregnancy have been supported, divided into studies of the role of infections in preterm labor and delivery, and the role of HIV in pregnancy. Few of these studies included the factor of population differences. When population differences were included, the vast majority addressed only African-American/ Caucasian differences.

USE OF GLUCOCORTICOID HORMONES FOR PREVENTION OF NEONATAL LUNG DISEASE

NIH supported a multicenter trial of dexamethasone for the prevention of chronic lung disease in preterm infants. That trial demonstrated that about 30 percent of the infants had a significant response to dexamethasone whether the glucocorticoid hormone was given at 2 weeks or at 28 days.[1] Results from a large number of clinical trials demonstrated a significant improvement in the outcome of preterm infants treated with glucocorticoid hormones prenatally, including a 50 percent reduction of the risk of death and severe bleeding into the brain of very-low-birthweight infants.

Prophylactic aspirin was studied as a means to prevent preterm delivery, eliciting only marginal benefit but significant risk from the therapy; the researchers recommended that this therapy not be used.[2] The National Institute of Child Health and Human Development (NICHD) also sponsored the Consensus Meeting on the Use of Prenatal Steroids for the prevention of neonatal lung disease. This conference reviewed the current literature and generated a set of recommendations.[3]

Prevention of Preterm Labor and Improvement in Outcome

Studies that have addressed prevention of preterm labor have focused on the infectious disease causes of preterm labor and the behavior that prevents women from interacting with the health care system to prevent the progression of preterm labor to delivery.

Elam-Evans, et al. reported that women who delayed prenatal care during one pregnancy tended to delay it in subsequent pregnancies. A previous pregnancy that resulted in a low-birthweight infant or infant death apparently encouraged women to seek early prenatal care in subsequent pregnancies.[4] The risk to the fetus from alcohol consumption is small in a multiple linear regression.[5] Interventions aimed at improving outcomes of pregnancy overall have demonstrated that focused interventions that provide women with information result in a lowering of preterm labor and improved outcomes.[6] Case management was not demonstrated to improve outcomes overall but did show a greater influence on pregnancies in African-American women compared to Caucasian women.[7]

Differences in outcomes by ethnicity have repeatedly demonstrated that Caucasians have a lower neonatal mortality than African Americans. While many studies substantiated this difference, they have failed to discern the cause. When controlled for socioeconomic status and with similar interventions, there appears to be a continued difference between the two groups.[8] Collins, et al. found that, when studied with logistic regression analysis, there remained an increase in preterm delivery in African-American pregnancies which was not due to an increased risk of an underserved minority status.[9]

Role of Nutrition in Maintaining Pregnancy

Brown, et al. reported that there were nutritional and non-nutritional benefits to participating in the Women, Infants, and Children (WIC) Food Supplement Program. Women who participated in WIC were less likely to deliver a low-birthweight infant than nonparticipants.[10] Folate for the prevention of spina bifida was studied by NICHD scientists.[11]

Motivation for Birth Planning

Lewis, et al. examined trends in the timing of prenatal care and found that women who plan their pregnancies seek prenatal care earlier than those who did not intend to get pregnant.[12] In 1993, NICHD began a comparative study of all marketed barrier contraceptives. Several studies addressed the estrogen component of the oral contraceptives and an initiative was begun on unplanned pregnancy.[13] NICHD has several studies ongoing that suggest that condom use varies by race, ethnicity, age, and marital age. Traditional types of relationships correlate to condom use and to specific HIV-risk behaviors.[14] Teenage women who were raised by single mothers are more likely to refrain from single motherhood themselves if the home structure was stable.

Transmission of Infections During Pregnancy

Role of infections in preterm labor and delivery. The role of infections in causing the onset of preterm labor and delivery has been an active area of research since initial papers suggested that the rise in prostaglandins during preterm labor might reflect infections in the mother or the placenta-fetal diad. Chlamydia trachomatis is a common sexually transmitted bacterial infection in the United States; it is known to be associated with preterm labor, premature rupture of the membranes, and stillbirths. This bacteria has been found to be present in as many as 9 percent of pregnancies in rural areas.[15]

Role of HIV in pregnancy. Many NIH-sponsored studies during the last 5 years have addressed the role of HIV during pregnancy. Results have demonstrated a lower rate of transmission from mother to fetus than was previously reported. In addition, therapies have been found to be effective in preventing the transmission of HIV, thereby significantly improving the pregnancy outcomes of women with HIV. Sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), the cellular immunity to HIV in mothers and infants is being studied by characterizing women's T-cell function, viral load, and exacerbation of disease after delivery.[16] NICHD, the National Heart, Lung, and Blood Institute (NHLBI), and NIAID are evaluating the effectiveness of hyperimmune HIV immunoglobulin in reducing perinatal HIV transmission.[17] Investigators have demonstrated that the therapy is well tolerated and has similar kinetics to IVIG. ACTG 076 has been studied by NICHD, NIAID, and foreign institutes, and has been found to decrease transmission of HIV from mother to fetus by 67 percent.

CHANGE IN QUESTIONS SINCE HUNT VALLEY

The clear evolution of questions regarding women's health generated from Hunt Valley points simultaneously to greater accuracy of representation for individuals from various, previously overlooked subpopulations and greater precision in measuring outcomes.

The primary recommendations for prenatal studies are directives to become more inclusive of diverse groups with respect to the following processes: setting the agenda, generating the questions to be studied, exploring the development of active participation of groups in clinical research, expanding the participation of groups in research through the process of evaluation of results and the dissemination of information, and education of professionals and the general public.

The significant gaps in knowledge about prenatal health have been identified from the perspective of lack of knowledge concerning the physiology of pregnancy — important issues concerning pregnancy have not been addressed in any substantial way by NIH-supported research. The primary gaps center around studies of population differences and inclusion of populations in study development. The role of population differences in successful pregnancy outcomes has not been emphasized in the research to date. Thus, while the studies of the physiology, biochemistry, pharmacology, and genetics of pregnancy must continue to identify the overall strategies for improving women's health, the challenge of improving the health of women must also emphasize the environmental, psychological, and population effects. To this end, we must recognize the complexity of human life and the powerful influence these factors exert on the successful outcome of women's health, while advancing the study of these issues.

Suggestions of the Hunt Valley conference and the further recommendations of the previous regional meetings are in line with appropriate goals for prenatal health research. Areas are identified that would interdigitate with the previously identified strategies and strengthen the applicability of results within diverse groups. Thus, the suggestions below are not a parallel iteration of areas of emphasis but rather the identification of issues to expand topics already identified.

Clinical Study Outcomes

It is unclear which clinical study outcomes are of priority interest to various subpopulations. These priorities must be identified so the scientific community can incorporate them and improve program success. It was anticipated that groups would more readily participate in studies, and thus improving them, if they were included at all levels of the research process.

Continuity in Research

Concern about maintaining continuity of research includes long-term commitment and community involvement, whereby the community carries on a project beyond the intervention. Strategies that have been successful in developing, funding, and evaluating studies; disseminating knowledge about outcomes; and re-identifying and recycling issues into a seamless process need to applied to women's research. Particular emphasis should be placed on the longitudinal perspective.

Research Design

The medical models of problem-based orientation to study design should be analyzed in comparison with other models that may, for example, originate from strengths in populations.

Clinical Trials

Pregnant women must be included in clinical trials. Historically, pregnant women have been excluded from trials because of concerns for the fetus. As a consequence of this choice by investigators, little is known about the effects of drugs and other interventions on the pregnant state. Studies should be designed to include women and to address issues specific to pregnancy.

Education

The emphasis on education of practitioners and the public has defined the at-risk period as the prenatal period. Many studies have suggested the need to begin education and intervention during the months prior to conception — the periconceptional period.

Environmental Effects

Animal models could be designed to study environmental effects periconceptually and in utero. However, knowledge is incomplete in many areas and, therefore, application to humans may be inappropriate. At the same time, some studies of adverse environmental effects are best approached using the animal model.

Technique Overutilization

Concerns were raised over the potential overutilization of Doppler, invasive procedures, and caesarean section in pregnancy. These concerns address not only the overuse of the technology, but also the potential use of these technologies within populations in which their use is not culturally acceptable.

Alternative Medicine

The extent and effects of alternative medicine during pregnancy need to be examined, with and without Western medicine. The identification of which medicine is "alternative" and which is "conventional/traditional" is dependent on the individual's perspective. From the culture of medicine to the cultures of humanity, the emphasis of such studies will depend on the populations setting the agenda.

Motivation for Care

Behavioral methods are needed to determine women's motivation for seeking prenatal health care.

RESEARCH RECOMMENDATIONS

Recommendations reflect a broad range of research issues in addition to educational initiatives and administrative concerns.

Observational Studies

- Study drug use and traditional practices among pregnant women in diverse groups.
- Determine the behavioral basis of motivation for seeking prenatal care.
- Explore and define cultural sensitivity in acquisition of genetic information.
- Encourage greater concern with qualitative studies.
- Examine probable overutilization of technology for pre- and perinatal medicine.

One of the major impediments to addressing the issues of differences among diverse populations is the lack of information concerning issues of importance to the study populations. Rather than being population-centered, studies have been designed as though populations are analyzed under a microscope. To illustrate this point, the vast majority of studies on drug use address illicit drug use rather than traditional medications and practices. The latter issues would be expected to address a larger portion of the total population compared to the number of people using illicit drugs; therefore, the impact on pregnancy outcomes will be greater.

Differences in access to care may be related to individual motivation. Understanding cultural reasons for choosing prenatal care may be important in improving the involvement of diverse populations in prenatal care and in clinical studies of models of prenatal care.

In order to have diverse groups participate in expanding knowledge in the area of genetics, more information is needed concerning the role of individual, family, and community in defining needs and concerns.

Populations should be described by both the general community and through qualitative studies that are developed in concert with the study population(s).

The balance between the positive outcomes and potential risks derived from the use of technology for the individual, family, and community should be defined specifically for each population and should be addressed by including the study population in defining the role of technology.

Clinical Studies

- Build and incorporate community values in diverse groups into outcomes measures.
- Compare susceptibility (needs) with strengths (assets) in individuals and groups with regard to adverse fetal outcomes.

- Conduct long-term studies of environmental exposure in human groups and animal models, both preconceptually and in utero.

- Investigate the pharmacodynamics and pharmacokinetics of drugs in diverse groups.

- Conduct longitudinal studies of multiple approaches to prenatal health.

Preconceptional/Perinatal Health Initiative

In areas in which adequate input from specific populations has been obtained, as outlined above, results of those studies should be incorporated into clinical and animal studies as follows.

Populations should be included in defining the appropriate outcomes for studies on pregnancy. Successful completion of a clinical study will be expected to be dependent on providing relevant endpoints for subjects who are being asked to participate.

Involvement of specific populations may be enhanced by requesting that they identify the strengths and assets that allow successful completion of pregnancy. The usual method of defining the susceptibilities and needs of a population should be compared to a strengths approach.

While strategies for improving the success of clinical studies should be of primary interest for improving the outcome of pregnancy as they relate to population-specific outcomes, animal studies will continue to be a important adjunct. In particular, the toxic effects of environmental contaminants and the use of medications during pregnancy, including traditional practices and medications, should continue to be tested in appropriate animal models.

American's use of medications is vast and changes little during pregnancy. Therefore, natural models exist for the study of the pharmacodynamics and pharmacokinetics, and these studies should be encouraged. The importance of understanding the differences among populations should address studies of the use of traditional medications for which little information exists.

The variety of results from the above studies would be incorporated into longitudinal studies of models of prenatal care. The models would recognize the need to address care from before conception, through pregnancy and followup, and beyond the neonatal period. In addition, the conventional models proposed in the literature for improving outcomes should be compared to population-specific models. These models would be derived from observational and clinical studies of the strengths and assets of populations, the differences in individual choice in obtaining prenatal care, the pattern of drug and medication use and metabolism by populations, and other important issues that may alter the outcome of pregnancies.

The role of the NIH-funded Periconceptional Health Initiative would be to: 1) fund studies that address population-specific outcome measures; 2) serve as a clearinghouse of information generated by these studies; 3) generate the models (and fund multicenter trials) to compare conventional prenatal care recommendations with population-specific models; and 4) distribute the results to professionals and the community through the multiple educational mechanisms available through NIH.

Genetic and Physiological Studies

Explore the genetic differences among diverse groups, with an emphasis on fetal outcomes.

- Coordinate genetic information with environmental differences.

- Investigate placental biology in diverse groups.

Descriptive studies concerning the differences in populations have only addressed markers of potential genetic differences. In particular, emphasis on defining the positive relationships of genetic differences on improving outcomes should be explored.

Defining genetic differences should provide information on population differences without placing the results in the environmental background. More integrated studies are needed to determine when and how genetics and environment influence fetal/pregnancy outcomes.

As studies address the relationship of mother to fetus, emphasis should be placed on defining the role played by the placenta as an environmental factor as well as an active component of the triad that includes mother, fetus, and placenta.

Interdisciplinary Studies

- Support multiproject studies from basic to clinical (e.g., SCOR).
- Encourage mechanisms to integrate basic with biobehavioral approaches.

The importance of the issues raised above would be emphasized by supporting interdisciplinary research in which investigators identify how they will explore a variety of issues at several levels of study (cellular, animal, clinical, community) with active involvement by the study population(s). The importance of the research could be approached by development of SCOR grants.

The use of biobehavioral approaches within studies would add depth to the information that could be generated by identifying factors that determine a “good” outcome.

Educational Initiatives

Educate the practitioner and the public to subpopulation needs by consensus, conference, and national programs.

- Use networking to engage appropriate self-identifying groups.
- Use interdisciplinary education.

One of the more important roles that NIH can assume in this process is to make information available to practitioners and the public about study development, funding, evaluation of results, and communication of conclusions following integration of results. This process should unfold as seamlessly as possible to allow for the rapid application of findings to the improvement of pregnancy outcomes.

As part of NIH’s communication role, the development of tools for networking self-identified groups will enhance the role of those groups in developing, participating in, and evaluating studies.

Rapid dissemination of information will be fostered by the use of interdisciplinary education. This communication tool should be used by NIH for dispersing new information concerning diverse populations and pregnancy outcomes.

Administrative Concerns

- Encourage investigations by recurrent regional training programs.
- Sensitize the Division of Research Grants to applications involving diverse human groups.

In order for investigators to appropriately address the issues outlined in this report, they must be trained on how to approach populations who are different from the culture of a medical center. Development of programs that aim to train investigators on the issues of importance for diverse populations will increase the level of expertise of investigators, while better serving the study populations.

Defining different populations has been and will continue to be an imprecise process. The lack of clarity inherent in these studies should not be used to exclude populations from studies. Rather, the DRG should be encouraged to take the lead in stating the need to study diverse populations while allowing for some ambiguity, due to the fact that this area of research is in its earliest phase.

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INFANCY AND CHILDHOOD YEARS

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BACKGROUND

The infancy and childhood cohort is large and diverse. Problems encountered by this group range from prematurity with multiple congenital anomalies to postpubescent pregnancy. The years between infancy and adolescence encompass, as well, a wide variety of changes in the areas of biology, physiology, psychology, and behavior. Needs in this age group vary widely — from the need for extracorporeal membrane oxygenation in a premature infant to the treatment of a sexually transmitted disease in an adolescent.

Development of an effective, comprehensive research agenda in this group is imperative for many reasons. First, many early behavior patterns and activities of a girl's childhood present lifetime effects on her adult health. Research in the areas of calcium intake, physical activity, and diet, for instance, serve to underscore the lasting impact of early female childhood behaviors and activities. Second, because of the relationship of childhood patterns to lifetime behaviors, interventions during this portion of the life span can be immensely effective. Finally, infants and children should have every opportunity to maximize all of life's possibilities in a healthy, positive fashion by benefiting from all the resources that science has to offer.

SCIENTIFIC PROGRESS SINCE ESTABLISHMENT OF ORWH

Since the Hunt Valley conference in 1991, the understanding of many diseases and conditions of infancy and childhood has advanced greatly. Many of these advances have already resulted in more effective clinical interventions and improved health outcomes.

Technological Advances

Many advances in the care of infants and children in the last 6 1/2 years are the result of new technologies such as molecular and genetic research. Examples of such advances include: the human genome map, PCR technology, linkage and segregation analysis, positional cloning, the use of a ligand receptor biology to develop designer drugs such as leukotriene blockers, and an increased understanding of the immune system to develop immunomodulations.

Additional progress has also been made in the area of noninvasive imaging. For instance, widespread use of functional magnetic resonance imaging (fMRI), magnetic resonance spectroscopy (MRS), positron electron tomography (PET), dual energy x-ray absorptiometry (DEXA), and vaginal ultrasound have afforded clinicians increased diagnostic accuracy in the measurement of structure, function, and metabolism of the human body.

There has been a worldwide explosion of access to information, data, and tools for use in scientific networking and collaboration. The general public has shared in this explosion of information through new forms of electronic communication.

Advances in Knowledge About Infants

One of the most impressive advances in the area of infant mortality is the drastic reduction in deaths from sudden infant death syndrome (SIDS). In a 1-year period (1994-1995), the percentage of deaths attributed to SIDS decreased 15.4 percent (National Center for Health Statistics, 1997). Treatment with intrauterine steroids has resulted in improved outcomes for girls born with congenital adrenal hyperplasia (CAH). Intrauterine steroid therapy and postnatal use of surfactants have greatly improved survival in babies with respiratory distress syndrome (RDS). In the neonatal units, high frequency ventilation and extracorporeal membrane oxygenation have improved outcomes for premature low-birthweight infants and infants born with congenital cardiac anomalies.

Additional developments also have improved the likelihood of fetal outcomes. These developments include the use of intravaginal ultrasound at 14 weeks, chorionic villus sampling, and the understanding of the relationship of bacterial vaginosis and premature delivery. The use of zinc and folate supplements have proven, as well, to be effective in the reduction of low-birthweight, small cranial circumference infants, and neural tube defects, respectively. With the development of the Hemophilus influenza type B vaccine, infant deaths related to influenza and pneumonia are at an all-time low, representing just 1.7 percent of total deaths (National Center for Health Statistics, 1997).

It is also noteworthy that there have been advances in understanding fetal brain development, sensation, and behavior, leading to further advancements in the understanding of life in utero.

Advances in Knowledge About Children

The period of time since the establishment of ORWH has seen great progress in childhood scientific development. Treatments and cure rates have improved in many types of childhood cancers. With the proven efficacy of topically inhaled steroids, control of acute exacerbations of asthma has improved. Moreover, treatment of girls with precocious puberty has now become reliably effective with the utilization of Gonadotropin Releasing Hormone analog (GnRHa). This condition affects ten times as many girls as boys.

The relationship of childhood behaviors and later development of chronic disease has been highlighted by new understandings. Among these are the relationship between calcium deficiency and osteoporosis, obesity as a cause of insulin resistance and coronary artery disease, and the correlation between decreased high-density lipoproteins, increased triglycerides, and increased apobetalipoprotein with increased prevalence of coronary artery disease.

Great strides have been made in the study of the brain and nervous system. These developments include diagnosis of learning disabilities by neuroimaging; greater understanding of children's pain, resulting in better treatment with greater control; and improved understanding of psychopharmacology.

GAPS IN KNOWLEDGE

While there have been great technologic and scientific advances made since Hunt Valley, significant gaps in knowledge remain. For instance, despite reductions in mortality from infectious and chronic disease, serious mortality remains from multiple acute conditions such as homicide, suicide, prematurity, asthma, and eating disorders. The percentage of low-birthweight infants in the United States increased from 6.8 percent in 1980 to 7.3 percent in 1995 (Federal Interagency Forum on Child and Family Statistics, 1995). Additional research in these areas is required. A high degree of morbidity has been identified in the areas of childhood obesity, asthma, and mental health, and the rates of these conditions continue to increase each year.

The rates of morbidity and mortality among ethnic groups remain significantly different. The relationship of causes of morbidity and mortality to ethnicity and socioeconomic status will require additional clarification and understanding. Once better understood, these relationships may shed light on other important correlations and may include, for instance, the variance in immunization rates among ethnic and economic groups; the drastic difference in rates of death, disease, and disability among ethnic groups; the relationship of ethnicity and economic status to frequency of accidents and injuries; and the disparity of prematurity incidence among ethnic and socioeconomic groups.

Finally, there will remain a gap in measuring the attributable effect of poverty and race. Studies for some diseases have indicated that, after controlling for socioeconomic status, little difference remains among ethnic groups. Other studies refute this finding, attributing the differences that remain to such causes as chronic stress caused by racism. These conflicting opinions underscore the need for the creation of tools and models that are better equipped to perform a true analysis of the effects of poverty and race.

CHANGE IN QUESTIONS SINCE HUNT VALLEY

Many relationships of behavior to illness have been discovered. What continues to elude scientists and health officials are the measures necessary to transfer the knowledge in health behaviors to entire populations. Second, deaths and disability from unintentional injuries continue to escalate; new and innovative preventive measures are critical. Third, although biologic bases of mental health disorders have been discovered, etiology and treatment will continue to benefit from refinement. Fourth, the environment has been implicated as a factor in a wide variety of diseases and disorders; the strength and degree of this relationship should continue to be investigated and measured. Finally, the influence and importance of genetic factors and development of disease continues to be an area of great scientific inquiry.

RESEARCH RECOMMENDATIONS

Research Methodology

Several themes related to research methodology overlay many of the research recommendations discussed below. For instance, the use of racial and socioeconomic demographic indicators must be included in all research. In the past, research and recommendations for girls have been based on race and ethnicity, often without taking into consideration their socioeconomic status. These indicators can — and must — be included as independent variables in all research efforts, in order to fairly assess needs for children of all races and economic levels. Higher rates of mortality, morbidity, and disability have been demonstrated to be associated with lower income, less education, lower occupational level, racial and ethnic minority status, and other social class variables (Montgomery, Kiely, and Pappas, 1996). Being raised at or near the federal poverty line ($15,141 for a family of four in 1994) means that not only does a child have a lower level of material goods than other children, but also that she or he is more likely than a nonpoor child to experience difficulties in school, to become a teen parent, and to earn less income and experience greater unemployment as an adult (United States Department of Health and Human Services, 1996). Socioeconomic variables can, therefore, be useful in determining prevalence rates and may also be used to examine why some populations have lower risks of morbidity and mortality.

Another crosscutting issue is the need for multidisciplinary and multiagency collaboration in developing and implementing research. Biomedical science is only able to discover the drugs and behaviors that will enhance health; other scientific disciplines must be enlisted to elicit adherence to regimens or to encourage adoption of healthy behaviors. The social sciences must assist in explaining and developing solutions to these problems. Once established, multidisciplinary collaborative research teams will be useful in developing creative strategies to prevent and treat major childhood deaths, diseases, and disabilities in the areas of prematurity, low birthweight, obesity, eating disorders, asthma, depression, and violence.

The importance of the multiagency, multidisciplinary approach is further evidenced by examining the 1995 top ten causes of disease for females of all ages and races. In that year, the causes and associated death rates were as follows:

- Heart disease (374,849);
- Malignant neoplasms (256,844);
- Cerebrovascular disease (96,428);
- Chronic obstructive disease and allied conditions (48,961);
- Pneumonia and influenza (45,136);
- Diabetes mellitus (33,130);
- Accidents and adverse effects (31,919);
- Alzheimer's disease (13,607);
- Nephritis, nephrotic syndrome, and nephrosis (12,287); and
- Septicemia (11,974).

(National Center for Health Statistics, 1997)

Major contributing factors to many of the 1995 top ten causes of death included tobacco use, diet and activity patterns, ethyl alcohol use, microbial agents, toxic agents, firearms, and motor vehicle operation (McGinnis and Foege, 1993).

Although most of the 1995 causes of disease and death manifested in adulthood, many of the contributory behaviors have their origin in childhood. The social sciences must, therefore, reinforce and enhance the findings of biomedical science. This need requires the development of effective scientific quantitative and social qualitative models, often targeting entire families and communities. It is, therefore, important that ORWH continue to facilitate the conduct of relevant research and training in grant writing or, at a minimum, training in the development of research questions for some of the less quantitative but equally important health questions. The technical assistance could help the public develop research questions and methodologies that fit into the context of the NIH model.

Cultural sensitivity and flexibility, must be incorporated into research models and questions. For example, in many cultures it would be inappropriate to begin an interview without first having established a rapport by questioning the subject about her family and life.

Morbidity and mortality statistical data must be as timely, accessible, and specific as possible. For example, child abuse and sexual abuse, when considered as secondary causes of morbidity or mortality, are "hidden" in homicide statistics and are, therefore, not easily identifiable. Moreover, some homicides may be listed under congenital anomalies when death occurs at home, even though the death occurred under questionable circumstances. This practice prohibits accurate awareness and subsequent planning. Physical abuse fatalities are often listed under homicide, which prevents clear, immediate recognition of prevalence.

It was recommended that one single depository be created for all statistics that is easy to find and is user friendly. Important variables that ought, at a minimum, to be included are race, ethnicity, age, socioeconomic status, morbidity, and mortality. Research centers should be aware of each other's existence and collaborate in the areas of knowledge and data in order to synergize their capacities. There is a strong need for intra- and interagency collaboration. In order to engender collaboration among research centers, definitions must be created that are universally accepted, used, and understood. For example, in the public health field the term "accidents" has now been replaced with "unintentional injuries." This category can be further broken down with such terms as "negligent gun use."

Finally, many of the problems of children manifest later in life and, therefore, would most effectively be analyzed in the context of a longitudinal model. For example, the measurement of healing after physical or sexual abuse or the impact of early-onset sexually transmitted disease may most effectively be measured using a longitudinal model.

Childhood Behaviors

Many of the conditions affecting adults later in life have their origins in childhood behaviors. Creative strategies, using multidisciplinary teams, will need to be developed and the use of family and community models for behavior change must be considered. These behaviors include, but are not limited to, calcium intake, diet, physical activity, and tobacco, alcohol, and drug use.

Calcium intake. One of the more startling discoveries of the past year has been the knowledge that peak bone mass in girls occurs during the peripubescent period prior to the age of 14. This discovery can have enormous impact on the avoidance of adult development of osteoporosis. As 50 percent of women will have an osteoporotic fracture prior to death, and 20 percent or greater will have a hip fracture after the age of 65, the impact of childhood research and prevention in the development of peak bone mass is critical (Chrischilles, Butler, Davis, and Wallace, 1991). Additionally, Matkovic, et al. (1979, 1992) indicated that a difference in bone mass of approximately 7 percent was associated to a difference in fracture rate of greater than 50 percent.

Additional relationships to childhood calcium intake and the development of adult osteoporosis must be elucidated. Examples of areas needing further clarification include:

- the relationship of phosphorus (diet soda and regular), smoking, pregnancy, and exercise to the development of peak bone mass in girls;
- the best source(s) of calcium;
- ethnic differences in lactose intolerance and calcium absorption;
- the relationship between genetics and environment in the development of peak bone mass;
- the benefit of childhood mineral supplementation;
- the relationship and effectiveness of Vitamin D receptor sites to peak bone mass formation; and
- the societal pressures that discourage girls from drinking milk (e.g., dieting).

It is estimated that only 30 percent of today's girls consume the recommended daily allowance (RDA) of calcium and even fewer engage in regular exercise routines (Key and Key, 1994). Due to the enormous potential impact of this discovery, it is recommended that a working group on bone and musculoskeletal disorders be formed to continue exploration of the above research questions.

Diet and physical activity. Healthy diet and fitness patterns are often set in childhood. Healthy behaviors in these areas can, therefore, prevent future heart disease, obesity, and myriad other diseases and conditions.

Measurement of poverty and its relationship to healthy behavior is of critical importance. For example, poverty has an effect on behaviors when a family cannot afford fresh food or has no access to organized sports or accessible playground facilities. In addition, children and youth in low-income families have significantly higher rates of activity limitation than children in more affluent families. Among children ages 5 to 17, 12 percent in families with incomes below $20,000 had activity limitation due to chronic conditions, while only 7 percent of children in families with incomes of $20,000 or more had such a limitation (Federal Interagency Forum on Child and Family Statistics, 1997).

It is also important to measure available income and to recognize the family member in control of total family income. For example, studies in developing countries have shown that children fare better when the mother has control over family spending (Kennedy and Peters, 1992).

Studies indicate that while boys are more active than girls and engage in more heavy physical activity, girls spend a larger percentage of their time engaged in light-to-moderate physical activities (Myers, Strikmiller, Webber, and Berenson, 1996). A study by Craig, Goldberg, and Dietz (1996) indicated that gender differences related to intent to participate in vigorous activity, perceived behavioral control, and sense of competency are already evident in the eighth grade and may actually begin by the fifth grade. These gender differences in perception therefore precede differences in participation in vigorous activity. Similarly, a study by Trost, et al. (1996) indicated that perceived confidence in overcoming barriers to physical activity and participation in community physical activity programs are factors related to the gender difference in physical activity. Many researchers have indicated that frequency of exercise decreases when girls reach puberty. The interrelationship between menarche, self esteem, and decreased physical activity is an area ripe for research.

Tobacco, alcohol, and other drug abuse. Although often underreported, experimentation with and use of drugs begin for many children in their pre-teen years. The National Institute on Drug Abuse and the University of Michigan's Institute for Social Research (1996) report tobacco, alcohol, and illicit drug use in 8th graders at 10, 11, and 15 percent respectively. Significantly, the use of illicit drugs for 8th graders doubled between 1992 and 1996.

A study of Mexican-American youth indicated substantial gender differences in experimentation with tobacco, alcohol, and marijuana. This study highlighted the need for further research exploring within-group variations in the substance use of various ethnic groups (Katims and Zapata, 1993). The importance of effective prevention interventions for these abuses cannot be stressed enough. For tobacco, alcohol, and drug abuse, multidisciplinary science can continue to refine effective prevention and treatment strategies as new information is generated.

Childhood Maltreatment

Research on the effects of child abuse and neglect indicate both immediate and long-term harm to infants and children. In the most extreme cases, the physical consequence of abuse is death. In many other cases, the outcome of maltreatment is serious injury, permanent disability, and/or an array of social, psychological, and cognitive problems. The results of a study of preschool children indicated that maltreated girls showed more shame when they failed and less pride when they succeeded than nonmaltreated girls (Alessandri and Lewis, 1996).

The National Research Council has distinguished four categories of child maltreatment: physical abuse, sexual abuse, emotional maltreatment, and neglect (National Research Council, 1993). In 1993, professionals reported approximately 1.6 million children as victims of maltreatment, either abuse or neglect. This number indicates a rate of 23.1 per 1,000 children under age 18. Of these children, approximately 743,200 suffered physical, sexual, or emotional abuse. Approximately 879,000 suffered physical, emotional, or educational neglect.

Specific subcategories of children are exposed to additional risks. For instance, girls are three times as likely to suffer sexual abuse than boys, children of single parents are at much greater risk of abuse or neglect than children living with both parents, and children from families with incomes below $15,000 are 22 times as likely to experience some form of maltreatment than children from families with incomes above $30,000 (Federal Interagency Forum on Child and Family Statistics, 1997).

Due to a variety of reasons, many cases of child maltreatment do not come to the attention of the justice or social welfare systems. Therefore, the actual incidence of child maltreatment is estimated to be three times as great as is commonly recognized. For instance, associative disorder is common in girls who have been sexually abused.

While it is recommended that all forms of abuse must be researched in the context of the social, cultural, and economic environment in which they occur, recommendations common to all forms of child maltreatment include:

- assessments for a generational and cultural component;
- exploring ethnic and cultural definitions of child maltreatment;
- exploring the relationship of child maltreatment to the development of adolescent or adult-onset mental illness;
- reviewing lifelong effects, both physical and psychological, of underreported incidence of all types of childhood maltreatment;
- developing instruments and techniques to obtain accurate statistical data;
- exploring the relationship of child maltreatment to later development of learning disabilities, failure to thrive, and drug use;
- developing instruments that measure both prevalence and effects of child maltreatment;
- measuring the relationship between child sexual abuse and early consensual sexual relations, pregnancies, and substance abuse; and
- continuing multidisciplinary, multi-agency collaborative efforts such as the effort between NICHD, NIMH, and the Office of Behavioral and Social Sciences Research that investigates precursors to abuse and the effort between NIMH and ORWH to explore causes of and treatments for chronic pelvic pain.

Normal Growth and Development

Prior to understanding disease in girl infants and children, a greater understanding of normal physical and behavioral development is needed. Knowledge of the pharmacologic differences between males and females and among different age and ethnic groups of children is also critical. The areas of differences between diverse groups of children that could benefit from further scientific explorations include:

- why certain diseases and conditions are more common in female infants and children and among certain ethnic groups;
- how the catch-up growth lag differs based on gender;
- how cell growth and differentiation are different between sexes;
- why girls injure differently than boys during exercise;
- the critical periods of development in organ systems, particularly the brain;
- how the lack of a nurturing environment affects emotional resilience;
- how the impact of the psychosocial environment of female children impacts nervous system development in childhood;
- how the physiology of the brain differs between girls and boys;
- the biochemical markers in childhood of chronic disease in later life;
- how molecular biology can be used to identify and understand the influence of human genes on childhood development, diseases, disorders, and conditions;

- how research can best make use of the human genome to improve child health;
- why different races and ethnic groups respond differently to different types of drugs;
- whether the most commonly used children's drugs are equally efficacious in children of different ages, genders, and races; and
- whether the most commonly used children's drugs are safe for use in children of different ages, genders, and races.

Interaction Between Girls and Their Parents

Children are dependent on their parents or other care givers to see that their life needs are met. It is for this reason that the measured effects of the following conditions may be insightful:

- What is the impact on children who come home from school without the benefit of parental or other adult supervision?
- What is the effect of maternal depression on girl children?
- What is the impact of poor and working-poor mothers and fathers on their children?
- How does decisionmaking authority differ among different ethnic, racial, social, and economic groups? An understanding of this relationship is important in order to target specific interventions.
- What is the correlation between quality of the parental relationship and learning disabilities, neglect, failure to thrive, and drug use?

Hormonal Influences

Hormones are highly influential on the developing child's body. Consequently, an increased understanding of how hormones affect the growing female child is imperative. Research in the following areas is suggested:

- the relationship of testosterone to male aggression and how it can ultimately lead to abuse of females;
- the effect of cerebral serotonin levels and serotonin receptors on depression and suicidal behaviors and ideations;
- the effect of cerebral serotonin levels and serotonin receptors on impulse control and thrill-seeking behaviors;
- the effect of estrogen and exercise on development of peak bone mass;
- the relationship of unopposed progesterone to halted bone density development; and
- the reason girls of short stature receive clinical diagnosis and treatment less frequently than boys with the same diagnosis.

Environment

In the years since the creation of ORWH, a greater understanding has arisen concerning the linkage between the environment and health. However, important related areas of further research remain:

- the influence of livestock hormonal supplementation on children's conditions;
- the environmental influence of schools, where children spend much of their day;
- the impact of infectious agents by age and gender;
- the relationship of environmental toxins to cancer, migraine headaches, adrenarche, toxic exposures, and birth defects;
- the relationship between environmental toxins and fertility; and
- the molecular effects of toxic exposures.

Asthma

Asthma is the most frequent chronic disorder in children (Nolan, 1994). Rates of asthma increased 79 percent from 1982 to 1993, and the current rate of what has become a modern-day epidemic is 72 cases per 1,000 children (U.S. Department of Health and Human Services, 1996). Diagnosis and treatment of this disorder costs $2.8 billion per year. The U.S. National Health and Nutrition Examination Survey (NHANES II) analysis indicated an increased risk of asthma for children in the lowest third of family incomes (Schwartz, et al., 1990). Although great strides in asthma treatment have been made since the establishment of ORWH, the following relationships require further exploration:

- the child's age and onset of disease;
- the relationship, if any, between the menstrual cycle and exacerbations of disease;
- the relationships between environmental toxins, air, genetic predisposition, carpet, mold, cockroaches, and schools to the development of disease and exacerbations of asthma; and
- the relationship between gender, racial, cultural, and socioeconomic factors and prevalence of disease.

Mental Health and Depression

In female children, aged 5 to 14, suicide is the seventh leading cause of mortality at a rate of 0.4 per 100,000 (National Center for Health Statistics, 1997). In 1994, 597,000 prescriptions for Zoloft or Prozac were written for children (Pina, 1997). These statistics indicate an alarming number of mental health problems in children. Despite the evident willingness of physicians to treat children's mental illness with medication, there are many questions that remain unanswered:

- Are drugs that are not approved for pediatric use (e.g., Zoloft and Prozac) safe for use in children?
- Is depression in children actually increasing, or is only the diagnosis of depression increasing?
- If depression is increasing in children, why?
- What, if any, is the relationship between female self esteem and drug use, eating disorders, and early sexual activity?
- By using Benson's Assets (Benson, Blyth, and Roehlkepartain, 1995), what determines resilience in children? What are protective and negative or harmful behaviors?
- What is the incidence of mental health problems in children?

Oral Health

Oral health in the developing child must be included in order to maximize a child's nutritional and health status. To effect this result the following recommendations are proposed:

- a study to develop interventions that are effective in eliciting donning of protective head gear in females; and
- a study that addresses the effect of dental anomalies on growth and development, nutritional consumption, enamel dysplasia, and self esteem.

CONCLUSION

Great progress has been made in infancy and childhood research since the first Hunt Valley meeting in 1991. The remaining challenge to researchers and practitioners is to ensure that the recent advances in biomedical and clinical developments are applicable to female children, as well as to diverse ethnic groups and special subpopulations of female children. This goal can be attained by inclusion of all groups of infants and children in research studies and by guaranteeing that nontraditional independent variables, such as socioeconomic status, are included in all reported study results, effectively resulting in both genuine scientific discovery and equitable research.

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ADOLESCENT YEARS

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BACKGROUND

The specific focus of this working group was to explore the differences in populations (cultural, ethnic, socioeconomic, rural/urban, and disabilities) with respect to female adolescent health issues. Adolescence is defined as the ages between 10 and 19 years; nearly 35 million people were members of this group in 1990. Adolescents were 14 percent of the 1990 U.S. population, with their number and population share both expected to decline in the future. Adolescents often live in single-parent families (26 percent) and many live in poverty (20 percent); 54 percent of the youth in single-parent families live in poverty. As it does for adults, living in poverty for adolescents plays a critical role in the shaping of their health outcomes.[1]

Adolescent Morbidity and Mortality

Major causes of morbidity among female adolescents are largely, but not totally, related to their behaviors. The two leading causes of death in female adolescents are nonintentional trauma (especially motor vehicle accidents) and suicide; the third leading cause of death is interpersonal physical violence.[2] The table on the following page illustrates the mortality rates for adolescents 15 to 19 years old by gender, race, and cause of death for selected years, 1980 through 1994.[3]

CONCLUSIONS FROM HUNT VALLEY

In 1991, ORWH established an NIH Task Force on Opportunities for Research on Women's Health. The principal objective of the task force is to devise a research agenda that will guide the direction of, as well as the funding priorities regarding, research on the health of women throughout the next decade. To collect comprehensive information on the current needs in women's research and gain perspective on the full spectrum of those needs, ORWH held a public hearing during which advocates for women's health and representatives of scientific and medical organizations were given an opportunity to provide input into the research agenda and plans for the scientific workshop. The contributions, commitment, and specific recommendations of those who presented testimony provided important guidance toward planning the Workshop on Opportunities for Research on Women's Health, in the course of the 3-day workshop held in Hunt Valley, Maryland, September 4-6, 1991. In addition to the public testimony, epidemiologic data were used to identify major factors related to women's morbidity and mortality, emerging areas of research, and topics needing further study. The purpose of the workshop was to arrive at specific workable recommendations regarding research activities on behalf of all the women in the United States.[4]

TABLE 1. Mortality Rates Among 15 to 19 Year Olds, by Gender, Race,[a] and Cause of Death,[b] Selected Years 1980-94[c]

	Deaths Per 100,000 Resident Population Ages 15 to 19						
Cause of Death	**1980**	**1985**	**1990**	**1991**	**1992**	**1993**	**1994**
Total, all races							
All causes	98.4	80.4	89.0	89.6	84.9	87.5	87.4
Injuries	78.6	62.9	72.0	72.3	67.9	70.3	70.1
Motor vehicle crashes	42.5	33.0	33.1	31.0	27.9	28.4	29.1
Firearms	14.8	13.3	23.6	26.6	26.4	28.0	28.4
Male, white							
All causes	143.5	112.1	117.7	113.6	107.3	108.8	109.6
Injuries	122.0	93.1	98.6	94.8	88.3	90.4	90.9
Motor vehicle crashes	68.1	50.3	49.5	44.4	39.3	41.4	41.5
Firearms	21.0	18.4	26.8	29.5	29.2	29.1	30.6
Male, black							
All causes	134.5	125.3	203.6	231.6	221.4	234.3	234.2
Injuries	105.5	96.6	177.5	202.4	192.6	205.9	204.2
Motor vehicle crashes	24.3	21.9	29.1	29.7	26.4	26.8	29.0
Firearms	46.7	46.5	122.0	142.7	142.8	154.8	152.7
Female, white							
All causes	54.1	46.6	45.7	46.8	43.4	44.7	43.4
Injuries	38.3	33.1	33.2	33.8	31.0	31.5	30.9
Motor vehicle crashes	25.6	22.4	22.2	22.8	20.8	20.1	21.2
Firearms	4.2	3.5	4.6	4.6	4.3	4.9	4.8
Female, black							
All causes	50.5	44.5	54.6	52.4	50.7	53.5	56.1
Injuries	25.6	22.9	31.0	30.3	28.6	31.8	30.9
Motor vehicle crashes	6.6	7.5	9.7	8.9	9.1	8.2	10.4
Firearms	7.5	6.1	12.2	12.7	12.4	15.8	13.4

[a] Each race category includes Hispanics of that race.

[b] Motor vehicle crashes and firearms are subsets of all injury deaths.

[c] The use of slightly different denominators accounts for minor differences in child and adolescent mortality rates reported in this report and in some publications from the National Center for Health Statistics.

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System.

The working group members, who focused on young adulthood to perimenopausal years, emphasized that the prevalence, incidence, and costs of death and ill health among girls and young women are related less to disability and disease than to injuries, environmental exposures/hazards, and risk taking. Injuries, including acts of physical and sexual violence, are the leading cause of death and ill health among girls and young women. In addition, prevention and control of sexually transmitted diseases, including AIDS, are critically important health issues. The working group further recommended that researchers study:

- the causes of greater incidence of obesity in certain ethnic groups;
- whether factors such as alcohol, drug, and tobacco use; the environment; and social pressure cause more injuries leading to death or disability among girls than boys;
- the reaction of girls to the divorce of their parents, compared with boys; the connection between family violence — such as physical or sexual abuse — during this age and risk-taking behaviors such as early unprotected sexual intercourse, delinquency, and tobacco, drug, and alcohol use;
- the factors contributing to girls' self esteem;

- ways to eliminate eating disorders and other psychological problems;
- what can be done to prevent women from getting sexually transmitted diseases, including AIDS;
- why so many more women than men suffer from depression after puberty;
- the causes of the increase in illicit drug use and alcohol use among women;
- how widespread physical and sexual abuse are among women, and what the physical and psychological effects are immediately and later on in life; and
- why injury is the overall leading cause of death among women ages 15 to 44 and what can be done to reduce injuries of all types, including motor vehicle accidents, drowning, poisoning, fires and burns, gunshot wounds, and suicides.[5]

Focus on Special Populations

A guiding principle of ORWH is that biomedical research must be targeted to all of America's women, of all races, all ages, and all socioeconomic and ethnic groups. In light of that principle, the July 21-23, 1997, meeting in Santa Fe, New Mexico, focused on factors that contribute to differences in health status and health outcomes among different populations of women including biology, genetics, race, culture and ethnicity, psychosocial and behavioral factors, educational influences, traditional and alternative practices, environment, poverty and socioeconomic status, access to health care, and occupation issues.[6]

Special populations also include persons with disabilities, immigrants, lesbians, ethnicity and culture, race, urban and rural, homeless, family origin links, socioeconomic and educational levels, and parenting teens. Many of these categories are not mutually exclusive and the interrelationships also need to be examined.

SCIENTIFIC PROGRESS SINCE ESTABLISHMENT OF ORWH

Physical Conditions

Obesity. Obesity affects 50 million Americans and increases their risk of high blood pressure, diabetes, heart disease, stroke, some cancers, and joint and back problems.[7] It has increased dramatically over the past decade and now is considered an epidemic in the U.S. population. Obesity is particularly a problem for women of color and is related in part to their sedentary lifestyles and to the "diets of poverty" (high in fat and low in fruits and vegetables) that many consume.

Results from the NHLBI Growth and Health Study (NGHS), a longitudinal study of African-American and Caucasian girls starting at 9 to 10 years of age, showed that differences in body mass index between African-American and Caucasian girls appear by the age of 10. Additional findings have been published on the relationship of socioeconomic status with obesity and nutrition, and on psychosocial influences including weight modification efforts and eating practices. In general, obesity was inversely related to household income and parental education in Caucasian girls but not in African-American girls. TV watching was associated with obesity more strongly in African-American girls than in Caucasian girls, and higher levels of household education were related to more favorable nutrient intake profiles. By 9 to 10 years of age, about 40 percent of both African-American and Caucasian girls reported trying to lose weight, although Caucasian girls were more dissatisfied with their weight and body shape than African-American girls, and African-American girls engaged more frequently than Caucasian girls in eating practices that are associated with higher caloric intakes.[8–11]

Although there are no current rates for obesity and being underweight among high-school girls, a national survey on youth reported that in 1995 more than one-third of young Hispanic and Caucasian females (38 percent) felt they were overweight, compared to 28 percent of young African-American females.[2] In the past 5 years, extensive research has investigated endocrine issues linked to obesity — referred to as syndrome X, insulin resistance in the clinical setting.[12]

Eating disorders, body image, and nutrition. Approximately 2 percent of adult women meet current diagnostic criteria for anorexia nervosa or bulimia nervosa, and even greater prevalence rates, 90 to 95 percent of cases, have been found among adolescent girls.[13,14] Eating disorders have a profoundly negative effect on physical and psychological health and on social and vocational adjustment. In many cases, these disturbances in health and adjustment are long lasting or even irreversible. Eating disorders are significantly associated with a variety of psychiatric disorders, including depression, anxiety disorders, personality disorders, and substance abuse.[15–19]

The physiologic sequelae of anorexia include amenorrhea and estrogen deficiency. Estrogen deficiency and poor calcium intake, which occur in women with anorexia, are associated with bone loss and increased bone mass.[14,20–22] Though regular physical activity is beneficial to most women, increased education and research are needed to reduce the potential health dangers associated with unrealistic weight goals.

In an attempt to understand why Caucasian women are more prone to develop eating disorders than African-American women, Powell and Kahn (1995), using self reports, found that Caucasian women chose a significantly thinner ideal body size than did African-American women, and expressed more concern than African-American women with weight and dieting.[10] Caucasian women also experienced greater social pressure to be thin than did African-American women. Ongoing research is needed in the area of perception of ideal body image among various ethnic/racial groups.

Injuries and violence — physical/sexual abuse. Violence affects the quality of life of young people who experience it, witness it, or feel threatened by it. In addition to the direct physical harm suffered by young victims of violence, research suggests that violence can adversely affect victims' mental health and social development, and increase the likelihood that they themselves will commit acts of violence.[4,23] Youth ages 12 to 17 are more likely than adults to be victims of violent crimes, which include simple and aggravated assaults, rape, and robbery. The rate at which youth were victims of violent crimes fluctuated between 79 and 87 per 1,000 from 1980 to 1986, and then began to increase from 89 per 1,000 in 1987 to 123 per 1,000 in 1993. The rate of violent crime against youth then decreased to 118 per 1,000 in 1994, but it is too early to know whether this is the beginning of a downward trend.

The third leading cause of death in female adolescents is interpersonal physical violence. In fact, rates of violent criminal victimization of adolescents has, for the most part, increased in the 1990s.[4] African-American youth are generally more likely than Caucasian youth to be victims of violent crime.[24] Female adolescents have a high risk of being sexually abused and assaulted, which is linked to the development of mental health symptoms.[3] Multiple forms of violence against women cause serious physical health consequences. For example, in primary care practice, women who have been raped report more symptoms of illness and more negative health behaviors — including alcohol use, smoking, and failure to use seat belts — than nonvictimized women. They visit their physicians more than twice as often as women who have not been raped.[15]

Pregnancy and unprotected sex. The United States has the highest adolescent pregnancy, abortion, and birth rates in the developed world, with 43 percent of all adolescent females estimated to experience at least one pregnancy before they reach age 20.[25] In 1989, the most recent year in which data was available, an estimated 1,050,040 females under the age of 20 experienced a pregnancy. Furthermore, 82 percent of adolescent pregnancies are unintended. Three-quarters of all unintended pregnancies occur to adolescents who do not use contraception. Birth rates for females under 20 declined from 60.5 to 51.7 per 1,000 between 1973 and 1987. By 1990, it rose to 61.7 per 1,000 adolescent females and has been increasing since then.[26] There are substantial racial and ethnic disparities in birth rates among young women ages 15 to 17. In 1994, the birth rate for this age group was 16 per 1,000 for Asian or Pacific Islanders, 23 per 1,000 for Caucasians, 51 per 1,000 for American Indian or Alaskan Natives, 74 per 1,000 for Hispanics, and 76 per 1,000 for African Americans.[4]

Research indicates that for a young woman, bearing a child during adolescence is associated with long-term difficulties for herself, her child, and society. These consequences are often attributable to the poverty and other adverse socioeconomic circumstances that frequently accompany early childbearing. Many teenagers enter into pregnancy with pre-existing conditions that may produce negative effects, such as drinking, smoking, drug abuse, poor nutrition, and sexually transmitted diseases.[4,26,27] In addition, pregnant teenagers are twice as likely, when compared to all pregnant women, to receive no prenatal care or care initiated only at the third trimester. For those under 15, more than 20 percent receive late or no care.[26]

The significance of pregnancy to an adolescent may vary depending upon the circumstances of the pregnancy and the support of family, school, and other systems. Boyers' (1993) research on the link between childhood victimization, rape, and sexual abuse is especially relevant.[26] Most fathers of babies born to adolescent females are older than 20. These interactions may involve a compelling power differential that is not acknowledged in research.[28,29]

There is little consensus in the United States about what to do about adolescent pregnancy, and very little research on pregnancy prevention is available. Doug Kirby's review of the school-based literature for the National Campaign to Prevent Teenage Pregnancy is one of the few examples of research that has investigated well-evaluated intervention efforts.[30] In order to produce scientific evidence about the effectiveness of intervention in the pregnancy prevention field, changes in adolescent pregnancy rates must be measured and those changes must be attributed to some program or to a specific curriculum or type of counseling.[26]

The birth-control pill and the condom are the most common methods of contraception used by teenagers.[14] However, about 8 percent of adolescent females 15 to 19 years of age do not use any method of birth control. Although condoms can protect from contracting HIV or other STDs and from unwanted pregnancy, many individuals who know this fact continue to engage in unprotected sexual intercourse. It is also important to note that desire for pregnancy may mitigate against birth control, including using condoms.[31]

STDs, HIV, and other infections. About 3 million adolescents contract a sexually transmitted disease annually,[32] about one-quarter of all STDs contracted nationally. Other sexually transmitted diseases of concern are chlamydia with an estimated 3 to 5 million adolescent cases annually, gonorrhea with an estimated one million adolescent cases annually, genital herpes with estimated current prevalence of 20 million adolescents and 500,000 new adolescent cases annually, condylomata, and other manifestations of human papilloma virus.[32]

The STD rates vary among adolescents of color. For example, in 1994 the rate of gonorrhea per 100,000 non-Hispanic African-American girls (10 to 14 years of age) was 467, nearly nine times the rate of gonorrhea among American-Alaskan native girls (52 per 100,000). Asian-American girls had the lowest rate of gonorrhea (11 per 100,000), followed by non-Hispanic Caucasian girls (21 per 100,000), and Hispanic girls (36 per 100,000).[2] Scientific progress has been made by urine testing for chlamydia and gonorrhea in adolescents. Additional research has investigated douching as a risk factor for chlamydia and gonorrhea, particularly in non-Hispanic African-American girls.[33]

One of the fears that has deterred education about STD preventative measures (condom, birth controls, etc.) is that providing this information will lead to an increase in the rate of sexual activity. However, research has shown that STD education programs in schools do not increase sexual activity among students.[31,34] Not only is morbidity associated with these sexually transmitted diseases, but having been infected with a sexually transmitted disease increases the likelihood of HIV infection.[35–38]

Women are biologically more vulnerable than men to HIV infection. Studies have found that male-to-female transmission appears to be two to four times more efficient than female to male transmission, in part because semen contains a far higher concentration of HIV than vaginal fluid. Young girls are particularly vulnerable. Their immature cervixes and low vaginal mucus production presents less of a barrier to HIV.[39] Among adolescent females in the United States, reported AIDS cases have jumped from 14 percent in 1987 to 32 percent by June 1994.

Behavioral and Psychosocial Conditions

Despite increased focus on medical and epidemiological aspects of women's health, research has not adequately addressed psychosocial and behavioral factors that contribute to health status. This gap is particularly crucial for adolescents because the most prevalent health risks result from psychosocial, behavioral, and economic factors.[15]

Alcohol and substance abuse. In the 1994 National Household Survey on Drug Abuse, almost half (46.8 percent) of all females in the age range of 15 to 44 years reported use of an illicit drug at least once in their lives.[40] Furthermore, 4.7 million women reported current use (i.e., at least once in the prior month) of illicit drugs, and women constituted more than 37 percent of the illicit-drug-using population in the United States. Six percent of women ages 15 to 54 have met the criteria for lifetime drug dependence.[41] Although approximately 22 percent more males than females use drugs, the consequences of drug abuse by women are often more severe and, after initial use, females may proceed more rapidly to drug abuse than males.[42]

Preliminary studies indicate gender differences in the etiology and consequences of drug abuse and highlight the need for additional work in this area.[43–45] The types of studies that are needed in this area include: the nature and extent of drug abuse in females of all ages, ethnic backgrounds, SES groups, and sexual orientations; the role of the menstrual cycle in modulating drug use and drug effects; gender-specific behavioral, biological, and medical effects of drug abuse; and gender-specific biological and behavioral mechanisms that underlie drug abuse and dependence.

Research is beginning to show that the progression or developmental stages of drug involvement is not identical for males and females. In the progression from legal drug use to illicit drug use, for example, cigarettes have a relatively larger role for females than for males, and alcohol has a relatively larger role for males than for females.[46] With regard to initiation into illicit drugs, data suggest that women are more likely to begin or maintain cocaine use in order to develop more intimate relationships, while men are more likely to use the drug with male friends and in relation to the drug trade.[47] The onset of drug abuse is later for females and the paths are more complex than for males.[48]

Childhood sexual abuse has been associated with drug abuse in females in several studies.[49] Research findings indicate that up to 70 percent of women in drug abuse treatment report histories of physical and sexual abuse with victimization beginning before 11 years of age.[50] A study of drug use among young women who became pregnant before reaching 18 years of age reported that 32 percent had a history of early forced sexual intercourse. These adolescents, compared with nonvictims, used more crack, cocaine, and other drugs (excepting marijuana); had lower self esteem; and engaged in a higher number of delinquent activities.[51]

The rate of co-occurring substance abuse disorder and other psychiatric disorders is relatively high for females. Additionally, high correlation appears to exist for females between eating disorders and substance abuse; as many as 55 percent of bulimic patients are reported to have drug and alcohol use problems. Conversely, 15 to 40 percent of females with drug abuse or alcohol problems have been reported to have eating disorder syndromes, usually involving binge eating.[16,20,52,53]

Tobacco. Tobacco use continues to be the single leading preventable cause of death in the United States, responsible for more than 500,00 deaths, 5 million years of potential life lost, and total costs of $68 billion annually.[54] Smoking rates among adolescents, which had declined for 20 years, have steadily increased since 1984 and, for young adult smokers, now surpass those of older adults.[55] Teens are starting to smoke at younger ages, portending a future of heavier use, greater difficulty quitting, and more tobacco-related illness.[56] Many adults who are today addicted to tobacco began smoking as adolescents, and it is estimated that more than 5 million of today's underage smokers will die of tobacco-related illnesses.[4]

The Surgeon General's report on smoking, issued in 1994, was the first to focus on the extensive data indicating that tobacco use is a serious public health problem among young people.[14] The major conclusions of that report are:

- Nearly all first use of tobacco occurs before 18 years of age.
- Most adolescent smokers are addicted to nicotine.
- Tobacco is often the first drug used by young people who subsequently use illegal drugs.
- There are identified psychosocial risk factors for the onset of tobacco use.
- Cigarette advertising appears to increase young people's risk of smoking.
- Community-wide efforts have successfully reduced adolescent use of tobacco.

Although the purchase and use of cigarettes is illegal for all high school students until they turn 18 years of age, 40 percent of Caucasian, 33 percent of Hispanic, and 12 percent of African-American female high school students are current smokers. Furthermore, approximately one-fifth of Caucasian (21 percent) and American Indian/Alaska Native (18 percent) females smoke frequently (at least 20 cigarettes per month) and/or daily. On the other hand, very few African-American females (1 percent) smoke as many cigarettes as their Caucasian counterparts. Hispanic females are in the middle: nine percent smoke frequently.[2] The percentage of 8th, 10th, and 12th graders who reported that they smoked cigarettes daily increased between 1992 and 1996. In 1996, 22 percent of 12th graders reported smoking daily during the previous 30 days, as did 18 percent of 10th graders and 10 percent of 8th graders.[4]

The increase in tobacco use by adolescents, particularly young women, has been largely attributed to heightened advertising and promotion by the tobacco industry, which spent more than $6 billion in 1993 (as compared with $4.2 billion in 1989 and $2.1 billion in 1980).[57–59] Youth are widely exposed to, aware of, and influenced by, and respond favorably to, tobacco ads (Surgeon General's Report, 1994). Adolescents are exposed to ads with themes that appeal to the young, with implications that tobacco use promotes independence, romance, fun, excitement, and glamour.[60,61]

A followup study of adolescents in the southeastern United States demonstrated that, among teenagers who did not smoke in the first phase of the study, more Caucasians than African Americans started smoking. Caucasian females in the study were more likely than African Americans to start smoking at 12 years of age. Peer pressure was correlated with the likelihood that Caucasian teenagers would smoke, but this factor was not important for African-American teenagers in this study.[14] Additional research is needed as to the reasons different populations of adolescent females start smoking. Moreover, research is needed to define the optimal combinations of interventions and policies to effect change, and to make progress toward reaching the national health objective of less than 15 percent of youth becoming regular smokers by age 20.[62]

Risk-taking, suicide, and delinquency. In 1991, suicide was the fourth leading cause of death among all women 15 to 24 years of age; among Caucasian women suicide ranked third and among African-American women it ranked seventh. Of other ethnic groups in the United States, the suicide rates for Native Americans, including Alaskan Natives, are among the highest. One in six Native American adolescents reported that they have attempted suicide. In contrast, recent data show that Hispanic females have the lowest suicide rates at all ages.[14] Research indicates that depression, anxiety, aggression, substance abuse symptoms, and low family support were significantly correlated with suicide attempts.[63] Although the suicide rates among females have recently decreased or remained stable, further research is required.

Suicide, HIV infection, violent victimization, homelessness, and substance abuse are known to affect lesbian youth at disproportionately high rates. Barriers within the health care system, as well as within other social systems, are specific to lesbian youth.[64] This topic demands further study.

The term “detached youth” refers to young people ages 16 to 19 who are neither in school nor working. Research suggests that this detachment, particularly if it lasts for several years, increases the risk that a young person, over time, will have lower earnings and a less stable employment history than her or his peers who stayed in school and/or secured jobs.[4] The percentages of youth who are detached measures the proportion of young people who, at a given time, are in circumstances that may seriously limit their future prospects. Almost all of the decline in the proportion of detached youth from 1985 to 1996 occurred among young women. In 1985, 13 percent of young women were neither in school nor working. By 1996, this proportion had decreased to 11 percent. Nevertheless, young women continue to be more likely to be detached than young men.

Physical activity. Physical activity holds the promise of improved physical and mental health for female adolescents. However, almost 60 percent of American women and almost 65 percent of ethnic minority women remain sedentary.[15] The Surgeon General’s report on physical activity found that adolescents involved in physical activity are less likely to use tobacco and to become pregnant as a teenager. Physical activity can be health-affirming for adolescents.[65] A majority of Caucasian non-Hispanic adolescent females (57 percent) reported that they participated in vigorous physical activity (activity that caused sweating and hard breathing for at least 20 minutes) on at least 3 of the 7 days preceding the administration of the 1995 Youth Risk Behavior Surveillance System (YRBSS). Smaller shares of African Americans and Hispanics also reported participating in vigorous physical activity. A smaller share of Caucasian adolescent females (17 percent) than of both African-American (26 percent) and Hispanic (28 percent) adolescent females reported participating in moderate physical activity (that is, walking or bicycling for at least 30 minutes) on 5 or more of the 7 days preceding the 1995 YRBSS.[2]

GAPS IN KNOWLEDGE

The gaps in knowledge in adolescent female health include:

- The impact of external forces such as the media and adult decisionmaking on adolescent behavior.
- The impact of violence:
  - Investigation of the perpetrators of violence against females and the effectiveness of intervention with this population.
  - Male behavior in the abuse cycle.

  - Increases in violence in adolescent populations.
  - The effects of living among violence (not necessarily being a victim).
  - The impact of the media on violence from the perspective of either the victims and/or culprits.
  - Identification of and statistical recordkeeping on young women brought into emergency rooms who have been involved in violence, suicide attempts, and/or drug abuse.
  - The increasing rates of incarceration of female adolescents.
  - Medical diagnosis of sexual abuse in female adolescents.
- STDs/HIV
  - The high rates of STD in incarcerated adolescent females.
  - Women-controlled methods of STD and HIV prevention.
  - Updated STD guidelines, for example, to investigate if infections are the result of sexual abuse.
  - General and genital hygiene, particularly in African-American girls, to discover potentially silent STDs that have thus far gone undetected.
  - Gaps in the relationship between douching and bacterial vaginosis, particularly the higher rates of douching in the African-American community and the establishment of these behaviors.
  - Risks among adolescents related to disabilities including cognitive, sensory, mobility, and physical disabilities, and the risky behavior that may lead to contracting STDs and/or HIV. The special vulnerability of disabled adolescents needs to be recognized and better understood.
  - The need to look at access for screening and intervention.
- Socioeconomic and Environment
  - The effects of poverty on health. (For example, a study in *Chest* [1997] found that poverty by itself is a risk factor for cardiovascular disease.)
  - The effects of high-risk environments on adolescent health behavior.
- Sexual Behavior and Contraception
  - Why teens in single-parent households are more likely to have early sex and less likely to use contraception effectively.
  - How to deliver Hepatitis B vaccinations to sexually active adolescents until the universal vaccination coverage catches up to the population.
  - The effects of methods such as douching and barrier contraceptives and the effects of various chemicals on the vaginal ecology.
- Tobacco
  - The optimal combinations of varied interventions and policies to effect change and progress toward reaching the national health objective of less than 15 percent of youth becoming regular smokers by the age of 20.
  - Periodic evaluations to determine the acceptance and effectiveness of interventions and the market's response to restrictions.
  - The reasons why adolescent females from various ethnicities, cultures, and races begin to smoke.

  - The relationship between self esteem and smoking and why girls with high self esteem smoke.
  - Is smoking more addictive in females than in males?
  - Which types of prevention programs work in the schools. (Past research indicates programs that target behavioral and self-esteem issues seem to be the most effective in decreasing adolescent tobacco use.)
- Substance Abuse
  - Drug abuse in female adolescent-specific populations.
  - The antecedents of substance abuse (replication and further study are needed).
  - Gender-specific prevention programs in every area.
  - Basic research, both human and animal, and epidemiological and longitudinal research directed at identifying gender and racial differences in the etiology and consequences of drug use, abuse, and dependence.
  - The antecedents, pathways, risk, and protective factors involved in drug abuse by girls (including special populations: ethnic, racial, cultural, lesbian, disabled, etc.), with emphasis on early identification and the full spectrum of prevention interventions.
  - The impact of violence and victimization on the psychosocial development and psychosocial functioning of girls as it relates to drug abuse and dependence.
  - The coexistence of drug abuse and dependence with psychiatric disorders, especially posttraumatic stress disorder (PTSD), anxiety, depression, and eating disorders.
  - The development and effectiveness of drug abuse treatment models specific to the unique needs of adolescent females. Such models should include treatment for dependence as well as any co-existing psychiatric disorders, and they must be culturally relevant.
- Mental and Physical Health and Suicide
  - Bipolar and anxiety disorders that begin in adolescence.
  - Migraine headaches in adolescent females.
  - Normal development: ethnic variations which must be continually assessed:
    - The ideal body image — how it is determined, whether it can be changed, and how it varies in different ethnic groups.
    - Behavioral influences on obesity, as governed by familial factors and cultural practices, and if these factors can be circumvented through education.
  - The high suicide rate among lesbian youth, specifically looking at the impact of homophobia.
- Ethical Considerations
  - Ethical concerns of doing research with people who are not at the age of consent; for example, doing research on alcohol with people under the legal drinking age.
  - Program research on confidentiality issues as related to access of STD services for adolescents.
- Prevention
  - The effectiveness of role models on teenage females; outcome research on these types of programs to assess if they help teens avoid engaging in risky behaviors.

  - Antecedents to adult diseases, such as osteoporosis, and intervention practices that are behaviorally orientated; for example, to ensure adolescent females are getting enough calcium and exercise to prevent the later onset of osteoporosis.
  - The use of hormonal contraception in adolescents and the effect of long-term consistent use on bone and hormonal development.
  - The appropriate targeting of intervention programs.
  - What occurs in the time frame before adolescence; many problems spring forth before adolescence is reached.
  - Resiliency and assets — why some adolescents do very well even though they have some of the risk factors.
- Research Methods
  - The interrelations among all of these problems.
  - Making funding agencies aware of crosscutting issues and moving away from funding only categorical research.
  - Cross-dependent variable research in addition to cross-disciplinary research (looking at the constellation of risk factors).
  - Effective evaluation tools, especially those that can be flexible and feasible enough to be applied to research so that evaluation methodology can still fit.
  - How to translate behavioral health interventions into new media formats, especially with adolescents who are users of these mediums.
  - Longitudinal and cross-generational studies.
  - An assessment tool for populations that are not the researcher's own.
- Diverse Populations
  - Within-group differences as well as among-group differences in groups of Native Americans, African Americans, Caucasians, etc.
  - Different interventions that were most effective in different subpopulations; for example, newly immigrated adolescents have better outcomes than second- and third-generation adolescents born in the United States.
- The impact of assimilation to U.S. culture on recent immigrants, both in psychosocial problems and its implications for changes in health behaviors.
  - Translating research on effective interventions; developing S models to fit different cultures and languages.
  - The effect of assimilation factors in Native groups and Pacific Islanders.

CHANGE IN QUESTIONS SINCE HUNT VALLEY

As new scientific areas have emerged, the questions have changed to include how to proceed more effectively and efficiently and how to get the best results most effectively. Research scopes should be enlarged to investigate phenomenon that are not necessarily specific to women, for example, drug abuse. In the case of drug abuse, researchers are not investigating gender differences — and should be doing so.

RESEARCH RECOMMENDATIONS

With an acknowledgment that most of the health problems in this age group are behavioral and community based, the following research recommendations are made:

Position Statement

Researchers should involve the diverse populations of female adolescents in the design, implementation, evaluation, and dissemination of health interventions and research activities. In doing so, there should be an effort to weave science-based methodologies into these processes to the maximum extent possible.

Normal growth and development. More research is needed on "normal growth and development" for the diversity within the adolescent female population. For example, what is the normal time for the onset of menarche may differ from one ethnic group to another; distinction and subsequent understanding must clarify these differences. Normal growth and development must be studied at physiological, psychological, and sociological levels as expressed in the diverse populations. Examples of areas to be studied under this topic include:

- breast development, hair growth, and development of genitalia;
- race and ethnic differences and an acknowledgment that "average" is not necessarily "normal;"
- effect of sexual abuse on physical and social development and the impact of assaults on normal development;
- onset of menarche and population differences;
- longitudinal work to determine normal growth and development; and
- normal development of sexual identity from infancy on and how that plays out in young females' lives and sexual orientation.

Health-compromising behaviors. The major causes of morbidity among female adolescents are largely, but not totally, related to their behaviors. To examine the determinants, pathways, consequences, and protective factors (assets and resiliency) of health-compromising behaviors, these behaviors should be addressed individually and in constellation. These behaviors include risky sexual behaviors; drug, alcohol, and tobacco use; and delinquency and victimization.

Risk factors must be studied, looking at the causes and the subsequent consequences. These risk factors include:

- poverty,
- victimization,
- racism and marginalization,
- school failure,
- disability,
- dietary and physical activity patterns that are antecedents of adult disease, and
- childhood behavior problems.

Research must be directed at understanding the disorders of adolescence: gynecological disorders including endometrial and menstrual, and mental disorders including depression, anxiety disorders, eating disorders, and suicide.

Prevention, identification, and treatment should be sequence based, targeted appropriately, and not generic, and evaluation must be over the long term to age 21 at least. Research is recommended for:

- physical and sexual assault prevention;
- new treatment modalities and prophylaxis for STDs;
- oral one-dose treatments;
- oral-administered partner treatments;
- science-based, female-adolescent-specific research targeted appropriately; and
- longitudinal studies to evaluate long-term impact.

Methods of research need to be re-evaluated and redefined, and community-based partnerships for participatory research should be fostered. For example, many studies are funded for too short a time frame to adequately involve communities. Working with communities should be a priority and diverse community stakeholders should be involved in the research design. Specifically, methods of research should be:

- multidisciplinary,
- multilevel (biological, psychological, and sociological),
- crosscutting,
- participatory,
- longitudinal,
- cross-generational, and
- qualitative in order to inform future research and to generate hypotheses.

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REPRODUCTIVE AND MIDDLE YEARS

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BACKGROUND

The validity of gender-specific health issues for women was recognized with the creation of the Office of Research on Women's Health (ORWH) in 1991. Research recommendations, founded on hard scientific data, have mainly focused on the major divisions of a woman's life span. The NIH mandate for the inclusion of women and minorities in all research studies reflects the understanding that women's health involves not only gender-specific concerns, but also the contribution of culture and ethnicity to the overall health status of women. Our objective is to expand current research by identifying strategies needed to examine the effects of ethnicity, culture, sexual orientation, socioeconomic status, and disability on the health of women.

PROGRESS AND GAPS

Women of Color

More than one-fourth (27 percent) of all women in the United States are women of color. Current ethnic and racial classifications include African American, Hispanic, Asian/Pacific Islander, Native American, and Alaska Native. This classification system is often misleading and inconsistent. For example, data on Hawaiians, Samoans, and other Pacific Islanders is often aggregated with data for Asian Americans, yet their circumstances and histories differ greatly. Similarly, there is great differentiation between Asian Americans and particular issues relevant to subgroups within Asian Americans gets lost in the aggregate data.

Current research studies are making some effort to distinguish among the various Hispanic subgroups (e.g., Puerto Rican, Mexican, Cuban) regarding health behavior and health outcomes. However, there is no similar breakdown in categories among other racial/ethnic populations, reducing the validity and specificity of data. Acculturation and intergenerational factors need to be given greater attention in the data collection. Studies are needed to address the health concerns of the Asian/Pacific Islander and Native American populations. Our literature survey highlighted some specific health problems among ethnic groups as they are currently classified (Table 1).

Access and Screening

Access to health care is a key concern for women of color. In 1995, 46 percent of uninsured women of all ages were women of color.[79] For instance, Caucasians are most likely, and Hispanics are least likely, to have employer-sponsored medical insurance in their own name, or in the name of another individual. Hispanics are most likely to be completely uninsured when compared to Caucasians.[36] Geographic disparities in the location and number of facilities make it difficult for many women of color to have access to health care. Concerning Native American women, for example, there are only two Indian Health Service (IHS) units east of the Mississippi River. Greater access to health care facilities is needed for all women of color. Fear

TABLE 1. Specific Health Concerns of Different Groups

Ethnic Group	Health Concerns
Asian American	Hypertension, Tuberculosis, Hepatitis B, Cancer, Diabetes
Hispanic	Obesity, Diabetes, HIV/AIDS, Alcohol, Occupational Health Hazards
Native American	Alcohol, Fetal Alcohol Syndrome, Substance Abuse, HIV,* End-Stage Renal Disease, Hypertension, Heart Disease, Exposure to Environmental Toxins, Diabetes
African American	Diabetes, Obesity, Hypertension, Depression, HIV, High Rates of Cancer, Lupus, Low-Birthweight Babies, Alcohol, Occupational Hazards

*Very few data exist on Native Americans and HIV.

of undocumented legal status being revealed may also be a factor in preventing women from accessing health care services. Among Asian Americans, this prevents women from utilizing health services and reporting domestic violence or occupational health hazards.[79] There is need for research on what is the impact of managed care on health outcomes for different subgroups and populations. Our group discussed the varied barriers for minorities to access managed care which includes biophysical, economic (such as transport, child care, job retention, etc.), and cultural barriers. Little is known about how minorities are faring with managed care. For example, in Hawaii, HMOs do not track ethnic data. However, the Agency for Health Care Policy and Research is funding a study on Hawaii's Quest Program (Medicaid) and its effectiveness. Thirty percent of its clientele is Native Hawaiian. The Quest Program has put AFDC clients into HMOs. Research indicates that AIDS patients are treated differently on the basis of socioeconomic status. This study related particularly to men, who were able to leave HMOs to seek better care. Further studies need to be conducted to determine whether HMOs appropriately care for women of color of different socioeconomic level with AIDS.

Fitness and Health

Obesity, a condition associated with diabetes, hypertension, and cardiovascular disease, is a problem for many women of color. It is related in part to their sedentary lifestyles and to the “diets of poverty” (high in fat and low in fruits and vegetables) that many consume. Native American populations are the most likely to be overweight or obese, which is defined as excess body weight for height. In 1987, nearly 60 percent of all American Indian women on reservations and 63 percent of urban American Indian women were obese. Based on data from 1982-1984, 1988-1991, and for 1991 for women 20 to 74 years of age, the percentage of overweight women ranged from 12 percent for Asian women, to 31 percent and 50 percent for non-Hispanic white and black women, respectively. Hispanic immigrants, who have resided in the United States for less than 15 years, are less likely to be obese (25 percent) than more acculturated immigrants who have lived here for more than 15 years (35 percent). Asian-American women, in general, have the lowest rates of obesity. As income rises among both black and white women, the percent of obese women declines, the percent of normal weight women increases, and the percent of underweight women remains nearly constant.[79]

Contraception[98,99]

The Philadelphia meeting mentioned some medical technologies that are still being researched. However, issues of reproductive control/abortion are still ignored. Still 50 percent of pregnancies are unplanned.[79] Research emphasis is still lacking for the development of new contraceptive methods for women to meet the various social, cultural, and physiological needs to different groups of women. More research is needed on the varied sexual needs and practices of different groups of women. While there are studies underway on microbicides, new barrier methods, and improved oral contraceptives, these studies need to focus on special needs of different ethnic and racial groups in order to meet their varying circumstances.

Infertility[100–103]

To date, there is inadequate understanding of why women of color underutilize infertility treatments. Some NIH-supported research exists on infertility among African Americans. Additional research is needed on the factors among different ethnic populations that lead to infertility. Issues that need exploration include examination of stress, diet, PID, and environmental toxins as causes of infertility among women of different ethnic/racial groups. Currently, NIH is supporting a study that is analyzing differences in the causes of infertility in minority and non-minority populations. While this comparative study is important, research on infertility within ethnic groups is necessary.

Birth Outcomes

Incidence of low-birthweight babies varies considerably by race and ethnicity of the mother, the highest incidence being among African-American women. Immigrant black couples, when compared to native black couples, have a lower incidence of low-birthweight babies. The incidence of low-birthweight babies among immigrant blacks is similar to that among white couples. Black babies born in more segregated cities have higher rates of infant mortality than their black counterparts born in less segregated cities, another suggestive finding that does not fully explain the differential incidence.[79] More research is needed on the factors that contribute to these outcomes. For example, according to Hayes-Bautista, et al., Latinos have high complete nuclear family rates and lower rates of low-birthweight babies as compared to blacks.[32] Access to prenatal care may contribute to birth outcomes as well. Half of Cambodian and Laotian women do not begin prenatal care during their first trimester and have higher birth risks as a result.[79] For example, folic acid has been shown to have a preventative effect for neural tube birth defects if supplemented before neural tube closure, which occurs less than 30 days after conception (i.e., the first trimester). Lack of prenatal care, such as information on birth defects, has an adverse impact on birth outcomes.[92,93]

Infectious Disease and STDs

Tuberculosis is four times higher among Asian Americans than in the general population. Hepatitis B and certain genetic abnormalities are more common among Asian subpopulations.[79]

The *Morbidity Mortality Weekly Report* (MMWR) September 1994 issue reported on AIDS among racial and ethnic minorities in the United States in 1993. It was indicated that there was a substantial variation in the modes of exposure to HIV. Diaz, et al. found that, in Hispanic women, the predominant exposure to HIV was a result of injection drug use.[4] Black women reported the greatest number of cases of AIDS among women.[79] There is a need for culturally sensitive AIDS prevention programs, with special emphasis on issues of drug use and unprotected sex. Special consideration should be given to the contribution of ethnicity and the degree of acculturation to understanding the spread of AIDS among different populations.[7]

PMS[94–97]

Research on PMS has been restricted to Caucasian women until recently. Currently, NIH is supporting two initial studies on PMS among African-American women. However, the prevalence of PMS and characteristics of different populations need to be studied and understood. Family history, depression, and cultural aspects of PMS and their impact on different populations need to be examined, which neither of the studies underway address. There is also a need for cross-cultural research in this area. For instance, there have been studies examining the prevalence of PMS among Jewish women compared to Caucasian women.

Substance Abuse

There is little data regarding ethnic and gender variation in how drug users perceive the need for treatment or predisposing factors that lead to such variation.[16] One study we found stated that even though the rate of alcohol consumption and mortality related to alcohol has decreased nationally, certain high-risk racial and ethnic groups may not benefit from this reduction.[43] For example, reductions in heavy drinking observed among whites were not observed among African Americans and Hispanics.[50] High rates of alcoholism exists among Native American communities (e.g., incidence was nearly 21 per 100,000 for ages 25 to 34 years).[79] Prevention efforts targeting drinking and heavy drinking among ethnic groups must be renewed and intensified.[50] The strong desire to maintain community social status has contributed to low utilization of treatment services for alcoholism and substance abuse in some ethnic groups.[79]

Osteoporosis [82–91]

An increased risk for osteoporosis and osteopenia exists among Asian-American and Caucasian women.[79] There is a NIH study underway to test the relationship of gene variants to bone mineral density, suggesting a gene for osteoporosis. The study tests the relationship of gene variants to bone density and osteocalcin among African-American and Caucasian women. Similar studies need to be conducted for other women of color groups, especially groups susceptible to osteoporosis and osteopenia.

Mental Health

Ethnicity affects utilization of mental health services. Underutilization of mental health services has been documented among Chinese Americans. Asian Americans often avoid seeking services due to fear of being ostracized in their communities.[79] In order to examine the effects of culture and socioeconomic status in mental health service utilization, primary data collection in large and diverse samples is needed.[22]

Cancers

Dangerous jobs may expose women of color to certain cancers to a much greater extent than whites. Lifetime risk for cervical cancer among black women is 2 per 100 (more than double that for white women), and age-adjusted death rates for black women are more than 2.5 times that for whites. Black breast cancer patients have a worse prognosis overall, a worse prognosis within each stage, and present with more advanced disease than either Hispanic or white breast cancer patients. A greater incidence or more aggressive tumors could result in a later stage at diagnosis and the poorer survival rates that make breast cancer a disease with lower incidence but higher mortality among black than white women.[79] A substantial difference in breast cancer incidence and mortality was shown among Hispanics, Native Americans, and Non-Hispanic whites in New Mexico.[78] This raises concerns in controlling the disease, as well as the desire to further investigate etiological factors.[18] Among Asian Americans, immigration to the United States from Asian countries increases - sive generations. Presently, there is little knowledge regarding the etiology of this discovery. Categorization of Asian subgroups and determination of generational status should not be overlooked in designing breast cancer studies.[80] Appropriately designed etiologic studies, in various racial and ethnic groups, could provide new insights into risk factors and preventative and treatment strategies.[15]

Violence

Between 1987 and 1991, the rate of violent crimes against women was highest among white women, followed by blacks, and then Hispanics. However, in 1992-1993, black women fell victim to violent crimes more often than either white or Hispanic women.[79] Kantor, et al. found an increased risk of wife assault by Mexican- and Puerto Rican-American husbands. The presence of cultural norms sanctioning wife assault in any group regardless of socioeconomic status is a risk factor for wife beating.[19] Injury rates were found to be highest among inner city minority women for nearly every major cause of injury and should be considered a priority health concern.[78]

Poverty and Urban Health

Poverty and socioeconomic factors were referred to in only a cursory way in the 1991 Hunt Valley Report (see pp. 12–13). A focus on poverty affects the way in which research is conducted and misses the importance of the socioeconomic gradient in health, disease, and mortality, and the fact that some diseases (e.g., breast cancer and melanoma) are inversely related to social class.

ORWH should recognize that the official poverty measure has been found inadequate by a National Academy of Sciences panel (1995), which recommended that the measure be totally revised. Also, ORWH needs to emphasize that the March 28, 1994 guidelines on the inclusion of women and minorities in clinical research state that “the understanding of health problems and conditions of different U.S. populations may require attention to socioeconomic differences involving occupation, education, and income gradients.” (*Federal Register*, 59(59), Mon., March 28, 1994, p. 14512.)

WOMEN WITH DISABILITIES

Sexuality and reproductive health issues. Women with disabilities have the same sexual feelings and desires as all women and the same reproductive health needs as women in general, yet these feelings, desires, and health care needs have been fundamentally ignored by health care providers, families, and even women with disabilities themselves. Because women with disabilities have often been viewed as being asexual, little information exists regarding their sexuality, entering into relationships, reproductive health, and parenting. New information has recently become available on the health care practices and sexuality of women with disabilities (ref. Nosek), pointing to the need for additional research.

Access and screening. Women with disabilities face substantial barriers that limit their access to health care services including physical, attitudinal, and policy barriers; lack of information about how disability affects health; limited finances; inappropriate health care coverage; and insufficient personal assistance. Although these barriers are beginning to be addressed through laws such as the Americans with Disabilities Act (PL-101-336), they continue to be prevalent in our society. In a recent study conducted by the Center for Research on Women with Disabilities, 31 percent report having been refused health care because of their disabilities. Research issues and access to preventive screening need to be addressed.

Fitness and health.[139] Little information is available regarding physical activity patterns (U.S. Department of Health and Human Services, 1996), weight management, nutrition, and stress management of women with disabilities.

Physical activity. Women with disabilities often are unable to exercise adequately due to a number of barriers including functional limitations, fatigue, lack of access to exercise facilities and equipment (including adaptive equipment), lack of financial resources, and lack of transportation.

Weight management. Both over- and underweight can be serious problems for women with disabilities. Immobility can result in obesity that can lead to health problems such as increased cardiovascular morbidity. Underweight may indicate poor nutrition and can increase the risk of pressure ulcers, osteoporosis, and fatigue.

Nutrition.[137–139] Little is known about the long-term nutritional needs of women with disabilities; most nutritional research has focused on the acute stages of disability. Women with disabilities may not eat a nutritious diet due to lack of functional abilities to prepare food, lack of funding for personal assistants to prepare food, lack of financial resources to buy nutritious food, lack of transportation to purchase food, and lack of knowledge regarding adequate diet.

Stress management.[127–136] Women with disabilities are at increased risk for perceived stress when compared with men with disabilities and when compared with able-bodied women. Stress has serious implications for health.

Secondary Conditions

The broader issues of health and wellness for women with disabilities are frequently overlooked by our health care system. As important as health and wellness messages are to able-bodied people, they may be even more important to women with disabilities whose independence and quality of life often require maintaining their current level of function. Of particular concern is the prevention of secondary conditions — any disabling condition that occurs more frequently among persons having a primary disabling condition. Among women with disabilities, some of the most frequently reported secondary conditions include pain, osteoporosis, chronic bladder infections, fatigue, depression, and weight management (Turk, et al., 1997; Nosek, et al., 1997; Vines and Shackelford, 1996). Information on the incidence and prevalence of secondary conditions is limited.

Infectious diseases. Vaginitis and urinary tract infections (UTI) are frequently reported among women with disabilities. A disproportionately high percentage of women with disabilities have never had counseling and testing for sexually transmitted diseases or HIV/AIDS.

> *Bowel and bladder management.* The ability to control body functions is critical for maintaining independence, self esteem, work, and personal relationships. Many disabling conditions can lead to compromised bladder and bowel function.
>
> *Violence.* Violence is a serious problem for women with disabilities. Results of a recent study by Nosek, et al. (1997) found that physically disabled women are at the same risk of physical and sexual abuse as able-bodied women but experience abuse over longer periods of time and have fewer resources to help them leave an abusive environment. Women with cognitive, psychiatric, or sensory impairments may be at even greater risk. In addition to the types of abuse experienced by all women, women with disabilities are sometimes abused by withholding needed orthotic equipment, medications, transportation, or personal assistance required for essential activities of daily living.

Substance Use and Abuse

Tobacco.[126] Women with disabilities who have impaired pulmonary function are at increased risk from smoking, yet a greater proportion of women with disabilities smoke compared to the general population.

Alcohol and other drugs.[141–158] Women with disabilities sometimes use alcohol and other drugs as a result of problems adapting to their disabilities, pain, and spasticity. They may have had substance problems prior to the onset of disability. In addition to the negative effects on health that these substances can have for able-bodied women, they can cause additional health problems for women with disabilities whose bodies are already compromised (e.g., decreased renal functions). These women may have impaired cognitive function or may be taking one or more medications that can interact with alcohol or drugs.

Lesbians with Disabilities

Lesbians with disabilities face significant problems in obtaining health care. In addition to the barriers encountered by women with disabilities, disabled lesbians face additional barriers associated with prejudices due to their sexual orientation. Little information exists regarding the health care experiences of lesbians with disabilities.

Pharmacokinetics[81]

Recent studies have shown differences, based on hard scientific data, between men and women in the pharmacokinetics and pharmacodynamics of drugs. Genetic variations among different populations in drug metabolism have also been documented. Further research is needed to identify possible variations in drug metabolism, particularly for drugs with narrow therapeutic indices. Research in this area needs to continue to expand and further evaluate gender-related health issues.

RECOMMENDATIONS

Women of Color

Access and screening. There is a need for research on the impact of managed care on health outcomes of different subgroup populations. Since 50 percent of pregnancies are unplanned, research is needed to determine why health care delivery systems make access to reproductive health care increasingly inaccessible to racial and ethnic minorities and rural women.

Fitness and health. Research is needed to identify the mechanisms and etiological factors for obesity impacting chronic diseases. Particular attention is needed concerning exercise, prevention of cardiovascular disease, and prevention of diabetes. Research is needed on how exercise has been quantified in different studies for female populations of varied ethnic groups.

Contraception. More research is needed on development of effective, culturally sensitive prevention interventions for different populations and culturally appropriate modifications of safe-sex messages for different populations. Continued research is needed on contraceptive development to understand which contraceptive methods work best for different groups of women. Research is needed to determine the physiological effectiveness, as well as social and cultural acceptability.

Infertility. Research is needed to identify the relationships between environmental factors and infertility among women of color who are differentially exposed to greater levels of environmental toxins than Caucasian populations. As 40 percent of infertility is due to male infertility, there is a need for research on what techniques can be used among different ethnic and racial groups to enhance partner participation in infertility treatment and diagnosis. There is still no data on whether there has been increased infertility among different ethnic groups or just more minorities seeking treatment.

Birth outcomes. Research is needed to find a possible connection between a pregnant woman's diet and fetal loss. If this connection exists, research is needed to determine if this is similar in all racial and ethnic groups.

More research is needed on explanatory factors for low birthweight, such as obesity and insulin resistance.

Research is needed to identify the cultural factors that are predictors of low infant mortality rates among different populations and how this can be transferred to other populations. What are the protective factors in different populations? For example, there is some research on Hispanic women and better birthweight outcomes even for Hispanics of low socioeconomic status. There is also an NIH-sponsored study underway which examines anxiety, depression, health habits, and immune functioning in mothers of low-birthweight babies, the sample is primarily African American.

Research is needed on premature labor and its prevention rates and identified causes in different populations. There is a fair amount of data on different urban populations. More research is needed on other groups.

Infectious disease and STDs. More research is needed on different ethnic populations with HIV, full-blown AIDS, and STDs to determine how the symptoms manifest and responses to treatment. Research needs to address such questions concerning how medications, inhibitors to medications, and treatments work differently for different racial and ethnic groups.

More research is needed especially for populations of women expected to be at low risk for AIDS in small populations such as Native Americans, Native Hawaiians, and Asian Americans who are not usually included in studies. There is some data on Native

Americans, Alaskan Natives, and Native Hawaiians through NNAACP which has a national Native American database.

There is a need for research in women of color and poor women with AIDS to see whether they are treated differently on the basis of access to care.

PMS. Research is needed to examine the family history of depression and the cultural aspects of PMS and their impact on different populations.

Substance abuse. Research is needed for studies on antecedents, risk and protective factors for substance abuse, trauma for different ethnic and racial groups, and the resulting consequences of substance abuse. There is a need to study the linkages between substance abuse, mental health, and comorbidity and trauma, and how these are culturally mediated. Grieving and loss and cultural dissonance, among different populations, need to be researched further.

Osteoporosis. Osteoporosis in specific groups needs to be researched in terms of prevalence, bone loss from age 25, and techniques for enhancing bone mass among different ethnic and racial groups.

Mental health. Research is needed on the efficacy of traditional approaches to mental illnesses. Alternative treatment interventions work for certain populations, as demonstrated among Cambodian women suffering from posttraumatic stress disorder. What we know about depression, anxiety, and personality disorders have largely been defined for Caucasians. More research on mental health for other groups, as well as their responses to different treatment modalities, needs to be examined.

Pharmacodynamics, drug efficacy, and side effects for different populations need to be studied. Similarly, postpartum depression among different racial and ethnic groups needs to be researched. There is a lack of information about the percentage of diagnosed clinical illnesses that contribute to postpartum depression. There is a need to study the factors among different groups that would impact postpartum depression.

Cancers. Research is needed on the relationships between nutrition and chronic disease. Research exists on the influence of diet and environmental factors for cancer in Japanese Americans. Research is needed to find the possible interventions to reverse this trend and to determine if similar trends exist for all women of color.

Violence. There is a need for research to identify and define abuse (physical, verbal, and sexual) among different racial and ethnic populations and how specific cultures contribute to abuse. Research is needed to find out what resources and interventions would be helpful in reducing abuse.

Endometriosis, fibroids, and hysterectomies. While there is a current NIH-funded study that examines potential risk factors for uterine fibrosis, new research is needed on the causes and prevalence of endometriosis and fibroids in these populations.

Research is needed to determine whether alternative treatments for hysterectomies are being offered to women of different ethnic and racial groups. Racial differences in efficacies of alternative treatments need to be researched.

Chronic pain. Research is needed to identify the major reasons for chronic pain among different ethnic groups. Are there physiological differences in pain — psychosocial and cultural determinants? Chronic pain factors need to be defined and evaluated for specific populations (e.g., sickle-cell anemia and Thalessemia) among different populations.

Lesbians. Lesbian health issues are very underresearched. There is a need for research in this population.

Poverty and Urban Health

- Develop and test measures of social class, for clinical and population-based health research, that are most reliable and valid for populations of women that differ by race and ethnicity, sexual orientation (or type of partnership), and age — at individual, household, and neighborhood levels.

- Describe social class heterogeneity in patterns of risk, disease, health, and mortality within racial and ethnic groups by gender.
- Investigate the interrelationship of social class and race and ethnicity for different types of cancers. Why is the gender-cancer relationship direct for some cancers and inverse for others?
- How does the lifetime trajectory of social class and socioeconomic position affect health, disease, and mortality among women? Are there age period and cohort differences? Are there critical inflection points when social class has its biggest impact on women's health? As increasing numbers of women spend a majority of their years in the paid labor force, often working a "double day," will their health profile become similar to men's (e.g., increased rates of smoking and CVD)?
- How can we best conceptualize and measure the material and social resources that have a critical effect on women's health and well being? To what extent are these related to and synonymous with social class and to what extent are they distinct?
- How does the interplay of genetic and environmental (including socioeconomic) factors affect women's health during the reproductive years?
- To what extent does migration and generation in the United States confer a protective effect on women, independent of socioeconomic position? Identify these prospective or detrimental aspects of immigrant women's lives.

Women with Disabilities

Research on body image. What is the impact of acquired or continuing disability on body image and self esteem? Which interventions will prevent social isolation and withdrawal from health-maintenance activities?

Contraceptive research. What are the choices of contraceptions for immobilized patients (ruling out thrombotic risk)? What are the contraceptive options for women with special disabilities such as MS, lupus, cardiovascular conditions, and stroke? Monitor adverse reactions of conventional contraceptive options for women with disabilities and possible interventions to make these options safer.

Infections Research (Non-STDs)

- Urinary tract infections (UTI):
    - interventions to prevent recurrent UTIs in women with neurologic dysfunction, for example, multiple sclerosis, CVA, and CP;
    - low-dose prophylaxis;
    - anticholinergics; and
    - modification in diet.
- Prevention of UTIs in women who use catheters, such as spinal-cord injury and spina bifida:
    - modified catheterization techniques and regimens; and
    - devices that improve sterileness and ease of access to urethral orifice.
- Vaginitis, of which yeast infection is the most common. Traditional approaches to prevent recurrent yeast infections are oral antifungals, vaginal antifungals, and topical antifungals. Are any of these options better in preventing recurrent yeast infections, and which work best: nontraditional approaches, acidophilus, caproic acid capsules, and Vagisil.

Infections Research (STDs)

- Research on prevalence of chlamydia and gonorrhea (and undiagnosed sequelae). Altered manifestations in sensory-impaired women.
- Incidence of abuse as a cause of STDs, chlamydia, gonorrhea, syphilis, and herpes.

Infections Research (Other STDs with Global Sequelae)

Hepatitis

- How often transmitted through transfusions after accidents (hepatitis C and D are not tested in blood transfusions)?
- STD and drug abuse etiologies may not have been picked up because they are overshadowed by other neurologic or medical conditions. What is the prevalence? Should these women be vaccinated?

HIV

- What is the prevalence in women with disabilities?
- Are manifestations different in women with disabilities? Do symptoms of their disabilities mask or mimic symptoms of HIV?

Research Regarding Pregnancy

Prenatal

- How does disability interact with pregnancy?
- What are the mobility adjustments related to pregnancy?
- What are the pressure points with wheelchairs?
- Is bladder dysfunction exacerbated by pregnancy?
- What are the ways to manage pyelonephritis?
- Alternative monitoring for contractions in women with sensory impairment: how effective is home uterine monitoring in these patients?

Intrapartum

- Management of labor: how does induction of labor affect neurologic conditions?
- Appropriate anesthetic agents for women with STI, MS, and CP. Does an epidural have lasting neurologic consequences?
- Increased risk of C-section: is there a true need for it or is a C-section performed because of the doctor's anxiety?
- Management of autonomic dysreflexia: how soon to intervene and what parameters to use.

Postpartum

- How do women with disabilities prepare for parenting?
- What adaptive strategies and techniques are successful?
- What adaptive equipment (disability-specific) is useful?
- How do mothers with disabilities adjust to the transition from pregnancy to postpartum: weight changes, independence issues, need for additional assistance, and incidence of postpartum depression (research on incidence on how to identify, intervene, and prevent).

Access and Screening

- All health clinics must be made accessible for women with disabilities. In addition to removing standard architectural barriers, medical equipment must be accessible.
- Crucial pelvic examinations for reproductive health care are often not obtained by women with physical disabilities, due to inaccessible examination tables. Inappropriate transfers and negative experiences have resulted in neglecting this screening for preventable conditions. Uniform guidelines for true accessibility need to be developed and implemented. Research and training is needed to educate health care providers to perform these examinations on women with multiple disabilities — safely, thoroughly, and in a dignified fashion.
- Breast care is suboptimal in many women with disabilities. Educational formats are not designed to train these women in techniques that would

empower them and educate them on breast health. Screening technology is often not accessible to women with upper body limitations such as CP, SCI, stroke, and MS. For this population, new screening technology needs to be researched to prevent malignancies being missed in such women.

- We must increase the number of physicians and allied health professionals who are knowledgeable about and sensitive to disability issues. Pilot studies to incorporate mandatory disability education, including issues pertaining to women, should be incorporated into certification and licensure for all allied health professionals.

Fitness and Health

- New methods of overcoming barriers are needed to enable women with disabilities to obtain the health benefits of regular exercise.
- Research needs to be targeted at the long-term benefits of exercise for women with disabilities.
- The effects of exercise and fitness on secondary conditions needs to be further explored, including prevention and intervention.
- Further research must be conducted regarding the impact of exercise by severity of disability.
- Research is needed regarding the attitudes of women with disabilities toward participation in physical activity, and the attitudes of individuals who provide services to them.
- Research is needed to overcome the barriers to adequate nutrition for women with disabilities.
- Techniques are needed to promote better weight management for women with disabilities.
- Research is needed on ways women with disabilities can manage stress.

Secondary Conditions

- Research should be targeted at basic epidemiology of secondary conditions. Understanding of the causes, risks, and consequences of secondary conditions must be improved, and effective strategies to prevent them must be developed.
- Multifaceted interventions to prevent secondary conditions must be developed; these interventions must consider the regular monitoring of women's health status and the availability of appropriate assistive technology and community support.
- Results of research findings should be widely disseminated, including translating scientific findings into nontechnical terms and distributing them through consumer-based networks.

Bowel and Bladder Management

Research is needed regarding:

- new technology,
- external collection devices,
- biomaterials for bladder and sphincter reconstruction,
- physiological consequences of disability,
- pelvic floor muscles,
- changes over long time periods,
- bowel irritation,
- stretching of urethra, and
- renal stones.

Violence

- Information is needed regarding the incidence and prevalence of abuse among women with disabilities. Information regarding violence as a cause of disability should be collected.

- Identify risk factors that contribute to violence and abuse against women with disabilities and develop effective interventions to reduce the risk of abuse.

- Health care providers must be trained to recognize the signs of abuse among women with disabilities.

- Battered women's shelters should be made accessible to women with disabilities.

Substance Use and Abuse

- Research is needed to determine the interaction between substances such as tobacco, alcohol, and other drugs, and various disabilities.

- Methods must be developed to prevent and treat substance abuse among women with disabilities.

- Focus should be on substance use and abuse issues for special subpopulations based on sexual orientation, race, and ethnicity.

Lesbians with Disabilities

- Research needs to be conducted to document the health care experiences of lesbians with disabilities.

- Where appropriate, research needs to be conducted on lesbians with disabilities as a separate and distinct population group.

- Heterosexual presumptions should be eliminated from medical history taking and research instruments and should be replaced with more appropriate language (e.g., "partner" or "significant other").

- Funding is needed to develop relevant educational materials that address specific health issues of lesbians with disabilities.

Pharmacokinetics

For research studies that still exclude or do not actively recruit women and minorities, NIH needs to support studies on the bioavailability and drug delivery from a social and biophysical point of view for various racial and ethnic groups.

Since folic acid has been recommended in the prevention of neural tube birth defects, the pharmacokinetics and pharmacodynamics of this vitamin need to be studied among women of different populations.

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PERIMENOPAUSAL YEARS

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BACKGROUND

The 1991 Hunt Valley conference, building on the work of the U.S. Public Health Service Task Force on Women's Health (USPHS, 1987), helped to establish new research priorities for the study of women's health issues, with particular attention focused on the perimenopausal to mature years. Participants in the Hunt Valley conference used the conventional definition of midlife that structures the life span analyses of most national health databases — the chronological ages spanning 45 to 65 years (USPHS, 1992). The menopausal transition is one of the unique aspects of a woman's middle years and participants in the Hunt Valley Conference identified the lack of knowledge about the fundamental biologic processes involved in menopause.

During midlife women also begin to experience many of the major chronic illnesses and Hunt Valley conferees emphasized the importance of determining how risk factor profiles change during midlife and which prevention strategies could be most effective for reducing morbidity during old age. Leading causes of death among women 45 to 64 years of age include: cancer, heart disease, stroke, chronic obstructive pulmonary disease (COPD), and diabetes. There is a large difference in cancer death rates for African-American and white women, with the cancer death rate being 29 percent higher for African-American women in this age group. The death rate for heart disease is 150 percent greater among African-American women than among whites. Death rates for women are 61 percent lower than for men. Lung cancer and COPD death rates have increased dramatically for women owing to smoking. Diabetes is an important underlying cause of death for women as well as an important primary cause of death. Arthritis incidence begins to increase in the middle years as does women's limitations as a result of it. The prevalence of osteoporosis increases over every subsequent decade of the life span. Disability also begins to rise during the middle years (National Center for Health Statistics, 1995). Women have higher rates of depression and anxiety disorders than do men, but there is no evidence of an increase in the rates of mental illness for midlife women.

Conference participants emphasized the confluence of physical and psychosocial changes occurring during midlife and their significance for health and health promotion as well as disease prevention and treatment. During midlife, women experience major transitions in social roles and life circumstances, including divorce, loss of a spouse through death, and changes in caregiving roles for their children and elderly relatives. In addition, many women are combining employment with demands related to their nurturant roles (USPHS, 1992). Finally, the perimenopausal experiences of women from differing socioeconomic, ethnic, sexual orientation, and disability groups remains to be described.

CONCLUSIONS FROM HUNT VALLEY

The major recommendations for research from the Hunt Valley Conference (USPHS, 1992) focused on three themes:

- understanding the effects of endogenous and exogenous estrogen on health;
- understanding the effects of behavior on health; and
- understanding differences in health status among socioeconomic, racial, and ethnic groups of women.

Effects of estrogen on health. Long-term risks and benefits of estrogen therapy for symptom management and prevention remain uncertain. Trials to assess fractures, heart disease, breast and other female cancers, cognitive function, and quality of life, as well as all cause morbidity and mortality, were recommended. In addition, observational studies to assess the risk of breast cancer among women treated with estrogen and combination hormone therapy were recommended.

Tracking the normal transition to menopause remains incomplete. Studies were recommended to:

- characterize changes in endogenous estrogen and other endocrine levels across the menopausal transition;
- describe cellular and tissue-specific effects of estrogen and estrogen deprivation in bone, breast and cardiovascular tissues; and
- examine mechanisms by which estrogen, progestins, growth factors, androgens, and neuropeptides may induce cell transformations and promote tumor growth.

In addition, participants identified the need to develop and test alternatives to estrogen for treatment of perimenopausal symptoms and prevention of diseases (heart disease, osteoporosis) for women who cannot use estrogen therapy. Other recommendations included studies of the effects of early menopause (chemically, surgically, or diseases-induced) in breast cancer survivors, and effects of hormone therapy for this group of women. A final recommendation was evaluation of the long-term consequences of in utero exposure to diethylstilbestrol (DES).

Behavior and health. A variety of research priorities related to behavioral effects on health were identified, including studies of:

- long-term weight management, including interventions to increase physical activity levels;
- optimum clinical decisionmaking strategies for women with common chronic conditions, such as cardiac disease; and
- stressors that most influence women's health and the biologic concomitants of stress for midlife women.

Screening. Given the increasing prevalence of chronic conditions during the middle years, early detection efforts could make a significant impact on women's morbidity and mortality during old age. A final recommendation included consideration of optimal approaches for cholesterol and bone density screening for women.

Focus on Special Populations of Women

The Hunt Valley conferees gave special emphasis to the importance of social, genetic, and biologic determinants of differences in health status among women of different socioeconomic, racial, and ethnic groups. In addition, the participants recommended study of the determinants of disability and injury in women of various socioeconomic, racial, and ethnic groups. Development and testing of research strategies to incorporate in studies examining the relationship of ethnicity, culture, sexual orientation, socioeconomic status, and disability to women's health was recommended.

SCIENTIFIC PROGRESS SINCE ESTABLISHMENT OF ORWH

Many of the research priorities identified at the Hunt Valley conference have begun to be addressed in a series of multisite studies as well as in singlesite, investigator-initiated research programs. In addition, there have been several significant meetings convened to extend and support the science related to perimenopause. For the purposes of the following discussion, menopause is said to have occurred when a woman's menstruation ceases for a period of 1 year. Menopause is marked by the last menses. The perimenopausal period encompasses the premenopausal years during which a woman is approaching menopause but continues to have regular cycles, the cessation of menstruation, and the postmenopausal period of 1 year after menopause (WHO, 1996).

To date, two large NIH-sponsored studies have begun to address women who are postmenopausal, linking hormone therapy to health outcomes. The Women's Health Initiative (WHI) and the Postmenopausal Estrogen and Progestin Intervention (PEPI) trial, as described below, include large samples of women who are postmenopausal, many of whom were enrolled in these studies during their 50s and 60s.

Women's Health Initiative

This multisite, controlled clinical trial includes over 160,000 postmenopausal women from 50 to 70 years of age sampled nationwide. The aims of the study include evaluating three preventive interventions (preventive hormone therapy, dietary modification — low fat, high fiber, and calcium/vitamin D supplementation) with multiple disease endpoints, including heart disease, breast and colon cancer, and osteoporotic fractures among others. In addition to the clinical trials, the study includes a cohort of nearly 100,000 women who will be followed for 10 years along with the women in the clinical trial. This study should help clarify the role of hormone therapy in long-term prevention and its relative benefits and risks. The WHI study design emphasizes recruitment of underrepresented ethnic groups of women by targeting funding to sites where large populations of African-American, Asian-American, Native American, and Hispanic women are likely to be recruited. The total enrollment of these populations will not assure adequate statistical power to analyze effects separately, but some analyses can be conducted within groups that will add to knowledge of how women of different ethnic groups age (Roussouw, et al., 1995).

The Postmenopausal Estrogen and Progestin Intervention Trial

The purpose of the PEPI trial was to examine the effects of conjugated estrogens and a variety of progestogens (micronized progesterone as well as medroxy progesterone acetate) given continuously or cyclically on risk factors for heart disease. Participants (n=875) were healthy postmenopausal women 45 to 64 years of age who were randomized to one of the estrogen or estrogen and progestin regimens and followed for 3 years. Results indicated that ERT and HRT improved lipoprotein patterns and lowered fibrinogen levels without adverse effects on blood sugar of blood pressure. A high rate of endometrial hyperplasia occurred in women using ERT who had a uterus. Women treated with ERT or HRT gained bone mass at the hip or spine (Writing Group 1995, 1996).

NIH Menopause Workshop

In 1993, the National Institute on Aging and the National Institute of Nursing Research cosponsored a conference on menopause for the purpose of generating a research agenda to guide studies of menopause. In particular, the workshop's goals included: 1) defining the status of the current scientific and medical knowledge base on menopause; 2) identifying deficiencies in knowledge and in methodology necessary for quality studies on menopause and the menopausal transition; and 3) formulating promising areas for future research. For the purposes of the workshop, menopause was considered as a biological transition in women's lives, one which many women associate with changing biology and aging bodies. Embedded in the context of women's lives, menopause has personal, social, and cultural significance. Although women's experience of the bodily changes of menopause and aging are inseparable from the context in which they experience them, scientists have not yet integrated the perspectives of multiple disciplines to provide a full accounting of women's midlife experiences.

Proceedings of this conference were published in a special issue of *Experimental Gerontology* (volume 29, 1994). Ethnic differences in the menopausal experience and endocrine transitions were identified as significant issues about which scientific information was lacking.

Study of Women's Health Across the Nation

In 1995, the National Institutes of Health launched the first large-scale national study to examine the health of women in their middle years (40s and 50s). Designed to track the health of nearly 3,200 women during the transitional years of middle age, this study is focusing on physical, psychological, and social changes that occur during midlife. One special feature of the Study of Women's Health Across the Nation (SWAN) Study is the inclusion of a large proportion of African Americans, Hispanics, and Asian Americans. The study is based at seven research centers across the United States. Initially, 15,000 women 40 to 55 years of age were surveyed, and 3,200 women have been selected to participate in the longitudinal component of the study. Measures at the different sites will include changes in body composition, bone density, and cardiovascular function, risk factors for cardiovascular disease and arthritis, endocrine measures, and sexuality. In addition, investigators will study effects of socioeconomic status, lifestyle (diet, physical activity, smoking, and alcohol consumption), social support, and occupational factors on health in midlife women. Menstrual bleeding patterns will be monitored and linked to diet, exercise, and well being. Social and personal aspects of women's lives, such as their relationships with family and friends, commitment to work, community values, and attitudes about aging, along with access to health care, will also be studied. This study is sponsored by the National Institute on Aging, the National Institute of Nursing Research, the National Institute of Child Health and Human Development, and the National Institute of Mental Health.

World Health Organization: Research on Menopause in the 1990s

This report summarizes a WHO conference on Menopause held June 14-17, 1994, in Geneva, Switzerland. The report of a WHO Scientific Group reviews current research on menopause including studies of symptoms and their treatment, and effects of menopause on the cardiovascular and skeletal systems. The Scientific Group assessed the relevance of existing data to women in developing countries. The report includes a discussion of the importance of contraception for women approaching menopause (i.e., in late premenopause) and examines the benefits of hormone therapy in reducing the risks of cardiovascular diseases and osteoporotic fractures in postmenopausal women, and the effects of such therapy on the risks of cancers of the breast, endometrium, ovary, and cervix.

GAPS IN KNOWLEDGE

A review of research published and in progress since the Hunt Valley Conference reveals that a number of gaps in knowledge about women's health during the perimenopausal period remain.

Limited Longitudinal Data about the Menopausal Transition

Although the menopausal transition is by definition dynamic, there remain few longitudinal studies with frequent sampling of endocrine levels to help characterize women's endocrine patters across the menopausal transition. One study of the perimenopause has incorporated daily sampling of urine specimens obtained across several menstrual cycles (Santoro, et al., 1996), but the followup was limited to 6 months. The Massachusetts Women's Health Study incorporated long-term followup of women across the menopausal transition, but endocrine sampling was done infrequently (McKinlay, et al., 1992). A longitudinal study conducted by Rannevik and colleagues also incorporated endocrine measurements, but at 6-month intervals (1995). The SWAN Study, in progress, will include a subsample of women who will provide annual samples, and a subset of whom will provide daily urine samples, for one cycle during each year of the study. Taken together, these efforts will contribute to characterizing the endocrine events of the menopausal transition as well as women's bleeding patterns and a variety of events that are part of midlife. This work is needed to help characterize normal vs. abnormal bleeding patterns and their endocrine correlates, and to assess the extent to which health in midlife is a product of menopause, life events, and the aging process.

Culture, Ethnicity, Lifestyle, Disability, and Menopause

Although women from some cultures do not complain of symptoms, such as hot flashes, and few use hormone therapy (Lock, et al., 1998; Lock, 1994; Avis, et al., 1993), there has been little study to explain why this is so. Cross-cultural comparisons are needed to fully account for why symptom patterns differ and what, if any, elements of lifestyle account for these differences. Studies of endogenous estrogen levels among women from cultures or ethnic groups, in which the prevalence of symptoms is low, are needed to determine if hormone levels mediate the differences. Little is known about how women with disabilities experience the menopausal transition and the consequences of their choices for prevention of osteoporosis and heart disease.

Physiologic Changes and Consequences for Health

Physiologic changes during the menopausal transition remain poorly understood, including the effects of changing endocrine levels on:

- bleeding disorders, some of which may result in unnecessary hysterectomies;
- symptoms women experience during and after the menopausal transition (e.g., hot flashes, depressed mood);
- emergent symptom complexes or recently defined diseases such as interstitial cystitis and fibromyalgia;
- pregnancy and fertility issues;
- urinary incontinence; and
- thyroid disorders.

Immune Functioning

Immune function in perimenopausal women has not been well characterized across the menopausal transition. Nonetheless, there are data indicating changes in women's immune response during pregnancy and across the menstrual cycle (Polan, 1988; McKane, 1994; Stimson, 1988). These findings suggest that the menopausal transition may produce endocrine changes that could influence the expression of immune disorders.

Also of concern is the effect that menopause has on long-term chronic illnesses in which immune functioning is altered, such as HIV/AIDS, lupus, thyroid disorders, scleroderma, rheumatoid arthritis, and endometriosis. For example, as the population of women with HIV/AIDS grows older and continues to survive, research should focus on how this disease will manifest within the perimenopausal period.

Fertility Issues and Menopausal Concerns

Later-in-life pregnancies and fertility issues lasting into the fourth decade have begun to emerge as women's lifestyles and patterns of participation in the labor force have changed. Some women are attempting to become pregnant during their 40s and 50s, and others are seeking safe and effective contraception. Whether the prevalence of early menopause is increasing is uncertain.

Mental Illness

Little understanding exists of the impact of mental illness on perimenopausal women, and few studies exist regarding established or acquired mental illnesses at this age. Prevalent mental illnesses of particular concern include: depression and bipolar disease. Understanding of the onset of mental illnesses during the perimenopausal period and of their relationship to the physiological changes occurring during the transition to menopause is limited (Matthews, et al., 1994). Grief experiences during midlife are likely to be linked to divorce, widowhood, and loss of parents and contemporaries (Avis, et al., 1993). Differentiating chronic mental illnesses that preceded menopause from those developing during the menopausal transition is essential to elucidating risk factors for these problems and designing appropriate treatment. In addition, fully understanding the pharmacokinetics of antidepressant drugs in a changing endocrine environment remains to be accomplished (Hamilton, 1996).

Context of Life in the Perimenopausal Period

Midlife is often equated with menopause, yet other events occur during this part of the life span. There is a lack of understanding about many aspects of women's lives that affect their health, directly and indirectly (Kaufert, 1994; Woods, 1996). Among these are:

- the spiritual dimension of women's lives and how they make meaning of their lives;
- the meanings of menopause and responses to the menopausal transition among women of different ethnic and socioeconomic groups;
- lack of rituals for and dealing with grief in some groups;
- concerns of women without children regarding their family support during old age; and
- concerns of women who have children, including prolonged financial dependency of some children.

Violence

The prevalence of violence among midlife women is unknown and likely to be underestimated. The cumulative effects of exposure to childhood sexual, physical, and emotional abuse, adult exposures to domestic violence, and exposure to other violent crimes such as rape, have yet to be fully understood. Their consequences for mental health and for somatic disorders among midlife women merit investigation (Plichta, 1995).

Hormone Therapy Effectiveness

Studies of effects of hormone therapy have been prevalent, with the bulk of the work emphasizing clinical effectiveness of therapies rather than the effects of changing endogenous endocrine levels on health. The majority of these studies have focused on white women. In most cases, endogenous endocrine levels have not been studied when women begin using hormone therapy. To be completed are longitudinal studies tracking long-term benefits and risks of hormone therapy and studies of women from ethnic groups, especially African Americans, Asian Americans, Pacific Islanders, Native Americans, and Hispanics. Taken together, findings of the PEPI trial, combined with the results of the Women's Health Initiative, will begin to fill this gap.

Alternative and Complementary Therapies and Natural Hormonal Approaches

Only recently has the large proportion of the public using alternative medicine been recognized, and women are particularly likely to be using both allopathic and alternative medicine approaches (Eisenberg, et al., 1993). Nonpharmacologic or alternative approaches to menopausal symptom management may include dietary modification, such as inclusion of phytoestrogens and soy supplements, and herbal preparations (Kronenberg, 1995). In addition, women report frequent use of exercise and cognitive strategies to manage symptoms (Shaver, 1994). Further investigation of alternative therapies is needed to establish their effectiveness as well as their safety, particularly when combined with hormone therapy. In addition, studies of alternative therapies used by different ethnic groups of women could shed light on the differences in rates of symptoms reported by women from different ethnic groups.

Decisionmaking About Treatment

Midlife women are increasingly confronted with decisions about adopting treatments such as hormone therapy for preventing diseases of advanced age. Nonetheless, little is known about how women make decisions under conditions of uncertainty. Moreover, little is known about how health professionals support women in the decisionmaking process and the development of decision aids related to hormone therapy is just beginning. Little understanding exists about the decision processes used by women across varying socioeconomic and ethnic groups (Rothert, et al., 1994).

Managed Care and Midlife Women's Health

Early evidence suggests that midlife women may experience difficulty obtaining services related to menopause, such as counseling about hormone therapy, in some managed care environments (Livingston, et al., 1994). Studies are needed to examine the impact of managed care arrangements on women's ability to access preventive services, screening for disease (such as cervical and breast cancer), and to obtain counseling regarding health promotion and prevention, including use of hormone therapy for prevention of diseases of advanced age.

Understanding of Informed Consent

A gap exists in researchers' understanding of the meanings of informed consent within certain populations. Cultural differences in beliefs about informed consent may influence how researchers are perceived and the willingness of consumers to participate in research studies.

Environmental Concerns

Understanding of the health consequences of environmental exposures for perimenopausal women is limited. Cumulative exposures to reproductive steroids, or other environmental factors that can cause endocrine disruptions, have begun to be examined, but little is known about their effects among different socioeconomic and ethnic groups. Research is needed to clarify the effects of genetics and environmental exposures to toxins linked to occupation, lifestyle changes or choices such as number of children, nutritional intake, work patterns, and stress. To date, some investigators are beginning to examine the role of the environment in the development of breast cancer and osteoporosis, but investigations of environmental factors and health outcomes among different socioeconomic and ethnic groups are needed.

Systems for Information Dissemination

Women have traditionally been the keepers of health in their communities and have had traditions of exchanging information about health and healing within their social networks. For some women, access to the Internet has multiplied their sources of information in a dramatic way. Information is not only disseminated to women by their health care providers, but by the communications media through technological resources such as personal computers, or books and magazines. Indeed, some health care providers may not be as well informed about new developments as their patients who have access to accurate and timely information through Internet resources. Women are asking questions that health care providers cannot answer because of differences in their access to information. Treating highly informed patients represents a new challenge. How new information and technologies are disseminated to health care providers and who receives what information remains to be identified. For women experiencing the transition to menopause, information is often conflicting, as exemplified by the results of studies of hormone therapy and breast cancer incidence (Stanford, et al., 1995; Colditz, et al., 1995). Some women will increasingly have access to information, but the information may be difficult to interpret without consultation from health care providers adequately trained to interpret it.

The Federal Government is attempting to enhance information flow through a women's information source begun in 1997: 1-800-994-woman. It is an effort at establishing quicker and more accurate communication, but there remains a need for a clearinghouse for health information that includes interpretation of the results of studies and their implications for treatment.

Rural Health Care

Access to and quality of rural health care is a continuing concern of both health care providers and consumers. The availability of appropriate care for women during the menopausal transition may be limited in areas of low population density. Development of technologies to advance health care during the menopausal transition for women residing in rural communities is needed.

Medical Training

Gaps exist in training of health professionals, resulting in a lack of support for women during the perimenopausal period. Women identify their dissatisfaction with their health care, emphasizing their perceptions of a lack of empathy from health care providers, their need to be heard, and their need for multidisciplinary approaches to diagnosis and treatment. These perceived characteristics of providers may support women's use of alternative therapies, or not accessing health care at all, due to their lack of trust in the health care system's ability to understand their concerns. Training should emphasize producing health care practitioners who are informed about the perimenopausal period in a woman's life and women's special health care needs, and who can communicate effectively about issues ranging from changing physiology to symptom management and strategies for prevention of diseases of advanced age (Weisman, 1996; Kaplan, et al., 1996).

CHANGE IN QUESTIONS SINCE HUNT VALLEY

Since the Hunt Valley Conference in 1991, several important social and health care changes have occurred.

Access to Information

Changes in women's health research have begun to reflect changes in women's access to information. The prevalence of computers in women's homes has increased, allowing access to the Internet as a source of information. In addition, some women have access to large numbers of cable television channels and other media forms that influence their health care decisionmaking processes. Of concern is the fact that some women remain at a disadvantage — those who are poor and cannot access information in their own languages. Researchers have begun to use computer-mediated technologies for menopause education and aids to decisionmaking (Mort, 1996).

Growth of Managed Care

Since 1991, managed care has grown dramatically and little is known about how these new health care financing arrangements will affect women's access to and use of services. Some studies indicate that managed care may benefit women with respect to some services but not others (Bartman, 1996).

Changing Models of Health Care: Emphasizing Holistic, Alternative, and Complementary Care

Health care providers have begun to move from concentrating solely on individual diseases to looking at the health status of the whole patient. This change is significant for understanding issues related to the menopausal transition and appropriate prevention and therapeutic efforts.

Changing Science

The Hunt Valley report began to broaden the understanding of the perimenopausal period to encompass the socioeconomic and ethnic differences in women's experiences. Moreover, the menopausal transition is viewed as a dynamic process without a discrete beginning or end and with much diversity. Since the Hunt Valley conference, there have been several important indicators of scientific progress in studying women's health during the perimenopausal period.

- There has been evidence that investigators are moving beyond studies that evaluate either biological or social changes across the menopausal transition to studies that incorporate indicators of multiple dimensions such as the cognitive, emotional, social, and biological dimensions of health.
- Interdisciplinary collaboration has become necessary to achieve integration of biological, psychosocial, and cultural dimensions of health.
- There is evidence of greater ethnic variability in study samples, as exemplified by the Women's Health Initiative and the SWAN Study.
- Investigators have moved beyond studying whether estrogen has effects on a variety of functions to studies of how estrogen and other sex steroids work.
- Researchers have begun to do the longitudinal work necessary to answer questions about the dynamic changes of the menopausal transition.

RECOMMENDATIONS

The overall goal of this agenda is to enhance the health and health care of women from diverse backgrounds and experiences, into and beyond the perimenopausal period, to enable them to engage in personally valued activities. In order to achieve this goal, we recommend the following:

Investigate lifelong developmental and contextual influences on the perimenopausal transition including physiological (e.g., endocrine, immune, genetics), socioeconomic, cultural, ethnic, and lifestyle (e.g., diet, activity) dimensions. In order to accomplish this research objective, we recommend:

- research approaches using the Anderson Model to guide multilevel analysis and using multidisciplinary collaboration to study diverse populations of women (Anderson, 1995);
- a proposed paradigm shift in which women help to set the research agenda by informing researchers about what questions women want to be answered; and
- studying some special populations in order to gain a window to understanding other special populations and the population as a whole.

Specific topics recommended for study include:

- basic biological processes across the menopausal transition;
- experiences of symptoms such as hot flashes and bleeding and how women make meaning of them as a basis for self care or seeking health care;
- mental health problems (especially depression) that can appear or continue into this period and the biological impact of the menopausal transition on mental health;
- relationships between cognition, emotion, and immune response (psychoneuroimmunology) during the menopausal transition as a basis for understanding how culture, lifestyle, and behavior affect immune response and chronic health problems;
- fertility management spanning pregnancy prevention, pregnancy care, and fertility enhancement;

- the life cycle course of health behaviors, such as nutritional intake and exercise patterns, and cumulative environmental exposures, including workplace exposures, as they are modified by pregnancy, birth, breast feeding, and menopause;
- environmental exposures (i.e., endocrine disruptors) and workplace stress — their consequences for midlife health;
- genetics and specific health problems such as cancers (breast cancer);
- midlife women's experiences of HIV/AIDS and the menopausal transition;
- midlife women's experiences of violence and models of violence prevention; and
- health care needs of special populations within this transitional period.

Enhance information dissemination and exchange for consumers and providers through the following efforts:

- identify information appropriate for special populations;
- promote understanding of the relationship between women and their health care providers and factors that enhance trust;
- develop a clearinghouse on perimenopausal issues that will include evaluation of information through mechanisms such as those used for evidence-based practice and the U.S. Preventative Services Task Force;
- investigate informed consent and ethics related to the conduct of research with different ethnic and socioeconomic groups; and
- study patient-provider communication patterns and effects on health outcomes.

Advance understanding of the therapeutic interventions available to women during the perimenopausal period:

- use of allopathic, alternative, and complementary medicine and their relationship to primary, secondary, and tertiary prevention (e.g., spirituality, vitamin therapy, alternate care providers);
- use of hormone therapies and interactions with genetics, other systemic conditions, environmental factors, and alternative therapies;
- patterns of use of hormones and alternative therapies in special populations including their use by women with HIV/AIDS; and
- understanding of therapies such as SSRIs and evaluation of them with respect to outcomes such as leaving violent relationships and changes in SES.

Studies of the effects of health care delivery system models that will encompass:

- training of health professionals;
- time spent with patients;
- provider-patient interactions; and
- women's access to health care and specific services as these are each linked to health outcomes.

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POSTMENOPAUSAL YEARS

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BACKGROUND

Currently, more than 35 million women, or one-third of the female population of the United States, is postmenopausal.[1] By the year 2000, 38 percent of women in the United States will be at least 45 years old, and by 2015, 45 percent of women will be in this age group.[2] As the population of older women continues to grow, it becomes increasingly important to expand the existing scientific knowledge base so that effective strategies can be developed to optimize the health status of postmenopausal women.

The major annual causes of death among U.S. women are cardiovascular disease, lung cancer, and breast cancer. Women between the ages of 45 and 64 make nearly 60 percent of their ambulatory care visits to family and general practitioners, internists, and gynecologists. Of these specialties, women received 55 percent of care from family and general practitioners, 22 percent from internists, and 24 percent from obstetricians and gynecologists.

Postmenopausal women have a higher level of chronic illness throughout life than men. In addition to heart disease, lung cancer, and breast cancer, these conditions include hypertension, diabetes, and colon cancer. Obesity is at epidemic proportions in postmenopausal women, contributing significantly as a risk factor to cardiovascular disease, diabetes, and arthritis.[3]

CONCLUSIONS FROM HUNT VALLEY

The Hunt Valley working group that focused on the perimenopausal to mature years identified three high-priority themes: understanding the effects of endogenous and exogenous estrogen on health, understanding the effects of behavior on health, and understanding differences in health status among socioeconomic, racial, and ethnic groups. More specifically, the working group members recommended that researchers study:

- the effects of hormone replacement therapy on heart disease; breast, uterine, and other cancers; osteoporosis; and mental health;
- the changes that occur in a woman when she reaches menopause;
- the effect of early menopause on the health of women; and
- the psychological, physical, and emotional effects on women as they change roles.[4]

Focus on Special Populations

Guiding all the efforts of ORWH is an overarching principle that biomedical research must be targeted to American women of all races, ages, and socioeconomic and ethnic groups.[5] This principle upholds the *NIH Guidelines on the Inclusions of Women and Minorities as Subjects in Clinical Research*, which states that "since a primary aim of research is to provide scientific evidence leading to a change in health policy or a standard of care, it is imperative to determine whether the intervention or therapy being studied affects women or men or members of minority groups and their subpopulations differently."[6] Therefore, this working group focused on examining the health status and health outcomes of special populations of postmenopausal women including racial, ethnic, and cultural origins; socioeconomic status; women living in rural and urban settings; lesbians; and women with disabilities, among others.

SCIENTIFIC PROGRESS SINCE ESTABLISHMENT OF ORWH

Since the establishment of ORWH, questions have increasingly been asked concerning the acquisition of scientifically sound evidence on the promotion of health and the prevention of disease in postmenopausal women. In addition, a heightened awareness has evolved regarding the heterogeneity of special populations and the need to focus on health issues specific to each diverse group. This heterogeneity is influenced by numerous factors such as environment, education, traditional and alternative medical practices, and access to health care. Accordingly, a growing recognition has emerged for the need to use qualitative research to develop research questions in special populations of postmenopausal women.

Health Behaviors

Many modifiable risk factors have been associated with diseases prevalent in postmenopausal women such as heart disease, cancer, and diabetes.[7] However, the interrelated behavior patterns that lead to many risk factors are dependent upon elements such as education and economic and social conditions, and these elements can vary greatly among different special populations.

Smoking. More than 140,000 deaths of U.S. women in 1990 were attributed to smoking. In fact, tobacco use has been identified as the single most important preventable cause of premature death and disease, such as coronary heart disease, chronic obstructive pulmonary disease, and lung cancer.[2] Furthermore, the age at menopause among smoking women is about 2 years earlier than nonsmoking women, which may further enhance coronary risk.[8]

The percentage of women who use tobacco fluctuates considerably among racial and ethnic groups. Asian-American women have a lower smoking prevalence (10 percent) than the average for all American women (25 percent), but this 10 percent overall smoking among Asian-American women varies for different ethnic subgroups. For example, Chinese-American women exhibit lower rates (7 percent) than do Japanese-American (19 percent) and Filipino-American (11 percent) women.[9] Smoking prevalence for Native American women varies by reservation, from a relatively low 14.7 percent in the southwestern states to a markedly higher 57.3 percent in the plains states.[10] Additionally, in recent years, smoking has declined among the upper socioeconomic classes for African-American and Caucasian women but not among Hispanic women, who appear to smoke at a slightly higher rate as their income increases.[8,11] African-American women are less likely to quit smoking than other ethnic groups and are more likely to smoke more high-tar, high-nicotine, and mentholated brands, which could serve to elevate the risk for CHD, cerebrovascular disease, and lung and other cancers.[12]

Alcohol. The average life span of women who are alcoholics is reduced by 15 years due to alcohol-related disorders such as cirrhosis of the liver and a higher incidence of alcohol-related accidents and suicides. Other alcohol-related disorders include hypertension, obesity, anemia, malnutrition, decrease in bone density, gastrointestinal hemorrhage, and early menopause.[8]

Rates of alcohol consumption differ among special populations and subpopulations of women. More Caucasian women are frequent drinkers than African-American, Hispanic, or Asian-American women.[2,13] Native American women are especially affected by alcohol consumption; their death rate is six times higher for alcoholism than other U.S. women, five times higher for liver diseases caused by alcohol abuse, three times higher for homicide and motor vehicle accidents, and twice as high for suicide.[6] Lesbians may be more likely than heterosexual women to abuse alcohol[14–16] (especially older lesbians[17]) and to have special recovery issues.[18]

Physical activity. Physical activity has demonstrated health effects pertinent to postmenopausal women on management or prevention of hypertension, coronary disease, diabetes mellitus, osteoporosis, osteoarthrosis, urinary incontinence, cancer, and moderate sleep complaints, among others.[19,20] For example, physical activity during leisure time and at work has recently been associated with a reduced risk of breast cancer for postmenopausal women.[21] However, older women exercise less than older men and also less than younger women and men. Caucasian women are most likely to exercise, followed by U.S.-born Hispanic, Asian-American, and African-American women, respectively.[2] Furthermore, physical inactivity predominates in populations with lower income and educational levels.[9]

Population recommendations to engage in regular physical activity have been found to be distinctly applicable to postmenopausal women.[20] Two encouraging specific instances of positive effects of physical activity on mortality and morbidity of postmenopausal women include higher levels of heart rate variability (low heart rate variability is a risk factor for coronary heart disease and cardiac sudden death),[22] increased bone mineral density, and maintained muscle strength.[23]

Nutrition. Awareness of nutritional practices beneficial to postmenopausal women — such as increasing consumption of vegetables, fruits, and fiber, and decreasing consumption of fat — has heightened significantly. Examples of the link between nutrition and health for postmenopausal women include:

- low incidence of breast cancer in Japan is attributed to the role of diet;[24]
- breast cancer risk factors, such as postmenopausal body weight and fat distribution, are directly related to nutrition;[25]
- calcium supplementation reduces bone loss experienced by Japanese-American postmenopausal women;[26]
- higher caffeine consumption results in significantly increased bone loss in comparison to lower caffeine consumption among postmenopausal women with below median calcium intakes;[27] and
- the intake of vitamin E from food by postmenopausal women is inversely associated with the risk of death from coronary heart disease.[28]

Screening. Access to preventive health care services — such as blood pressure monitoring, Papanicolaou test, breast examination, and mammography — has improved for many postmenopausal women. However, significant variations still exist in the use of these services among different groups of women and different health care specialists.[8] Twenty-nine percent of minority adults do not receive preventive care services compared with 26 percent of Caucasian adults. Some minority groups, such as Puerto Rican (38 percent), Mexican (39 percent), and Vietnamese (47 percent), are much less likely to receive these services.[29] Postmenopausal women, especially non-Caucasian groups and lesbians, have lower rates of preventive health tests.[7,30,31] Although separating the effects of ethnicity and socioeconomic factors on screening rates is difficult since a number of women within each ethnic group are socioeconomically disadvantaged, studies have shown that women who have limited disposable income or are uninsured are less likely to be screened due to factors such as screening cost, time lost from work, and transportation and child care costs.[32–34] Factors that appear to improve the likelihood of postmenopausal women of color obtaining screenings include:

- tailoring messages, based on individual needs and circumstances, from physicians (especially effective for African-American women and women of low socioeconomic status);[35]

- personal contact by telephone from acquainted women (particularly among women with low to moderate income);[36]

- personal visits and home-viewed videos, but not written translated materials sent by post (proven useful for Asian-American women);[37] and

- receiving an educational program (proven useful for eastern band Cherokee Indian women in North Carolina).[38]

Immunizations. Immunizations for influenza and pneumococcal pneumonia are recommended by the Advisory Committee on Immunization Practices[39,40] and the U.S. Preventive Services Task Force,[41] but their overall use is low in those at high risk for these infections, especially among U.S. minority populations.[42,43] The higher mortality among women of color, compared with Caucasian women, from pneumococcal pneumonia and influenza may be partly explained by the lower rates of administration of effective vaccines among women of color. However, the promotion of immunizations and other preventive measures among individual minority patients by individual physicians may be unsuccessful without communitywide interventions that address the minority group as a whole and set health problems in the broader social context.[44]

Occupational/environmental exposures. Naturally occurring and manmade chemicals and radiation are environmental triggers of cancer. For example, the pesticide DDT is linked to a higher risk for breast cancer in African-American and Caucasian, but not Asian-American, women. Occupational exposure to chemicals and chemical processes have been linked to breast cancer in nursing aides and orderlies, thyroid cancers among dentists and dental assistants, invasive cervical cancers in maids and cleaners,[45] and premature menopause in workers chronically exposed to carbon disulfide.[46,47]

Women in the military have expanded in numbers as well as in roles. There are currently approximately 340,000 women soldiers in both the active and reserve components, about 88,400 of whom are older than 30 years of age, with minority women representing a significantly larger proportion of the military population than within the civilian sector. African-American women comprise approximately 31 percent of women in the military, Hispanic women 5 percent, and “other” women 4 percent, for a total of 40 percent minority women for the Department of Defense (DoD) overall. In 1994, the need for increased research focus on military women was addressed through a Congressional directive which mandated that women be included in all DoD-sponsored research, resulting in the establishment of the Defense Women’s Health Research Program. Furthermore, the 1995 Defense Authorization Act specifies that research needs to include:

- epidemiological research on a variety of deployment issues affecting women;

- development of a database in which to facilitate future research;

- policy and standards issues research; and

- research on interventions that could potentially affect the health and well being of military women.[48,49]

Health Professional-Patient Interaction

There is increasing evidence that ethnicity is an important element that serves as an integrating force to assist postmenopausal women in interpreting their personal experiences with aging and in passing through significant life changes. Ethnicity also influences older women's interactions with health professionals.[50] Cultural beliefs, family values, and traditional health and healing practices are all factors that impact the interactions between postmenopausal women of special populations and their health care professionals.

Communication. The leading reason women change their doctors is because of communication problems (32 percent). Though women of color are less satisfied with their physicians than Caucasian women, they are less likely to change physicians.[51] Language differences are a problem for 21 percent of minority Americans in receiving care: among those who do not speak English as their first language, 26 percent of Hispanic adults and 22 percent of Asian-American adults need an interpreter when seeking health care services.[33] Past negative communication experience in health care settings is a principal reason that lesbians do not receive needed health care.[17,52,53]

Alternative medicine. Alternative and complementary medicine has a tremendous presence in the U.S. health care system. Alternative therapies are being used widely without rigorous scientific research to guide the decisionmaking process.[54] One in three adults used unconventional therapy in 1990. Roughly one in four Americans who see their medical doctors for a serious health problem may be using unconventional therapy in addition to conventional medicine for that problem — 7 out of 10 of these meetings take place without the patients telling their medical doctors that they use unconventional therapy. This utilization of alternative medicine is distributed widely across all sociodemographic groups[12,55] and includes lesbians to a higher degree than the rest of the population.[19,56]

As a response to this growing prevalence of alternative medicine, the Office of Alternative Medicine (OAM) was established at NIH in 1992 to more adequately explore unconventional medical practices. The purposes of OAM are to establish an information clearinghouse to exchange information with the public about alternative practices, to facilitate the evaluation of complementary and alternative medicine (CAM) treatment modalities, and to support research training. The scope of CAM practices addressed by OAM encompasses individual treatment modalities and systems of practices in the following categories: alternative systems of medical practice; bioelectromagnetic applications; mind and body control interventions; herbal medicine; diet, nutrition, and lifestyle changes; manual healing; and pharmacological and biological treatments. Currently funded research topics include: women's health, aging, general medical disorders, stroke and neurological conditions, cancer, HIV/AIDS, addictions, asthma, and pain.

Health systems and policy. A variety of national medical organizations are currently involved in efforts to promote the value of women's health, including the National Academy of Women's Health in Medical Education, the American College of Physicians, the Federated Council for Internal Medicine Task Force on the Internal Medicine Residency Curriculum, and the National Institutes of Health. For example, in 1994, the National Academy on Women's Health Medical Education (NAWHME) was founded with the mission to integrate women's health education into all phases of the medical education curriculum (undergraduate, graduate, and postgraduate). The organization published and distributed its curriculum in 1996: *Women's Health: A Resource Guide for Faculty.* This guide defines women's health within the context of:

- preservation of wellness;
- prevention of illness in women;
- screening, diagnosis, and management of conditions that are unique, common, and more serious in women;
- recognition of the importance of the study of gender differences;
- multidisciplinary team approaches;
- values and knowledge of women and their own experience of health and illness;

- diversity of women's health needs over the life span and how these needs reflect differences in race, class, ethnicity, culture, sexual orientation, education level, and access to medical care; and

- empowerment of women, as for all patients, to be informed participants in their own health care.[3]

Another system impacting the health of postmenopausal women is telemedicine, one of the fastest growing areas in health care technology today. Telemedicine is a high-tech solution to the universal problem of access to health care because of its demonstrated potential to improve access, reduce costs, reduce professional isolation, and improve care quality. However, issues such as security of medical records and the potential liability created by telemedicine suggest that this joining of medicine and technology be approached with caution.[57,58]

Today, applications of telemedicine affecting postmenopausal women include:

- networking large health care groups, linkages among rural health clinics and to a central hospital, and multicampus linking of research centers and hospitals;

- instant access to, and aided search techniques for, gathering information from electronic library collections or databases;

- use of video and satellite relay to train health care professionals in widely distributed or remote clinical settings;

- physician-to-hospital links for transfer of patient information, patient scheduling, diagnostic consultations, research literature searches, and video program distribution for public education on health care issues;

- transfer of diagnostic information such as x-rays or electrocardiograms;

- capturing "grand rounds" on video for use in remote consultation or training;

- video links between physician and patient for diagnostic interview purposes;

- videoconferencing among members of health care teams; and

- various forms of prison telemedicine services.[59–62]

Functional Status and Quality of Life

Quality of life refers to the physical, psychological, and social domains of health. These domains are seen as distinct areas that are influenced by a postmenopausal woman's perceptions, experiences, beliefs, and expectations, which vary widely among diverse populations. While studies of interventions must "show that the observed changes in patients that are due to treatments and programs of care are important and substantial enough to warrant further consideration in medical practice and policy planning,"[63] the changes observed by the clinician need to be focused on the postmenopausal woman's perspective rather than the researcher's or physician's perspective.

Health Effects of Aging

Physical Effects

Cardiovascular/cerebrovascular disease. Heart disease is the major cause of death for all females, except Asian and Pacific Islander females for whom it is the second major cause of death.[10] Heart disease is also a major cause of disability. Menopause has been associated with a significant rise in coronary events as well as a shift to more serious manifestations of the disease.[9] For example, myocardial infarction and coronary death have been commonly observed in postmenopausal women but not in premenopausal women.[64,65] In fact, one in eight or nine women aged 45 to 64 years has clinical manifestations of coronary heart disease, and 23,000 women under the age of 65 die of coronary heart disease annually. In the 55- to 64-year age group, 36 percent of women with clinical evidence of coronary heart disease are disabled by the symptoms of their illness. The lifetime risk of a postmenopausal woman in the United States for coronary heart disease is approximately 31 percent, compared to 2.8 percent each for hip fracture and breast cancer and about 0.7 percent for endometrial cancer. Despite these statistics, many postmenopausal women do not perceive coronary heart disease to be an important part of their illness experience.[66] Recently, socioeconomic status has been determined to be a possible independent risk factor for cardiovascular disease.[67,68]

Cancer. Cancer is the second most common cause of death for all females, except Asian and Pacific Islander females for whom it is the main cause of death.[10] An estimated 62,000 women die each year from lung cancer, which has surpassed breast cancer as the leading cause of cancer death among women. In fact, the lung cancer death rate among women has increased by more than 400 percent during the last 30 years and continues to increase.[8]

The risk of developing breast cancer for women 40 to 59 years of age is one in 26. Although breast cancer occurs more frequently among Caucasian women over the age of 45 than in African-American women in this age group,[2] African-American women and Native American women have a higher mortality rate.[10] In a recent development, adjuvant tamoxifen therapy has been given to large and increasing numbers of women with early-stage breast cancer with promising results pointing toward an additional benefit of likely reduction in the risk of cardiovascular disease in postmenopausal women.[69]

The use of screening techniques, such as mammograms and Pap smears, have proven to be effective in detecting cancer early, thus reducing the number of deaths among women.[70] Unfortunately, numerous obstacles to screening exist, such as:

- lack of medical insurance;
- lower educational attainment for women 50 years of age and older;
- fear of substandard care for and homophobic responses toward lesbians;
- preference toward the use of different traditions by American Indian and Alaska Native women; and
- influences on Hispanic women of migration history, degree of acculturation, and English language proficiency.[71–74]

Gynecological disorders. Approximately one percent of women enter menopause before 40 years of age.[75] Predictors of early menopause include smoking status,[10] more rapid oocyte loss,[76] cytotoxic chemotherapy,[77,78] treatment for cancer during adolescence,[79] and possibly family history.[80,81] Furthermore, a high proportion of premature ovarian failures involve immune mechanisms.[82–84]

Women who have early menopause experience declining bone mineral density for up to 12 years,[85,86] resulting in higher risk for osteoporotic fractures.[87,88] Early menopause is associated with quantitatively higher bone loss than in women with later-onset menopause,[89–91] and it has also been linked to significant positive trends in low back pain.[92] Hormone replacement therapy treatment has been demonstrated to increase bone mass specifically for early postmenopausal women,[100,93] and women who have surgical menopause are more likely to utilize hormone replacement therapy.[94,95]

Surgical menopause with bilateral ovariectomy results in higher atherogenic metabolic risk than in spontaneous menopause, and ovary conservation in hysterectomized women seems to only partially protect against this increase. Again, hormonal replacement therapy treatment has been demonstrated to reverse these atherogenic changes.[96–98] Surgical menopause has also been associated with:

- subclinical cognitive and affective dysfunction, which is improved by estrogen replacement therapy;[99,100]
- reduction in the incidence of ovarian carcinoma;[101] and
- greater discomfort and frequent symptoms of urogenital atrophy.[102]

Urologic disorders. The social stigma of incontinence has been decreasing while the use of medications for urologic disorders, such as antidepressants and estrogen creams, has been increasing. Evidence as to the effectiveness of surgery for incontinence is weak, but it appears that colposuspension may be more effective and the effect longer lasting than that following anterior colporrhaphy and needle suspension. Sling procedures have even less information available as to their effectiveness. Preliminary results appear promising for peri-urethral silicone microimplants in women with an average age of 50 years.[103]

Sleep disorders. Ninety-five percent of the adult population has experienced insomnia. One-third of all people have sleep problems during a given year, and only half of those people consider their problem serious enough to seek medical advice. Women appear to be affected by sleep disorders more often than men, and complaints increase with age. Older people have difficulty maintaining sleep while younger people tend to have trouble falling asleep.[104] Furthermore, midlife women reporting poor sleep are likely to have higher psychological distress and somatic symptoms, especially musculoskeletal discomfort and fatigue.[105–107] Among working women, higher incidences of sleep disturbances and excessive sleepiness are experienced by night and rotating shift workers, with age and family factors (rather than alcohol and caffeine intake) contributing to the differences in types of sleep disturbances experienced.[108,109]

Diabetes mellitus. Diabetes mellitus is the fourth leading cause of death in African-American, American Indian/Alaska Native, and Hispanic women; the sixth leading cause of death for Asian and Pacific Islander women; and the seventh leading cause of death in Caucasian women.[2,10] The prevalence of diabetes for women between 55 and 64 years of age has been found to be as high as 92 percent among Yaqui Indian. The health outcomes also vary among women of different color. For example, the health outcomes of African Americans with diabetes are much worse than those of Caucasians: African Americans are more likely to become amputees, develop end-stage renal disease, be blinded, and die from diabetes than Caucasians.[10]

Osteoporosis. Osteoporosis is a significant cause of bone fractures in postmenopausal women. Among Caucasian women under the age of 75, fractures of the distal forearm are the most common.[2] The risk of a hip fracture for a 50-year-old Caucasian woman during her remaining lifetime is about 17 percent.[110] These fractures can be partially attributed to the fact that women over 50 years of age with osteoporosis have a bone mineral density more than 2.5 standard deviations below the norm. More than one-fifth of Asian-American and Caucasian women are believed to have osteoporosis and an additional 39 percent have osteopenia, a less severe form of osteoporosis. American Indian/Alaska Native and Mexican-American women have an estimated 16 percent occurrence of osteoporosis and a 36 percent occurrence of osteopenia, and African-American women have an estimated 10 percent occurrence of osteoporosis and 29 percent occurrence of osteopenia.[2,10]

Treatment and prevention options for osteoporosis have increased with the recent approval of alendronate (Fosomax) and nasal calcitonin (Miacalcin Nasal Spray).[111–113] Some concern exists that these new agents will unduly reduce the use of estrogen, which many believe should remain the mainstay for prevention of bone loss and fractures in postmenopausal women.[114] Weight-bearing exercise has also proven to be an effective prevention option for treating osteoporosis in postmenopausal women.[115–117] Other promising nonestrogen approaches include a diet rich in calcium and limited in protein, alcohol, and caffeine, and avoidance of smoking.[118]

Obesity. Obesity, a condition associated with an increased risk of high blood pressure, diabetes, heart disease, stroke, some cancers, and joint and back problems, is a serious problem for many postmenopausal women in special populations. The percentage of overweight women ranges from 12 percent of Asian-American women to 75 percent of certain groups of

American Indian women. Immigration status, sexual orientation, and income level are also correlated with weight.[12,17,54,119]

New research has suggested that obesity is a complex biological phenomenon influenced by both environment and genetics.[131] Recent gene and drug treatment advances for obesity include leptin gene therapy[120–122] and treatment with drugs including dexfenfluramine,[123–126] fluoxetine,[127–130] mazindol,[131] metformin,[132–134] bromocriptine,[135] exogenous growth hormone,[136,137] sibutramine,[138,139] cholecystokinin,[140] ephedrine/caffeine combination,[141,142] gliclazide,[143] cimetidine,[144,145] phenylpropanolamine,[146] and orlistat.[124,148]

Oral health. There is an increasing awareness that postmenopausal women need oral health care and a proper integration of oral health and other health care to decrease morbidity and to ensure a better quality of life. Women aged 45 to 54 have a 12 percent prevalence of complete loss of teeth. Some of the most common oral health diseases that occur in postmenopausal women are temporomandibular disease, trigeminal neuralgia, atypical facial pain, pemphigus, burning mouth, discoid and systemic lupus erythematosus, periodontal disease, fibrous dysplasia, and oral cancer. Oral symptoms can be the prodrome to systemic diseases such as anemia, multiple myeloma, Paget's disease of bone, and diabetes mellitus.[149]

Pharmacologic issues. Postmenopausal hormone replacement therapy (HRT) use has fluctuated during the past 50 years due to changes in the perception of its benefits and risks. The present scientifically evidenced benefits of HRT include protection against osteoporosis, an apparently substantial decrease in the risk factors associated with heart disease, relief of urogenital atrophy, decreased urinary incontinence, and improvement of menopausal symptoms. Benefits supported by observational evidence include decreased risk of heart disease, colon cancer, improved verbal memory skills, increased dermal and total skin thickness, improved sense of well being in patients with rheumatoid arthritis, and improvement of emotional stability and depression. However, HRT use is also associated with an increased risk of breast cancer and an increased risk of endometrial cancer in women who have an intact uterus and do not receive progestin.[150–152] Current use of HRT is estimated at more than 6 million women, and several cross-sectional and cohort studies in the United States have reported estimates of the proportion of postmenopausal women who take HRT in the selected studied populations ranging from 12 to 47 percent.[153] Affluent women are most likely to be receiving HRT, but they are at greater risk for breast cancer and relatively low risk for cardiovascular disease. Women of lower socioeconomic status are less likely to receive HRT but may be at greater risk for cardiovascular disease and comparatively low risk for breast cancer. It is therefore possible that a subgroup of higher-risk, less affluent women who may benefit from HRT is being undertreated.[154]

Not all women will accept or tolerate HRT; for these women, alternative treatments for menopausal symptoms include:

- alternative drugs for treating hot flashes, such as clonidine, ceralipride, and megestrol acetate;
- lubricants to counteract vaginal dryness;
- surgery or Kegel exercises to help with incontinence;[91,92] and
- selective estrogen receptor modulators (SERMs), which display potent estrogen antagonist properties in the breast and uterus while possessing estrogen agonist-like actions on serum lipids and bone tissues.[155–157]

Long-term oral contraceptive use has been associated with an increased risk of liver tumors,[158,159] breast cancer,[160,161] a slightly increased risk of developing systemic lupus erythematosus[162] and symptomatic gallstones,[163] a reduced risk of endometrial cancer,[164,165] and, debatably, colorectal cancer.[166]

Mental Health Effects

Depression. Major depression is the most common severe mental disorder among women. Hispanic women are more likely to suffer from severe depression than African-American women, and African-American women are more likely to suffer from severe depression than Caucasian women. Thirty-eight percent of women ages 45 to 64 report severe depression in a given week, compared to 32 percent of women age 65 and older and 43 percent of women ages 18 to 44. On average, the female to male ratio for the prevalence of major depression is 2:1. An explanation for this occurrence, as well as the marked increases in severity of depression with menopause, is that women, in addition to their own burden, are often the primary source of emotional support during difficult times for family members and friends (such as adolescent children, ailing spouses, and aging parents). Depression has also been found to be correlated to demographic characteristics such as less education, lower income, unemployment, lower occupational status, and racial and ethnic discrimination.[2,10,33]

Stress. Daily events have been determined to be generators of stress for women 45 to 64 years of age and, combined with major events, impact physical and psychological health. It is important to attend to women at this stage of their lives from an integrated and interdisciplinary perspective including physiological, psychological, and cultural features.[167]

Sexuality. An estimated one in ten females in the United States is lesbian.[168] Lesbians face ostracism and discrimination from many sources, including some health professionals.[169] Older lesbian women have been “invisible” due to the triple minority status of their gender, age, and sexual orientation. They also may be deeply closeted or especially secretive about their sexual orientation because they grew up before the time of the Gay Liberation Movement. This has resulted in older lesbian women being at risk because health care providers lack information and sensitivity about their concerns.[18] Furthermore, many lesbian clients feel that heterosexual psychiatrists and psychologists suggest that the homosexual lifestyle is subnormal or less preferable.[98] These pressures lead to psychiatric complications in lesbians, such as depression.[99]

Cognitive function. Studies in women who have undergone oophorectomy have shown that menopause is associated with subclinical cognitive and affective dysfunction.[170–172] These women’s cognitive functions, as well as other postmenopausal women’s verbal memory skills, have been demonstrated to improve with estrogen replacement therapy.[173]

Sociocultural Effects

Violence. Evidence is growing that the psychological, physical, and sexual violence to which battered women are subjected contributes to the development of serious health problems including injury, anxiety, posttraumatic stress disorder, chronic pain, depression, gastrointestinal disorders, substance abuse, suicide, and homicide.[174] Violence victims may suffer long-term effects, and it appears that a transgenerational effect projects the impact of violent crimes into the future.[2] Consider that:

- battered women account for 22 to 35 percent of all women seeking emergency medical services and 50 percent of women over 30 years old who have been raped;
- one study found reports of physical abuse in 25 percent of lesbian relationships and 7 percent of rape by female dates;
- up to 50 percent of homeless women in this country are fleeing domestic violence;[175]
- homicide and legal intervention are the tenth-ranked causes of death for African-American and Asian and Pacific Islander females;
- half as many American Indian/Alaska Native women die from homicides and firearm-related deaths as do African-American women; and

- African-American women show the highest rate of victimization, followed by Caucasian women and then Hispanic women.[2]

GAPS IN KNOWLEDGE

Reflecting the diversity of special populations, there exists a wide range of perspectives connected with current gaps in knowledge of postmenopausal women's health. However, five major themes emerge under which specific gaps and recommendations can be identified:

1. health status of special populations of postmenopausal women;
2. behavior and health in special populations of postmenopausal women;
3. environmental exposures and health in special populations of postmenopausal women;
4. health provider's and researcher's interactions with special populations of postmenopausal women; and
5. research methods in special populations of postmenopausal women.

Health Status of Special Populations of Postmenopausal Women

- Descriptive epidemiology informed by special needs of postmenopausal women's subpopulations is lacking.
- A limited understanding of the impact of chronic disease on quality of life in special populations of postmenopausal women exists at a time during which survivorship is increasing.

Behavior and Health in Special Populations of Postmenopausal Women

- Scientific evidence is incomplete for the role of menopause vs. aging in conditions common in postmenopausal years and chronic diseases.
- The most effective approaches for encouraging subpopulations of postmenopausal women to apply scientific knowledge for improvement of women's health are not known.
- Smoking cessation information relevant to postmenopausal women's subpopulations is incomplete.
- The reason(s) that exercise testing for cardiovascular disease is not as useful a diagnostic test for women as for men is not understood.
- Explanations(s) for coronary bypass surgery and angioplasty not being as effective for women as for men are deficient.
- Physician and patient awareness of the need for colon cancer screening is low.
- The effects of hormones other than estrogen are relatively unexplored.
- Comparisons among different estrogen treatments are limited.
- Long-term drug effects (including cosmetics such as wrinkle cream) on postmenopausal women are generally unknown.
- Current information concerning drug and drug interactions in postmenopausal women is insufficient.
- An explanation for gender differences in mental health effects is missing.

Environmental and Occupational Exposures and Health in Special Populations of Postmenopausal Women

- The accumulated effects of premenopausal environmental exposures and lifestyle on postmenopausal health are not fully recognized.
- Health effects of low-level and multiple chemical exposures (e.g., latex) and workplace stressors on postmenopausal women of different subpopulations are not completely understood.

- Concerns related to postmenopausal military women's health including: (1) addressing women's health needs that do not set women apart from men; (2) fit of uniforms, boots, and masks; (3) access to choice of health care; and (4) effects of the Armed Forces' physical testing on disordered eating behaviors.

Health Provider and Researcher Interactions with Special Populations of Postmenopausal Women

- Postmenopausal women of special populations have unique needs pertaining to factors such as socioeconomic status, spirituality, and family that are not always taken into consideration during health care professionals' interactions with these women.

Research Methods in Special Populations of Postmenopausal Women

- Barriers for participation of special populations of postmenopausal women in biomedical research are not fully understood or adequately addressed, including such factors as: (1) transportation, (2) responsibilities (e.g., child care), (3) not being asked to participate, (4) no member of population on research staff, (5) mistrust of the medical research establishment, and (6) access.

- Gaps exist between efficacy research and effectiveness that are particularly relevant to special populations of postmenopausal women.

- Longitudinal studies are currently conducted with insufficient priority.

CHANGE IN QUESTIONS SINCE HUNT VALLEY

- Research questions have taken on a more longitudinal emphasis, which requires more longitudinal studies.

- Research questions are becoming focused more on subpopulations of women, for which prior data collection instruments may be inappropriate.

- Research questions are beginning to shift from a disease-model focus to a health/wellness model focus; therefore, perceptions and determinants of a healthy state in subpopulations of postmenopausal women need to be ascertained.

- Research questions are becoming increasingly multidisciplinary and interinstitutional, with multilevel analysis (e.g., molecular, cellular, population).

- Research questions are reflecting cumulative risk and protective factors.

- Research methodologies are expanding, reflecting a broadening theoretical framework including: (1) instrumentation reliability and validity for special populations (e.g., translation issues); (2) qualitative measures; (3) need to consider broader range of literature (e.g., other countries, multidisciplinary); and (4) new strategies for subpopulations.

RESEARCH RECOMMENDATIONS

Health Status of Special Populations of Postmenopausal Women

- Research should examine descriptive epidemiology on occurrence of risk factors and diseases in postmenopausal women of special populations.

- Definitions are needed of characteristics that influence health status and behaviors to reflect the heterogeneity of special populations.

- Studies need to inspect the health outcome differences in racial subgroups of postmenopausal women.

- Research should explore the impact of survivorship of chronic disease on quality of life as perceived through the special population individual's perspective in terms of the physical, emotional, social, and economic changes they experience.

Behavior and Health in Special Populations of Postmenopausal Women

- Studies should investigate the effect of accumulated risks on specific health problems and special populations of postmenopausal women.
- Research needs to examine the influence of living in Western societies on the increased rate of breast cancer in Asian women in the United States.
- Studies should investigate the health of women with disabilities in the postmenopausal years, including facilitators and barriers to their optimal health.
- Scientific evidence for the role of menopause versus aging needs to be studied in conditions common in postmenopausal years and chronic diseases.
- Research needs to investigate differences between postmenopausal women and men in response to surgical and pharmacological treatment interventions.
- Studies should identify differential risk factors for stroke in postmenopausal women and men and in subpopulations of women.
- Research should examine possible explanations for the differing prevalence of diabetes among subpopulations of postmenopausal women.
- Studies should explore how to improve rates of regular mammography, clinical breast exams, and colon cancer screening, focusing on minority and underserved postmenopausal women through the use of innovative, culturally appropriate strategies.
- Studies should also address ways of improving compliance with followup and treatment recommendations following abnormal diagnostic and screening tests in postmenopausal women. These efforts should include the examination of psychological effects of positive testing.
- Research needs to examine the actions of all natural hormones (e.g., DHEA, natural estrogens, melatonin, human growth hormone, natural progesterone, thyroid hormones) in postmenopausal women.
- Studies should compare the effectiveness of different estrogen treatments in postmenopausal women of different subpopulations.
- Research needs to explore pharmacologic differences in drug outcomes and drug-drug interactions specific to postmenopausal women.
- Research needs to investigate the reasons for drug use and misuse among postmenopausal women of special populations (e.g., Hispanic women share medications and do not follow drug-use directions).
- Studies should delineate mechanisms underlying postmenopausal women's and men's differential sensitivity and responsivity to pain-threshold and tolerance measures. Studies should also validate measures of pain in subpopulations of postmenopausal women, informed by specific cultural beliefs and practices.
- Research should explore possible explanations for gender and age differences in mental health effects. For example, studies need to determine why there is a lower incidence of depression among postmenopausal women than among women under the age of 40, as well as why depression in postmenopausal women is more severe than in women of other ages.
- Research should identify the effects of racism on the health of postmenopausal women in special populations.
- Studies need to explore the mental and physical issues specific to postmenopausal lesbian women.

Environmental Exposures and Health in Special Populations of Postmenopausal Women

- Research needs to explore the effect of environmental toxins on postmenopausal health.
- Studies need to examine the effects of the workplace on postmenopausal low-income service workers (e.g., women who clean buildings and hotels).
- Research needs to investigate the effects of pesticides on postmenopausal migrant workers.
- Studies should explore the nature and outcomes for postmenopausal women of stressors associated with military life.
- Research needs to examine how the stress of war affects postmenopausal women in comparison to men and what interventions, if any, exist to lessen these effects.

Health Provider and Researcher Interactions with Special Populations of Postmenopausal Women

- Efforts should address ways of training health care providers to consider postmenopausal women of different subpopulations in terms of their entire needs — emotional, rehabilitation, social, and financial — when treating illnesses.
- Research needs to investigate how to improve health provider and researcher sensitivity, such as how questions are asked and body language.
- Studies should determine the most effective mixture of health care provider types for delivering health care to special subpopulations of postmenopausal women.

Research Methods in Special Populations of Postmenopausal Women

- Research needs to address the role of incentives for recruitment and retention of special populations of postmenopausal women in studies and to provide allowances for funds in clinical trials for recruitment and retention of participants. These funds would cover costs for recruitment strategies, especially needed to recruit minority and underserved women, and for incentives and other types of flexible and creative retention strategies to maintain compliance and reduce attrition rates in studies. These strategies should assist in increasing the representation of minorities in clinical trial research.
- Research activities need to be coordinated with community hospitals, clinics, and reservations so that postmenopausal special population women can access them. Community "navigators" (laypersons) need to be trained so that they may guide research subjects effectively through the process.
- New strategies for instrumentation reliability and validity for postmenopausal special populations (e.g., translation issues) must be constructed. This should include the use of qualitative measures and a broader range of consideration of multidisciplinary literature and literature from other countries, as well as statistical methods appropriate for evaluation of small-sized samples.
- Studies should increase the use of behavioral research and strategies to accompany medical diagnosis and treatment procedures for special populations of postmenopausal women. Such research and strategies should be designed to improve compliance, educate women, and address health-related quality-of-life issues.
- Research efforts for special populations of postmenopausal women need to transpire through multidisciplinary collaboration to maximize outcomes.
- Additional longitudinal studies need to be funded for special populations of postmenopausal women.
- A clearinghouse needs to be established for rapid dissemination of research findings to researchers, health care providers, and the public, and an inventory and distribution center for intervention materials that have been proven effective.

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ELDERLY AND FRAIL ELDERLY YEARS

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BACKGROUND

In considering the health of older women, the World Health Organization concept of health applies: all aspects of women's physical, social and behavioral, and environmental health are important. It is particularly important to consider the full range of older women's health needs, including physical, medical, dental, sensory, pharmacologic, and psychosocial health; aspects of cognitive and spiritual needs; and the interactions of all health aspects. Across the diverse and growing populations of older women in the United States, these needs require adequate access to, and coordination of, a wide range of health care providers and care givers.

In many ways, older women's health issues are similar to those of the general population (Bee, H., *The Journey of Adulthood*, Prentice Hall, NJ, Third Edition, 1996). Although older populations suffer disproportionately from chronic diseases, lumping all persons older than 65 into a single class is inappropriate. In the 6 1/2 years since the Hunt Valley Report, people are living longer and there has been a 6 percent decrease in disabilities. Examination of older women's health issues requires a review of functional status, prevention, and maintenance as markers apart from age. (Manton, K., *The Threshold of Discovery: Future Directions for Research on Aging*, Report of the Task Force on Aging Research, Department of Health and Human Services, April, 1995).

Women age 85 and older can be considered among the oldest old and constitute a group with differing needs, a greater likelihood of chronic illness, and increased frailty. Evidence in the older population of women with regard to physical and mental health, functional status, health care access, and utilization shows variation by age, social class, culture, and ethnicity. However, there is substantial heterogeneity within age groups and within ethnic groups, indicating a need to further understand aging processes within and across these diverse groups.

The following assumptions underlie this working group report:

- Women outlive men and greater frailty and probability of chronic disease is concomitant with increased longevity.
- Causes of death among ethnic groups are similar, though demographics suggest the order of disease mortality differs slightly.
- Across ethnic and cultural lines, changes in family structure may impact health status.
- Ethnic and cultural groups have different concepts of and attitudes about health, disease, and aging, and different attitudes about their bodies.
- Environmental differences in urban, rural, and island communities require study with respect to access to health care and the effects of pollution.

Using as its baseline the 1991-92 Hunt Valley Report, *National Institutes of Health: Opportunities for Research in Women's Health*, this report examines progress made since 1991 and continued research needs for populations and subpopulations of older women in the following areas: biological and physiological, psychosocial, health practices and interventions, effects of interventions, informal and formal caregiving, provider-client interaction, and methodological issues, with an added section on death and dying research needs.

BIOLOGICAL AND PHYSIOLOGICAL

It is now recognized that women's biological and physiological makeup, health status, health practices, and disease processes differ from that of men and, as such, form a separate base for research study. Growing evidence from research suggests a diversity among populations and subpopulations of women in the United States, impacting diagnosis and treatment.

Progress

- Gains in knowledge have been made in the following disease processes: osteoporosis, cardiovascular and cerebrovascular disease, Alzheimer's disease (AD), and cancer.

- Development of pharmacologic and nonpharmacologic interventions have been made for osteoporosis, cardiovascular and cerebrovascular disease, AD, and cancer.

- Knowledge has increased about the prevalence, causes, consequences, and treatment of urinary incontinence.

- Gains in knowledge continue regarding genetic predictors of the risk for developing AD and the impact of those predictors on treatment.

Research Needs

- Studies are needed to determine the effects of chronic illness and disability, such as AD and other dementias, cancer, and osteoporosis, on the quality of life for older women and frail elderly women.

- Research that results in applications is needed on the biomechanics of older and the frail elderly.

- Research should continue on the longitudinal, multigenerational effects of DES.

- Examination should be undertaken of drug action and effects in relation to age, racial and ethnic groups, and gender.

- Research on multiple drug, drug-food, alcohol, tobacco, and other interactions is crucial.

- Studies are needed on the impact of natural and synthetic estrogens on different physiological systems including the immune, endocrine, and cardiovascular systems, and on cognitive and affective processes, and on sleep.

- The impact of oral health on quality of life and the general health of aging women, as well as on specific diseases, needs to be investigated.

- Research studies need to be conducted on less well known physiologic conditions in elderly women (e.g., angiodysplasia of colon, vertigo, hiatal hernia).

- There continues to be a gap in research studies on alternative or nontraditional health practices on physiological processes and health outcomes. The National Association of Women's Health Professionals (NAWHP) has reported, in public testimony in Santa Fe, New Mexico, on July 21, 1997, that "complementary and alternative medicine has an enormous presence in the U.S. health care system" and "is emerging as a significant area for scientific research and clinical care, with medical, psychological, and sociocultural dimensions." NAWHP recommends to NIH that "scientific studies are needed to evaluate the effectiveness, benefits, risks, and costs" of alternative and complementary medicine.

- Research is needed on the shift from subclinical to clinical conditions in older and frail elderly women.

- Study is needed on multisensory impairment in older women.

- Research is needed for a better understanding of the physiological aging processes across racial and ethnic groups of women.

PSYCHOSOCIAL

An article by D. Sobol entitled “Rethinking Medicine,” published in *Psychosomatic Medicine*, is instructive for study in the health of older and frail elderly women.

> “Thoughts, feelings, and moods can have a significant effect on the onset of some diseases, the course of many, and the management of nearly all. Many visits to the doctor are occasioned by psychosocial distress. Even in those patients with organic medical disorders, functional health status is strongly influenced by mood, coping skills, and social support, yet the predominant approach in medicine is to treat people with physical and chemical treatments that neglect the mental, emotional, and behavioral dimensions of illness. This critical mismatch between the psychosocial health needs of people and the usual medical response leads to frustration, ineffectiveness, and wasted health care resources. There is emerging evidence that empowering patients and addressing their psychosocial needs can be healthy and cost effective. By helping patients manage not just their disease, but also common underlying needs for psychosocial support, coping skills, and sense of control, health outcomes can be significantly improved in a cost-effective manner. Rather than targeting specific diseases or behavioral risk factors, these psychosocial interventions may operate by influencing underlying, shared determinants of health such as attitudes, beliefs, and moods that predispose toward health in general.”
>
> (Source: Sobol, D. Rethinking medicine: Improving health outcomes with cost-effective psychosocial interventions. *Psychosomatic Medicine* 57 (1995): 234–44.)

The effects of spirituality on women’s health is another element of psychosocial processes addressed as needing study. It was suggested that ORWH add to the introductory remarks in the Hunt Valley Report (pg. 4), which reads: “....make more intensive efforts to address the health needs of the whole woman, interweaving both medical and behavioral issues — the body and the mind” the following words “and the spirit.” In addressing the spiritual dimension of older women’s health, questions arise as to the relationship between high levels of health promotion strategies and spirituality and whether spirituality has a positive impact for women with long-term chronic illnesses.

Progress

- There is recognition of the diversity and variability of the aging population, resulting in changed attitudes toward the role of older people in society.

- Older people provide valuable resources to family members and society; they are not simply recipients of care.

- Knowledge is emerging about the transition to retirement.

- Factors associated with successful aging and generativity are being addressed.

- Depression and anxiety are being recognized for their impact on physical and psychological health and on health practices, including on compliance with medications and rehabilitation regimens.

Research Needs

- Research studies are needed on the relationship between self efficacy and positive self image and outcomes such as functional independence and self care as mediated by family and social supports.

- Study is required on the concepts of health (body image), aging, disease, and disability (and causes and consequences of each) as a function of age, knowledge, and attitudes about aging, ethnicity, and cultural background.

- Gaps in information must be addressed between the end of the working years and the transition to the need for assistance and nursing care.

- The developmental course of aging and functional levels must be identified, to allow older people and care givers to know what to expect.

- Research studies are needed on the role of multisensory impairment on personal and social functioning of older women.

- Questions about living environments — including physical and social parameters of older women — produce the need for further research.

- Examination is needed of the influences of spirituality on health outcomes in diverse groups. Studies should demonstrate cross-cultural research in the relationship of spirit, mind, body, and environment and the impact on functional well being and perceptions of aging.

- In light of growing evidence, crucial research must be conducted on the causes, consequences, and interventions related to physical and emotional violence, abuse, and traumatic stress in older women. Methodology should include interface with the peace and justice systems.

HEALTH PRACTICES AND INTERVENTIONS

One of the gaps in women's health research is a lack of documentation of the effectiveness of gender-specific education methods in primary and secondary prevention.

Progress

- Epidemiologic studies have demonstrated the continued importance of health practices and lifestyle factors as risk factors for morbidity and disability in later life.

- There is growing recognition that older persons can change health behaviors effectively.

Research Needs

- Research is needed to study the influence of gender, age, culture, and SES on older women's health practices and the receptivity to lifestyle interventions, and the effectiveness of health behavior interventions in different population groups of older women.

- Evaluation studies need to be conducted on elderly and frail elderly women's use of alternative and complementary health care services, focusing on self care and health education preventive services.

- Studies should examine health and life choices as they impact living arrangements (independent, congregant, family, or institutional) and health care decisionmaking.

EFFECTS OF INTERVENTIONS

Are interventions that are effective for younger women applicable to older women and to the oldest old, and are they applicable across ethnic and cultural subgroups?

Research Needs

- Regarding health behaviors and lifestyles of older and frail elderly women, studies are needed about the differences in intervention applications for exercise, smoking cessation, and nutrition.

- Research studies should be conducted on the effectiveness of interventions on health conditions and health events in the lives of older women and frail elderly women, particularly in regard to:

  - Continence,
  - Falls,
  - Depression and anxiety,
  - Cognitive impairment,
  - Sleep, and
  - Traumatic events such as physical and emotional violence.

- Medication use by older and frail elderly women, particularly HRT and polypharmacy, needs further study.
- Research is needed on patterns of alcohol and substance abuse in the various populations and subpopulations and across the socio-cultural spectrum.
- Research should address the cost of intervention choices for different populations.

FORMAL AND INFORMAL CAREGIVING

"Related to older women's health is the change in living conditions brought about by women working outside the home. This social change is creating change in the caregiving role, geographic disruption, and the demise of the extended family, all of which have changed the whole pattern of intergenerational living. These factors have created caregiving and housing problems of large proportions. Though studies about caregiving exist, agencies which have attempted to address this issue are divided among city, state, and Federal Governments. How can these services be integrated to best serve all ages and economic levels?" (Long, L.G. and Carritt, J., Age and Aging: Women's Health Issues, Public Testimony, Santa Fe, NM, July 1997).

Research Needs

- Research on formal caregiving should address the following questions:
  - How are care givers selected?
  - What training and education is given to care givers, and is it adequate?
  - Is it necessary to have a cultural match between care giver and client?
    - When does that match make a difference?
    - Are there differences among population groups?
  - What are the implications of transition from family to paid caregiving, or a mix of both?
  - What work conditions maintain, strengthen, or sustain quality caregiving?
    - For family care givers?
    - For volunteer care givers?
    - For care givers in institutions?
    - Impact on health status of care givers?
  - Are outcomes measured?
    - Measures of care giver training?
    - Measures of care giver effectiveness, including client satisfaction?
    - Impact of caregiving on care givers?
- Research on family caregiving is needed.
  - What work conditions maintain, strengthen, or sustain quality caregiving?
  - What are the multiple caregiving roles and how are they handled by families?
  - What are the cultural and socioeconomic differences in family caregiving?

  - What are the intergenerational relationships and family dynamics involved in caregiving?
  - Examination is needed concerning the role of older women as care givers.
- Investigation should be undertaken regarding the new models for providing care, including research on the effectiveness of alternative caregiving arrangements for long-term care.
  - Assisted living options.
  - New ways of providing care in traditional settings, e.g., special care units.
  - Role of volunteerism to reduce the burden of care givers.
- Research studies are needed to understand the factors associated with access to care across age, gender, and ethnicity, and on the levels of functioning.

PROVIDER-CLIENT INTERACTION

Little is known about the factors that produce gender differences in the use of health care resources and those that may differentiate women in their health care use patterns. Studies of the experiences of different women with health care providers are needed to determine what factors produce either perceived or real differences in treatment.

- Older people have diverse service needs. Because existing community care systems are fragmented, people may not receive the services they need and available services may not be used. The newly demonstrated regional variations in physician-induced preferences and demand for specific treatments must be integrated more fully into use and cost models.
- Analyses of the costs of illness and of the economic savings of interventions and prevention programs are essential to tracking the efficacy and efficiency of the national health system and in setting research priorities.
- A number of different methodologies exist for computing costs of illness, but new methodologies are needed. Without new methods, many proposed interventions may use incorrect and inappropriate cost-benefit measures.
- Community care systems in other countries provide models of alternate methods of services coordination and delivery. Cross-national research should be conducted to describe and analyze these systems and determine their potential usefulness as models for responsive community care systems in the United States. (Citation: *The Threshold of Discovery: Future directions for research on aging.* Report of the Task Force on Aging Research, U.S. Department of Health and Human Services, pg. 223,242,275, April 1995).

Progress

- Progress has been made in studies that consider gender, age, and ethnicity as separated variables, and investigations have shown how these variables influence provider behaviors and attitudes.
- Studies have provided emerging knowledge of collaborative, multidisciplinary, client-focused management including pharmaceutical care.

Research Needs

- Research continues to be needed to investigate gender, ethnic, and regional influences on health care practices of older persons, especially diagnosis and treatment.
- Studies need to examine the interactions among patients and care providers, particularly among different cultures, ages, SES groups, and defined racial and ethnic groups.
- Research is needed on enhancing patient-provider interaction of elderly and frail elderly and its relation to quality of care, patient and provider satisfaction, prescribing patterns, and health outcomes.

- Characteristics and training of health care providers who provide service to older people need examination.

- Investigation is needed concerning barriers to the receipt of appropriate health care to the homebound and disabled, and of health care to older women in general.

- To help identify barriers to including older women in research studies, informed consent and the decision process for participation in health care or research should be investigated.

- The impact of changing health care financing and delivery systems on subgroups of older women requires study.

METHODOLOGICAL ISSUES

"If the goal of this commentary (sic) is to raise our collective consciousness about the occasional limitations of secondary data analysis and to promote a more self-critical use of this strategy, then what answers do I have to the challenge that secondary data analyses are cheaper and NIH applications with smaller budgets have a better chance of funding? I have none, and I recognize the serious dilemma. But collectively, as independent investigators, applicants, and reviewers, we are not without influence on funding agencies such as NIH...Addressing explicitly in our applications the issue of relative suitability of secondary data for answering a particular research question, compared to new data collection, may have multiple benefits, such as: We will become familiar with a wider set of "public use" data sets; we will become more sensitive to the cost/benefit dimension of different research strategies, and we will have a more acute sense of the difficulties attending a true accumulation of useful scientific knowledge." (Citation: Kasl, S.V., Comment: Current research in the epidemiology and public health of aging — the need for more diverse strategies. Pg. 334, *American Journal of Public Health* 87(3) (1997): 333–34.)

Progress

Progress has been made in understanding the multidimensional quality of life. Well-being measures and methods have been developed.

- Measures of functioning and physical performance have been developed. Performance-based assessments are available.

- Studies have begun to include more diverse populations, i.e., ethnic, racial, and sexual.

- Women are being included in federally funded clinical research.

Research Needs

Measures need to be developed, for nursing home residents, that are culturally and ethnically sensitive for quality of life, SES differences, and different levels of cognitive functioning.

- The oldest old and institutionalized persons need to be included in studies, and the ability to analyze such data by age and gender needs to be developed.
  - – Investigate age in terms of younger elderly (65 to 84) and older elderly (85+).
    - Compare outcomes.
    - Differentiate groups by functional status vs. by age groups.

- Research strategies should be developed to recruit old and oldest-old women, as well as members of all ethnic and SES levels, as research participants and to include community organizations and their members as partners in research.

- Are there circumstances in which it is appropriate to consider age vs. functional status as a criterion for access to care, participation in research, etc.?

DEATH AND DYING

Death now occurs, for many people, as a negotiated decision in hospitals and nursing homes. What is the accepted practice around death decisions? The NIH model has been that of fighting disease instead of approaching death. What is a good death — it is more than just pain management. The impact of HMOs and rationing of care is the compression of morbidity; rationing says, in effect, "we will give you X number of years of good quality of life, and then we have to take care of younger people." Example: Governor Lamb's remark on the duty to die.

Research Needs

Investigation is needed into attitudes toward death as a function of ethnicity, culture, and age.

- Research studies should examine end-of-life decisions, including end-of-life care and cultural and ethnic backgrounds and their influence on such decisions.

- Research is needed on managing death and ethnic and cultural differences regarding:
  - pain management,
  - family support,
  - place of death,
  - dignity,
  - special needs of women as informal care givers for dying persons, and
  - assisted dying.

- Research should include quality of dying and ways to improve the end of life for patient and care providers.

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CAREER ISSUES FOR SPECIAL POPULATIONS OF WOMEN SCIENTISTS

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BACKGROUND

This report reflects the discussions and testimony of the Career Issues for Special Populations of Women Scientists Working Group. For purposes of this Career Issues Working Group, the term "special populations of women scientists" includes female scientists, science students, and health care practitioners identifying with the following population groups: persons with a physical or mental disability; racial and ethnic minorities (including African Americans, Hispanics, American Indians or Alaskan Natives, Asians, and Pacific Islanders), and lesbians.

The working group drew participation from a diverse group of invited participants and workshop registrants who were familiar with the career obstacles confronting many special populations of women scientists. They were asked to focus on the characteristics important to special populations of women scientists and to pursue strategies for improvement that encompassed these unique characteristics. While the proposed solutions were, in many cases, specific for a particular group under discussion, the working group generated recommendations to enhance career development that are common for diverse groups of women.

Women of all races and abilities encounter many of the same experiences and have to overcome similar burdens in their quest for career development and advancement. Working group participants agreed that special populations of women scientists face unique challenges in striving to move forward in their academic and/or medical careers; challenges that transcend common elements familiar to all women scientists. This working group provided a forum conducive to confronting a broad array of complicated issues unique to special populations of women scientists.

The Office of Research on Women's Health (ORWH) of the National Institutes of Health (NIH) convened a meeting in Hunt Valley, Maryland in 1991 to set the research agenda for women's health issues.[1] One of the objectives communicated in the Hunt Valley Report related to the benefits accrued in recruiting more women in science and engineering that can expect to ultimately reduce the disparities in medical treatment and research. This same argument can be supported when addressing inequities in the professional development of special populations of women scientists. Simply increasing their numbers in leadership positions in teaching, research, and medicine could go a long way in defining the problems and diversifying solutions for changes in health priorities and outcomes.

On March 2-3, 1992, a public hearing was held on the topic of "Recruitment, Retention, Re-entry, and Advancement of Women in Biomedical Careers."[3] The purpose of the hearing was to identify barriers and develop a slate of recommendations for action. The following key issues were discussed, along with barriers and recommendations for each:

- Recruiting women to biomedical careers;
- Visibility — role models and mentors;
- Career paths and rewards;
- Re-entry into a biomedical career;
- Family responsibilities;
- Sex discrimination and sexual harassment;
- Research initiatives on women's health;
- Gender sensitivity; and
- Minority women in science.

Women in Science

> *"Women constitute 51 percent of the U.S. population, 46 percent of the U.S. labor force, but only 22 percent of scientists and engineers in the labor force."*[2]

Women have made significant advances in recent years in the field of medicine. For example, in 1990, 20.7 percent of U.S. physicians were women, an increase from 13.4 percent in 1980.[12] In 1995, more than 39 percent of graduates from U.S. medical schools were women, an increase from 13.4 percent in 1975.[5]

While the career status of women, in general and in science particularly, has improved in recent years, gender inequity persists. "Women in science, including medicine, are paid less than men, are more likely to be unemployed or underemployed, receive fewer prestigious awards and honors for scientific achievement, appear far less often on advisory panels making decisions on national science policy and funding, and are, overall, largely absent at the top."[4]

While recruitment of women into science education and careers is critical to addressing the long-term gender disparities, it is equally important to address barriers to advancement for women scientists and health care practitioners. In 1995, female medical faculty represented approximately one-third of all medical faculty, including basic science and clinical medicine. However, as full professors they represented 13.7 percent of basic science medical faculty and 9.3 percent of clinical medical faculty.[5] Likewise, in 1996, less than 10 percent of full professorships in U.S. medical schools were held by women.[13] "Possible reasons for the difference in promotions for women and men have been proposed: lack of proper mentoring from senior scientists, exclusion from the inner circles of departmental politics and influence, isolation within the department and the discipline, conflicts between professional and personal lives, and outright gender bias."[4]

Traditionally, women have assumed primary responsibility for family and household duties. In the current economic climate of two-paycheck families, this traditional role creates career barriers for women. "Increased visibility of women scientists, equitable entry- (and re-entry-) level packages, absolute salary equity, 'family-friendly' policies in the workplace (e.g., adequate child care, family leave, extended tenure), elimination of sexual harassment and other forms of discrimination, and accountability for improving the climate for women scientists — these are strategies that can increase the numbers of women who enter the sciences and maintain productive careers throughout their lives."[4]

Racial and Ethnic Minorities

"(In 1993) underrepresented minorities as a whole were about 23 percent of the U.S. population. Blacks constituted about 12 percent of the U.S. population, Hispanics about 10 percent, and American Indians about 1 percent....As a group, they are only 12 percent of the bachelor's degree recipients in science and engineering, as they are of bachelor's degree recipients in all fields....blacks, Hispanics, and American Indians are more likely to earn degrees in the social sciences than in the natural sciences or engineering."[1]

Six percent of the doctoral degrees in science and engineering fields were earned by African Americans (2 percent), Hispanics (3 percent), and American Indians (1 percent); the most popular field was psychology.[1] In 1996, while 40.9 percent of medical graduates were women, 68.3 percent of female medical graduates were of Caucasian racial origin, 16.1 percent were Asian/Pacific Islanders, and only 10.2 percent of female medical graduates were from underrepresented minorities.[11]

Women of color also do not advance to the highest levels of academic advancement and continue to experience subtle and overt forms of discrimination during their training and careers. They too have similar experiences moving from the instructor and assistant professor levels. "The larger problem facing all minorities in science is the same: to live up to our potential and achieve in our careers, avoiding the pitfalls aided by cultural differences and prejudice. We should focus on what we have in common — our love of science — and what the diverse viewpoints of all minorities and women can contribute to the scientific enterprise."[6]

Persons with Disabilities

Persons with disabilities, both men and women, are also underrepresented in science and engineering. About one in five persons has some form of disability; about one in ten has a severe disability.[7] "In 1993, persons with disabilities were only 6 percent of the undergraduate enrollment, 4 percent of graduate enrollment, 1.3 percent of science and engineering doctorate recipients, and 6 percent of scientists and engineers in the labor force."[1]

Lesbians

Based on several health surveys and studies conducted between 1976 and 1992, there are important epidemiologic differences between lesbians and heterosexual women which indicate that lesbians may be at higher risk and may suffer higher morbidity and mortality from breast cancer, lung cancer, ovarian cancer, endometrial cancer, colon cancer, cervical cancer, and heart disease and stroke.[8] One recent study indicates barriers to care that are unique to lesbians as well as negative attitudes by physicians and medical students that may impact on education and career development for lesbian physicians.[9] However, relatively little is known about the career issues and barriers specific to lesbian scientists and lesbian science students.

PROGRESS SINCE ESTABLISHMENT OF ORWH

The following programs represent achievements towards gender and race equity for women scientists:

- ORWH Program Promoting Re-entry into Biomedical and Behavioral Research Careers for Extramural Scientists;
- Women's Health Initiative Minority Investigator Career Development Award;
- ORWH and NIH Office of Science Education Collaborative Programs targeted for women scientists;
- "Women in Biomedical Careers: Dynamics of Change; Strategies for the 21st Century" Workshop;[10] and
- NIH research supplements targeting underrepresented minorities and individuals with disabilities to promote their entry into biomedical and behavioral research careers.[15]

Other exciting initiatives at organizations throughout the country include faculty development and diversity (Harvard Medical School);[14] mentoring, leadership training, a networking database, and the Academic Climate Study Program (Association for Women in Science); the Women in Health Center at the University of Puerto Rico; studies by the National Research Council's Committee on Women in Science and Engineering;[15] and the Women in Science bill passed by the American Psychology Association in 1996.

Continuing Gaps in Career Advancement for Special Populations of Women Scientists

Respecting institutional culture while urging changes in policy and programs was the underlying focus in several recommendations put forth in the workshop “Women in Biomedical Careers: Dynamics of Change, Strategies for the 21st Century.”[15] Task force deliberations and public hearing testimony served as the foundation for planning this 1992 workshop that was especially significant for introducing recommendations that yielded strategies for enhancing recruitment and promotion of women in science. The discussion in the chapter, “Minority Women’s Perspectives,” presented the complexity of issues unique to minority women, and the need for institutions to provide unequivocal commitment to the special considerations of minority women in biomedical careers.[10]

CAREERS ISSUES FOR SPECIAL POPULATIONS OF WOMEN SCIENTISTS

While progress has been made in identifying relevant issues and barriers, major gaps persist in the broad themes that comprise 1) collecting, monitoring, and disseminating data; 2) monitoring education, training, and professional development trends; 3) improving institutional accountability; 4) enriching communication and networking skills; 5) securing leadership opportunities; 6) enhancing cultural acceptance; 7) attaining mentoring competency; and 8) developing disability and access initiatives targeted for special populations of women scientists.

Collecting, Monitoring, and Disseminating Data

- Lack of awareness of programs that impact special populations of women scientists;
- Insufficient information exchange, recognition, and appreciation of programs that impact on diverse groups of women; and
- Lack of data and dearth of studies on career development issues for lesbians and disabled women.

Monitoring Education, Training, and Professional Development

- Changes in affirmative action policies are threatening all levels of the pipeline;
- Scarcity of special populations of women scientists in industry, academia, and government;
- Difficulty characterizing promotion criteria used for academic and career advancement;
- Excluding experienced women scientists who are changing careers or re-entering the workplace from programs addressing the pipeline will be problematic in the long term; and
- Gender discrimination and sexual harassment.

Improving Institutional Accountability

- Scanty representation of special populations of women scientists in research groups;
- Inconsistent evaluation and review of programs targeted for special populations of women scientist;
- Using the deficit model rather than a culturally sensitive model when interacting with diverse populations of women scientists;
- Unclear expectations for promotion and tenure;
- Gender discrimination in hiring and promotion; and
- Accepting the myths and misconceptions about lesbians as health care providers and researchers.

Enriching Communication and Networking Skills

- Ineffective communication and interaction among students, faculty, and administrative staff;

- Poorly developed skills and venues for career exploration and development (both internal assessment and external appraisal); and
- Unproductive networking opportunities.

Securing Leadership Opportunities

- Dearth of representation in key leadership and policymaking positions; and
- “Mid-career despair” representing stagnation in promotion and advancement beyond the middle management levels.

Enhancing Cultural Acceptance

- Family concerns related to child rearing, elder care, and extended family responsibilities;
- Lack of acknowledgment and acceptance of cultural diversity;
- Overcoming cultural myths and overriding cultural and community influences that define career paths; and
- Identifying barriers that transcend gender.

Attaining Mentoring Competency

- Difficulty finding mentors and role models;
- Lack of rewards for mentors; and
- Problems with critical skills, (e.g., negotiation and conflict resolution).

Developing Disability and Access Initiatives

- Inadequate attention paid to the environmental and physical needs of disabled women scientists; and
- Lack of training programs targeted to disabled women scientists.

CHANGE OF QUESTIONS SINCE HUNT VALLEY

The issues for special populations of women in science have not changed since the Hunt Valley Conference in 1991, except that refinement of ongoing questions have emerged as recurrent themes:

- Greater emphasis on inclusion,
- Promotion and integration of cultures and cultural frameworks,
- Attention to the importance of access, and
- Enhanced recognition of institutional accountability.

RECOMMENDATIONS

The working group focused on determining the opportunities most likely to be successful at solving some of these critical issues. The following recommendations are presented for consideration.

Data Collection, Monitoring, and Dissemination

- Create a comprehensive PHS/ORWH database and facilitate dissemination and publication of data about special populations of women scientists.
- Collect outcome data that demonstrates the effectiveness of programs targeted to special populations of women scientists.
- Develop a database and disseminate information on participation of special populations of women scientists in NIH programs.
- Establish a database of senior special populations of women scientists available for study sections, advisory boards, and recruitment efforts.

Education, Training, and Professional Development

- Continue and expand the ORWH Re-entry Program.

- Aggressively recruit, hire, and retain special populations of women scientists.

- Establish collaborative programs with the Department of Education and the Department of Rehabilitative Services to support the career pipeline.

- Develop and expand scientific programs to support precollege special populations of women.

- Support protected time for research.

- Continue and expand the WHI Minority Investigator Career Development Award to other research areas.

Institutional Accountability

- Maximize attention to special populations of women scientists to realize their full potential, as opposed to marginalizing their status within the organizational structure.

- Build in and formalize evaluation and assessment of principal investigators who receive support to train special populations of women scientists (e.g., RSUM).

- Expand collaborative research programs with minority institutions.

- Expand numbers of special populations of women scientists in study sections, NIH, and other advisory bodies.

- Facilitate mechanisms that enable special populations of women scientists to meet family, work, and community responsibilities (e.g., flexible time schedules and more flexible “tenure clock”).

Communication and Networking

- Expand collaboration and partnerships with underserved community organizations and scientific and professional societies, especially those focused on special populations of female scientists at all levels of the career pipeline.

- Formalize networking opportunities for special populations of women scientists.

- Improve mechanisms for disseminating information on new and existing funding support for grants and training programs.

Leadership and Policy

- Increase collaboration with all U.S. Department of Health and Human Services offices and other federal agencies to assure a sustained focus on careers of special populations of women scientists.

- Support workshops and provide funding to stimulate appropriate professional societies to develop management and leadership training programs.

- Aggressively recruit special populations of women scientists for top leadership positions.

- Encourage private industry and academic institutions to formalize policies for recruitment, retention, and promotion of special populations of women scientists.

Cultural Framework

- Celebrate the uniqueness and promote the acceptance of special populations of women scientists in all areas of the scientific community.

- Support programs that encourage diversity and heightened cultural sensitivity in all facets of the academic and medical environment.

Mentoring

- Work with professional societies and other agencies in defining, generating, and publicizing successful models.

- Clarify roles and expectations of both mentor and mentee before the relationship begins.

- Provide special training, rewards, and recognition for mentors of special populations of women scientists.

- Develop a database of senior scientists who are willing to function as advisors to review papers and discuss career options with special populations of women scientists.

Disability and Access

- Collaborate with other organizations to ensure that the environmental and physical access needs of disabled women are met at conferences and meetings.

- Ensure that disabled conference participants receive housing at the geographically closest hotel; avoid making a disabled attendee part of a lottery system for housing.

- Provide a secure location near the conference site for overnight storage of mobility devices such as wheelchairs and scooters.

- Delegate one person to troubleshoot unexpected obstacles, including knowing the location of the elevators and ensuring that they work at all times.

- Reserve aisle seats for disabled attendees.

- Prearrange complimentary shuttle service for transporting disabled attendees between conference sites, individualize a transportation plan prior to the meeting, and include this complementary service as part of the usual registration fee.

SUMMARY

The working group sought to identify and highlight areas that offer the greatest potential for advancing the careers of special populations of women scientists. A variety of opportunities exist to expand their participation in research careers. Sharing resources, extending partnerships, and implementing these recommendations can yield significant advancement for special populations of women scientists, and have potential benefit for both the scientific and nonscientific communities.

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PLENARY PRESENTATIONS

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The Influence of Culture on Health

I was asked to address how culture influences Hawaiian health. My quick response is to ask how can culture not influence health, since culture is the window through which we view all of our experiences. Even the standards of Western medicine are influenced by European cultural standards of how the body is viewed; what is considered mental illnesses versus what are considered physical illnesses; and who is allowed to mediate or facilitate in a person's health.

However, my long answer is to address three specific areas in regard to the way culture influences Hawaiian health. These are:

- Current practices with regard to health;
- Cultural dissonance, colonialism, and cultural genocide; and
- Research practices.

Current Cultural Practice with Regard to Women's Health

Hawaiians women have very high rates of diabetes, cardiovascular disease, lung, breast and cervical cancer, and high teen pregnancy rates. Culture influences both the reasons that these diseases are so prevalent in the Hawaiian community, and how Hawaiian women decide to get these diseases treated.

Diet

The single most important factor in Hawaiian health is nutrition. People's attitude toward food, of course, is very much influenced by culture. Modern Hawai'i is a food paradise, while also being a garden of temptation. Local dietary practices, which have incorporated the best of all cultures in Hawai'i, tend to be high in fat and salt content, while also being low in fiber.

The traditional Hawaiian diet, on the other hand, was high in fiber and low in fat. Traditional diet programs are popular in Hawai'i today, but getting people to maintain the diet is difficult. The diet does not have enough variety for modern tastes and getting native Hawaiian food, like poi and fish, can be very expensive.

Western Medicine

The treatment of a person's health or body is also influenced by culture. Our research has shown that women, especially, are very uncomfortable with Western medicine. This is especially true for Hawaiian women in rural areas who are having to change to managed care. Unlike 10 years ago, when doctor's were a part of one's community, many people today don’t know their doctors. In a managed care system, you may see your own doctor on one out of every three visits. Also, the time a doctor spends with a patient has decreased. Doctors are not allowed to take the time to get to know their patients.

My father is a rural doctor on the island of Kaua’i. For a long time, he also served as a doctor in the United States. Almost overnight, Hawaiian language became illegal in the schools, Hawaiian practices were devalued, and Hawaiian people were disenfranchised. This happened a mere three generations ago, and many people are still not sure where they fit in the new world order. Its is as difficult to negotiate a middle path between Hawaiian values and practices as it is to chose to walk a purely Hawaiian path, or a purely *haole*, or foreign path. It is the people of my parents and my generation who are beating these new trails, and many people are losing their way.

Health programs have to build on Hawaiian cultural pride and the resurgence of cultural values. They also have to take into account a more holistic view of health. For example, substance abuse and teen pregnancy are family issues, not individual issues. Both men and women who abuse substances affect their families and are affected by their families. Teens who get pregnant do so within a context of values and beliefs and friendships, and they raise their children in that same context. Thus, I believe that most women’s health issues must be contextualized because women rarely operate in a vacuum. Much of what they do is affected by, and affects, their children, their significant others, and their friends.

Research

This interconnectedness of women needs to be reflected in research done with women. Issues such as transportation and child care need to be addressed in research protocols. Followup medical care and insurance also needs to be addressed in screening protocols. What is the point of telling an uninsured woman that she has cancer if she doesn’t have the resources to do anything about it? I would also suggest that the role of a woman’s family, and the safety of her children, should be addressed in some research protocols because, no doubt, all of these things affect a women’s health.

Mahalo Nui for this opportunity to speak.

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IMPACT OF TRADITIONAL AND CULTURAL HEALTH PRACTICES ON AFRICAN-AMERICAN WOMEN'S HEALTH

My talk will focus on African-American women. To speak meaningfully about the impact of traditional and cultural health practices on the health of African-American women, it is important to preface any such discussion by making three important points: First, the term "traditional" is used in this discussion to refer to the mainstream medical system and health practices. Second, traditional health practices and services cannot be separated from the overall structure of U.S. society with its stratification system, stereotyping, discrimination, and all the implications that that carries in terms of access to resources such as health care. So, for disproportionately large numbers of African-American women, traditional health practices are indeed unrealistic, unavailable, inaccessible, and culturally unacceptable. My third point is that African-American women are not homogeneous. Passage of the McCarren-Walter Immigration Act of 1965 opened U.S. borders for the first time in its history to large numbers of non-white people. As a result, a marked degree of cultural diversity exists among women of African ancestry in the United States today.

The black women we collectively call African American come from several specific cultural experiences that differ in language, learned behavior, beliefs, and values. They come from the African continent, from the English, French, Dutch, Portuguese, and Spanish-speaking nations of the Caribbean and throughout the Americas, as well as urban and rural areas of the United States. Because they mingle, live in the same neighborhoods in the United States, share a commonality of black skin and physical features, and to some degree relative poverty, society has chosen to aggregate their health and social problems as though they share the same backgrounds, health beliefs and practices, and health-seeking behaviors; eat the same foods; and have the same family structure and belief systems. Now, if the traditional system carries a double whammy for the native-born African-American woman, author Paule Marshall tells us the foreign-born woman of African ancestry is in triple jeopardy as she is black, female, and an immigrant.

While I recognize that it is easier to conduct research if we do not disaggregate all these different cultural groups, I need to issue a caveat. Failure to do so will yield research that masks much that we would learn about illness behavior, preferences in health practices, health care utilization, and so much more. Then, when we researchers proffer solutions for the "average African-American woman," and they do not work, we wonder why these solutions fail.

Traditional Practices

Having put these two issues on the table, I want to examine first the impact of traditional practices on African-American women's health, then we will look at cultural practices. Let me begin by clarifying terms. Traditional health practices refer to the Western biomedical model which is an outgrowth of 17th century Cartesian reductionism. This model is concerned with essentially four concepts: the patient, the disease, the diagnosis, and the treatment (Foss and Rothenberg, 1987). Medical training based on this model does not prepare today's physicians to ask questions about the feelings and emotions of their patients or to include the effects of social, economic, political, environmental, and cultural forces in their diagnosis and treatment recommendations. By discounting so much of people's lives, traditional health practices have minimal, if any, impact on the health of African-American women of all ages, which is evidenced by their high degree of noncompliance with routine medical instructions. If you live in a project that serves as a regional base for drug sales, if your sons and daughters have been murdered in drive-by shootings while sitting on your front porch, if the daily stress of making ends meet is constantly with you, it is highly unlikely that you will opt to follow prescribed medical instructions, because those instructions have no meaning within your life.

An equally significant impact of traditional health practices on the health of African-American women is the historical exclusion of African-American women from policymaking and decisionmaking positions of power. This issue, I am happy to point out, is being addressed by ORWH through various programs that develop strategies to recruit, train, and retain minority women scientists on research projects, and systems to monitor inclusion of women in clinical trials.

Let us be clear that whatever criticisms we may have, traditional health practices must be credited with having made great strides in technological advancements that must be duly credited with improving and saving lives throughout the course of this century. The downside is that this technology is not always available to African-American women for many reasons. First, the majority of health services we receive in this country are available only through possession of public or private health insurance. Many black women work in the secondary labor market of service type jobs that do not come with health insurance, nor do these jobs pay enough to cover the out-of-pocket expenses for the purchase of health insurance. Second, because of the nature of their work, and the hours that these women work, the hours of operation of many traditional health service providers render them oftentimes inaccessible. In the case of immigrant women, traditional services are usually culturally unacceptable.

Cultural Practices

As a matter of survival then, African-American women have had to rely on cultural health practices for centuries, passed on from generation to generation and available either through self management or indigenous healers. As a result of reliance on cultural practices and the marginalization they experience from the traditional providers, African-American women, and indeed the entire African-American community, have developed a lack of trust in Western or traditional health practices, which has led to a negligible use pattern for many women of color. This mistrust is not totally unfounded, if we recall Tuskegee, and before that, the eugenicists and their impact on the health of not only African-American women but also Indian women and poor white women.

So, what do we mean by cultural health practices? Well, that depends on one's culture. For many African-American women, especially from rural areas or developing countries, illness behavior tends to follow a slightly different pattern from that of traditional mainstream U.S. society. The first course of action for many people is to self diagnose, which is the case in many European cultures as well. In the case of a child, the parents would diagnose and use herbs, powders, teas, etc. to treat. If that did not work, the second step would be to ask trusted family members and friends to help diagnose and prescribe treatment. When, and if, that didn't work, the third step was to seek out the services of an herbalist, curandero, santero, babalao, obeah man, or in the United States — especially in the South — a roots worker. When all else failed, only as a last resort would many people seek the services of the trained Western physician.

Talk of roots, herbs, and teas may sound strange to some people but let us recall that 30 years ago Chinese acupuncture was also viewed as strange, but now it is part of mainstream medicine, covered by many insurance policies, and is an integral part of pain management. Today, there is some excitement around what is called alternative medicine. Many of the products I was given as a child growing up in Latin America have now been studied and their properties more clearly understood, and are being sanctioned by the health care industry. The good news is that many of the cultural health practices that African-American women relied upon as a matter of survival certainly do have merit. But there is also bad news. The proliferation of healers of all kinds, especially in large cities in the United States which have significant numbers of multicultural populations, include shamans, quacks, and others who are not trustworthy. Many people, including African-American women, have been deluded into thinking that they can rely exclusively on alternative medicine without seeking traditional services. The most devastating consequence of this behavior is that reliance on either self management or alternative healers, in many instances, leads to delays in seeking traditional health services. This means that by the time some African-American women access services, their conditions, which were either preventable or treatable by Western medicine, are too advanced. Studies have shown that although African-American women, in this instance Haitian women in Brooklyn, do not contract breast and cervical cancer in greater numbers than white women in that borough, they die from these diseases in greater numbers because their cancers have already metastasized by the time they seek traditional health services.

I want to caution providers about two issues. The first concerns the increase and proliferation of alternative medicine. Many patients will decide to use both traditional and cultural health practices. How many physicians in this room ask their patients, or teach their medical students to ask questions, about the alternative treatments that are being used in conjunction with the traditional treatments that you prescribe? A 1993 study by David Elsberg indicates that one in four Americans may be using alternative therapies along with conventional ones, and seven out of ten patients do not tell their doctors — doctors have to ask. Other studies have shown that women use alternative therapies along with conventional ones more than men.

The second issue regards compliance. You are more likely to motivate and encourage compliance with prescribed medical regimens if you do not appear to be disrespectful or condescending toward cultural behaviors that differ from your own. Medical education must include courses on cultural awareness.

There is so much we still do not know. Unless we conduct research on the health practices and belief systems of African-American women from different cultures, how can we be presumptuous enough to think that we can design and implement programs that will effectively reach *all* African-American women? For example, we know very little about the health of immigrant women. Although it is understood that immigration is a selective process and the healthier, younger, stronger people tend to journey out, studies now suggest that while immigrants enter the United States in optimum health, within 10 years their health status mirrors that of the communities into which they move. For women of the African diaspora, that is frightening. What is it about the living conditions in our communities, or our health beliefs and practices, that contributes to deterioration in health status whether native or foreign born?

Recommendations

I would like to close with three recommendations that I believe we would do well to include in the agenda for women's health in the next century. I make these recommendations out of a quest for, and actually the need to find, ways to integrate the viable components of traditional and cultural health practices for the benefit not only of African-American women, but indeed all women.

We must conduct research that examines the health impact of cultural variation in health values, beliefs, and practices among African-American women, and how these combine to influence both preventive behaviors and illness behaviors.

Research is needed on the relationships between levels of provider education in the areas of culture, race and ethnicity, and health outcomes for African-American women.

Finally, we must change the way we do research. We need new research paradigms. We must not go into communities that we do not know, with our survey instruments, and believe that (1) people have any obligation to tell us anything, and (2) whatever they tell us need bear any resemblance to the truth. So much for scientific inquiry. I say that we have to partner with indigenous leaders and CBOs and train community people. Let them help us to define the problem and the questions, to ask the questions, to collect relevant data that will tell us what their treatment preferences are, and ultimately to interpret the results. In this way, the community owns their health problems and, in the process, they can become empowered to resolve them.

ETHICS AND RESEARCH ON WOMEN'S HEALTH

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New Perspectives in Applied Ethics

- Assumptions
- Focus on Values
- Contextual Approach

Narrative and the Creation and Communication of Meaning

Power

Implications for Research Scientists and Subjects

TABLE 1. Skillful Questions for Eliciting Values

Questions are the creative acts of intelligence. If they are formulated well, they open doors, generate valuable information, and lay a firm foundation for thoughtful decisionmaking. These questions should help you understand the values context for your decisions.

- Why is this important to you?
- What is important here that we need to look at?
- What do you think lies at the heart of the matter?
- What matters to you most in this situation?
- What seems to matter to others?
- What can you tell me that will help me understand the importance of this issue to you?
- What do you think our duties and obligations are in this situation?
- Who do you think will be affected by our decision?
- What do you think the effects and consequences (intended and unintended) of our decision will be?
- What standards do you think they will use to judge the fairness/rightness/goodness of our decision?
- What is most meaningful to you in the comments and ideas we have heard up to now?
- What is significant about ______ for you? How do we know that this is the right thing to do?
- What makes this an inappropriate way to proceed?
- What worries you about this issue?
- What standard(s) should we use to make a decision?
- What criteria should we use to determine the best approach?
- What would you do if it were your decision? Why?
- What criteria will our stakeholders use to evaluate our decision?
- Why do you think this is a good decision?
- Why don't you think this is a good decision?
- What would you like to see come out of this?
- What do you hope for?
- When we look back on this decision 1 year from now, how will we know we did the right or best thing?
- If your teenager was watching us make this decision, and asked why we did it, what would you say to her or him?
- How would you feel if the *Albuquerque Journal* ran a front page story analyzing this situation and the decision you propose to make?

ANTHROPOLOGICAL PERSPECTIVES ON RACE, CULTURE, AND ETHNICITY

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Anthropologists have been important contributors to the study of race and racism since Franz Boas argued in 1908 that "racial" characteristics could undergo generational change among central and southern European immigrants as they moved from Europe to the United States (Sanjek, 1996). The American Anthropological Association is in the process of drafting an official statement on race that emphasizes the conclusion that "the concept of 'race' has no validity as a biological category in the human species." In part the statement now reads:

> The human species is highly diverse, with populations varying in observable traits such as body size and shape, skin color, hair texture, facial features, and certain characteristics of the skeletal structure. Populations also differ in their percentage frequencies of blood types (A, B, AB, and O), and other known genetic traits. This variation is a product of evolutionary forces operating on human groups as they have adapted to different environments over thousands of years. . . . Variations in any given trait tend to occur gradually rather than abruptly over geographic areas. And because physical traits vary independently of one another, knowing the frequencies of one trait does not predict the presence or frequencies of others . . . . Genetically there are greater differences among individuals within large geographic populations than the average differences between them. Because of our complex genetic structure, no human groups can be seen as homogeneous or "pure" (Smedley, 1997). Anthropologists agree that from a biological point of view, no groups are physically, intellectually, or morally superior, or inferior, to others.

However, the term "race" (and with it "racism, both as individual prejudice and institutional practice), is a culturally constructed reality of recent historical development. Racial categories arose following European expansion. As anthropologist Ralph Linton put it in his 1938 textbook, *The Study of Man*, prior to the 16th century the world was not race conscious and there was no incentive for it to become so... It was only with the discovery of the New World and the sea routes to Asia that race assumed a social significance ... . Europeans have not been content merely to accept their present social and political dominance as an established fact. Almost from the first they have attempted to rationalize the situation and to prove to themselves that their subjugation of other racial groups was natural and inevitable (Sanjek, 1994).

In eastern North America, Europeans developed a tri-racial system of white/black/red — contrasting Europeans with enslaved Africans and conquered "Indians." Colonial slavery, unlike earlier systems, was based on, and justified through, concepts of racial identity in which physical characteristics played a large role. Ideas about savagery vs. civilization were mixed along with physical attributes in racializing Native American populations. In the southwest, the Spanish colonial system during the 18th century created a much more elaborate system of "*castas*" with white *Espanoles* on top, *Mulatos* and *Coyotes* in the middle, and *Genizaros* (captured Indians raised in Hispano households) and *Indios* on the bottom (Gutierrez, 1991). With the displacement of Native American Indian populations onto reservations over the course of the 19th century, racial categorization focused primarily on the white/black dichotomy (Sacks, 1996: Chapter 5: 23). And thus, the United States is often thought of as a bipolar racial system (white/black).

However, it is important to note that there have always been other racialized groups, not only Native Americans but also the Chinese on the west coast, Mexican Americans and Hispanics in the southwest, and European immigrants in the east and midwest. At the turn of the century, Jews, Italians, Poles, and other Slavic populations were seen as members of the Semitic, Mediterranean, and Slavic races and their neighborhoods, described as dirty and diseased, filled the popular press (Sacks, 1994). Since World War II, partly through the GI bill, the break-up of ethnic neighborhoods, and the growth of suburbs, Jews and ethnic groups of European ancestry have become "white," often losing their distinctive "ethnic identity" as they gained "whiteness." With the revision of U.S. immigration laws in 1965, new immigrants have come primarily from Asian and Latin American countries, increasing the number of Asians (a racial category) and Hispanics (an ethnic category). In the 1990s, the United States is again being seen as a plural, multiethnic society with many Americans coming from a wide range of national backgrounds and ancestries.

Karen Sacks has argued that "race" is an externally imposed social identity and that ethnicity has been an internally constructed social identity as populations have coalesced around common ancestry, heritage, and language, often in order to create mutual aid organizations (to provide loans, health benefits, pensions, and burial sites) as well as a sense of common identity (Sacks, 1996; Aronowitz, 1974). Nevertheless, both racial and ethnic categories have been utilized by the state in counting and enumerating segments of the U.S. population. And, ethnicity and race have become important variables in the study of women's health. There is a sense in which individuals can "choose" their race and ethnicity on census forms and the 100 or more other forms that individuals often have to fill out (e.g., job applications, college forms, health records, drivers' licenses, etc.). But they choose within a limited set of options and there is a growing sense that these categories are arbitrary and do not fit the identities that individuals choose for themselves.

The issue is particularly complex for Spanish-surnamed New Mexicans, and I will use this example since we are in Santa Fe today. Many Spanish-surnamed New Mexicans define themselves as Spanish or Spanish Americans (in English) or *Hispanos* (in both English and Spanish). Those from northern New Mexico often see themselves as *Mexicanos* or *Nortenos*. On the 1990 Census, in Rio Arriba County (a county north of Santa Fe), 83 percent (20,652) of "Spanish/Hispanic Origin" population filled in the circle "Other Spanish/Hispanic" while 16 percent marked "Mexican, Mexican-American, Chicano." What we cannot tell from these figures is whether those who filled in the circle marked "Mexican, Mexican-American, Chicano" are from the same families and networks as those who felt more comfortable with the label "Other Spanish/Hispanic." Some may have considered themselves *Mexicanos* (tracing their ancestry back to when northern New Mexico was part of Mexico). Others, from northern New Mexican families, may have seen themselves as "Chicanos" allied with the Chicano movement, and others may be recent immigrants born in Mexico. Particularly in New Mexico, there is a relatively poor fit between census categories and self identity. (There is also evidence that "racial categories" do not fit. In Rio Arriba County, 80 percent of the respondents of Spanish/Hispanic origin circled that they considered themselves white but 18 percent filled in the circle Other race, suggesting that some may consider Mexican as a racial category.)

What does all this have to do with issues of women and health? And how might research on women's health issues be more sensitive to the constructed nature of the categories we use? First, we need to recognize that categories are culturally constructed by institutions (branches of the U.S. and state governments, hospitals, clinics, etc.) and that they lump people together not only of different physical and genetic characteristics, but also people who have a wide variety of social and economic experiences. Alternatively, categories (e.g., Other Spanish/Hispanic and Mexican, Mexican American, Chicano) may separate people of similar background. Further, racial and ethnic categories on forms may not reflect the identities that clients would choose for themselves.

Second, racial categories, because of their history, always carry the possibility of stigmatization. Tables constructed by race or ethnicity ask us to focus on those with the highest rates of a condition, a situation which sometimes leads to an assumption that something is wrong with this population. It is not far from this to the possibility of blame, even though this was not the original intention of such charts or tables. We can especially see this in the analysis of single motherhood. Since 20.2 percent of white mothers are single parents, while 58.4 percent of African-American mothers are single parents, this has led to the widespread notion that most single mothers are black. However, if we look at all single mothers, 63.2 percent of single mothers are white and 33.6 percent are African American. In other words, there are a high proportion of female-headed families among African Americans, but more single parents (who presumably need social services, for example) are white. Likewise, in examining issues related to women's health, it would be important to pay some attention not only to risk factors within a subpopulation, but the actual numbers of those who are at risk within the total population. We need to be reminded that although rates for heart disease, cerebrovascular diseases, homicide, and AIDS are more than twice as high for black women compared to white women, many more white than black women die of these causes (and presumably are treated by the health care system) (National Institutes of Health, 1992). Thinking about the statistics in these two different ways provides a sort of double vision that helps diffuse the potential of stigmatization.

Third, studies need to focus on class as well as race and ethnicity. Americans are particularly reluctant to acknowledge that the United States has a class structure, and we admit only to a three-class system — the small numbers of wealthy, the vast middle class, and the stigmatized poor. But it is important to examine the differences in the vast middle, between what I would call the working class, the middle class, and the upper middle class, i.e., between those who have medium incomes and below (mostly likely high-school educated, blue collar, and service workers), and those who have incomes in the next 30 percent (those with some college or even college degrees), and those in the top 20 percent (the postgraduate professionals or upper middle class, as well as the wealthy or upper class). So rather than just looking at poverty rates and health status, we need two or three other categories — working class, middle class, and upper middle class — to help examine the way income, diet, environment, and other socioeconomic factors may relate to prevention and access to heath care, which in turn affect risk for disease and death.

In sum, it is important to examine the similarities and differences *among women* as we focus on women's health care. But we need to remember that racial and ethnic categories are culturally constructed and racial terms carry the historical baggage of stigmatizing many populations. We need to pay attention to the impact of other social indicators, particularly class on women's health, and utilize analytic strategies that will illuminate the complex ways in which environment, social context, and biology interact.

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LATINAS/HISPANIC WOMEN AND RESEARCH ISSUES: IMPACT OF TRADITIONAL AND CULTURAL HEALTH PRACTICES

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Cultural practices have never been static, even in isolated communities whose contact with others unlike themselves was limited. Today, mass media and the rapid and widespread mobility of people creates a dynamic cultural change and exchange unparalleled in human experience. The challenge for researchers is to probe beliefs and practices accurately, while at the same time acknowledging their dynamism.

For Latinas and researchers on Latinas and health, the challenges of understanding the impact of traditional health practices are as exciting as they are daunting. Latinas are markedly heterogeneous in nationality, religion, ethnicity, race, class, immigration history, and other variables that clearly preclude generalizations. Their common feature may be language, but, even language is extremely diverse.

Still, there are shared beliefs among behavioral and social scientists that Latinos share cultural values. Salient among them are *personalismo,* personal relationships that are warm and trusting. This shapes expectations and interactions with health care providers. *Respeto* and *dignidad* refer to observance of traditional expectations in form of address, dress, and professional and personal space. Health professionals need some basic understanding of the social hierarchy and customs of Latinas to stay within acceptable boundaries. When in doubt, more, rather then less, formality is most advisable. Latinos expect social conversation to precede human transactions and as a prerequisite to establishing *confianza* or trust.

What seems most relevant to women is that Latinas rootedness in culture norms and practices appears to have a protective effect on their health status.[1,2] This has been most studied among Mexican women, whose birth outcomes are very good as compared to others in similar social and economic circumstances. Mediating factors identified are better nutrition, lower rates of smoking and alcohol use, and customs that support the maternal role.[2,3] Researchers are now beginning to focus on resiliency elements and on constructing assets-based models.

We may gain further understanding of the relationship of cultural frameworks to behavior as we understand the many variables created by social class. The effects of class and community context are perhaps among the least studied phenomena in health sciences.

Cultural Definitions of Health and Illness

Latinas may see the causes of illness or sense of not being well in the context of individual responsibility, their views of the natural world and of the social world. Individual responsibility is translated into psychological states and emotions; envy, fear, worry, or sin. The natural world encompasses environmental factors such as *sereno* (night air), a chill, excessive heat, or food poisoning.

The Latinas' social world may be inhabited by spirits and evil persons capable of casting spells and *mal de ojo* or evil eye. Envy evidenced by others is thought to be particularly malevolent. The use of talismans is very common. An example is *la manita de azabache,* a small black onyx hand placed on or near babies to ward off the possibility of envious evil eyes.

The central role of families in Latino culture is well recognized by the health community. The Latino family remains an untapped resource for healing and change in health behaviors of its members toward optimal health. Health professionals are recognizing the key role of men in the Latino family as an asset in securing health for the whole family.

Traditional Health Practices

Traditional health practices are extremely diverse among Latino populations. They are, however, common among all. Folk medicines, self and other prescribing, pharmacists as a source of health care, and use of traditional healers are widespread. Providers need to establish trust and create a nonjudgmental exchange that opens communication if they are to study health practices that differ from what they would recommend.

If we are to learn anything from the growing literature on alternative therapies and choices that people make, it would be that unless you ask in an accepting way, they certainly will not tell.

In my teachings on cross-cultural issues in treating patients, I would advise students to concentrate only on changing behaviors that were harmful. The concern with behaviors that may be neutral in their health effects, or even beneficial, often kept young professionals from establishing trusting relationships with their patients. It is useful to point out that the health belief model can help us recognize an individual's willingness to change behavior. It holds that behavioral change is a result of triggers in areas of beliefs about susceptibility, severity, and benefits of treatment[4] (Rosenstock, et al., 1988). It follows that Latinas' beliefs must be explored in the appropriate cultural context to identify the areas of readiness to change.

Clinicians and clinical researchers must cultivate the communication skills necessary to elicit all information necessary on their patients' views and use of traditional diagnostic and healing practices. In the process, they will expand the body of empirical knowledge of what Latinas really do value and help guide future research. It is imperative that behavioral hypotheses on health practices be tested and re-tested before establishing that the research methods are applicable.

A research project recently completed by a team of the Pacific Institute for Women's Health, in which I participated, illustrates the need for that process of testing and re-testing. It also illustrates that the establishment of trust with the community, in this case with both the provider community and the individuals who use the clinical services who became the subjects of the study, is a requirement of effective research to gain understanding of cultural issues.

The project consisted of a series of couple-based studies to examine perceptions and behaviors related to the male role in reproductive decisionmaking and condom use for prevention of HIV/STDs among Latino men and their heterosexual partners. The four primary objectives were to: 1) examine the feasibility and difficulties of couple recruitment for participation in qualitative interviews using women versus men as the initial contact for linked interviews; 2) reconceptualize the definition of a couple in a form that is relevant to the circumstances of inner city Latino men and their sexual partners; 3) examine the relationship of power differentials within heterosexual partnerships to communication about reproductive issues and decisions about condom and contraceptive use; and 4) investigate the effects of Latino cultural norms and personal beliefs about gender roles on sexual behavior and condom use.

Establishing an understanding of the community and the study population required initial ethnographic interviews and participant observation. Before the structured qualitative interviews were carried out, the initial pilot interviewees had provided information on the characteristics of different types of relationships. The refined hypotheses about behavior of couples in different types of relationships were based on what the respondents themselves had identified. In addition, the sensitive manner in which the researchers approached the clinical personnel and the potential subjects established that people were held in respect and laid the basis for the trusting relationships that followed.

I will not describe in any detail the study methodology or its implications for future research, I wish merely to use some of the aspects of the study as illustrative of the need for specific research in specific communities of Latinos before generalizing on their cultural beliefs and values and their effect on health behaviors. The study yielded major findings in areas that included:

- *Issues in Couples Research.* Compared to telephone recruitment, face-to-face recruitment at a clinic is a more effective strategy to utilize when recruiting couples. Also, recruitment of couples for linked interviews may be more feasible when the woman is the initial contact.

- *Concordance Between Partners.* An important, but not surprising, issue that emerged was that individuals in a dyad do not always agree on events, behaviors, intentions, attitudes, and perceptions. Level of agreement among couples is higher for objective reports of contraceptive and sexual behaviors compared to more subjective reports of opinions or perceptions regarding reproductive matters.

- *Heterosexual Relationships and Roles.* Heterosexual relationships can be classified according to at least six criteria: formality; social acceptability; sexual intimacy; time frame; cohabitation status; and financial commitment. Types of relationships described by respondents include those of *novia/novio, evosa/esposo, amiga/amigo, mujer de occasion or prostituta,* and *amante or querida.*

- *Gender Roles.* Roles perceived as appropriate for Mexican immigrant women include household chores and maintenance; child care; waiting on, attending to, and supporting the male partner; and financially contributing to the household through employment. The appropriate male in Mexican culture brings in money to support his family; *helps* with housework and child care; educates his children; and respects his partner. The *machista* man is perceived negatively by most respondents and seen as very different from the gender-role-appropriate male. The *machista* is perceived as controlling, irresponsible, and physically and/or verbally abusive.

- *Immigration to the United States.* Three-fourths of the women and 87 percent of the men believe women have more influence in heterosexual relationships after moving to the United States. The major reasons for women's greater influence involve protection from domestic violence, increased independence and freedom for women, and increased opportunities for women to work outside of the home.

- *Sexual and Contraceptive Behavior.* While women are unlikely to have had another sexual partner, close to 40 percent of the men have had sex with a prostitute and approximately 40 percent report having had sex with a causal partner. Thirty-four percent of the Phase III sample and 54 percent of the Phase IV sample report some current use of condoms. When reasons for and circumstances surrounding condom use were examined using Phase III data, by far the most often noted reason for using condoms was the avoidance of pregnancy. Circumstances which promote condom use included periods in which couples experienced problems associated with other contraceptive methods, the birth of a child, and the beginning of a relationship. Clinic services played a major role in influencing the use of condoms among participants. Most often the woman suggested use of condoms to their partners. Structured items from Phase IV tap into a set of widely shared beliefs about contraception and condom use among Mexican immigrant men and women. As a group, women showed greater agreement with the underlying set of beliefs than men. Among men only, recent immigrants were significantly more likely to agree with these beliefs than were respondents who were more acculturated to the United States.

- *Influencing Strategies in Heterosexual Relationships.* The two most common influencing strategies used by women that emerged from the qualitative data were affection and sex and seduction. The dominant themes that emerged about how men get what they wanted were affection and doing something tangible for the partner, such as giving gifts or money and taking her out. Cultural consensus modeling indicated that structured interview items appear to tap into a set of widely shared beliefs among Mexican men and women on the topics of what strategies men and woman use to influence their partners. Recent immigrants were significantly more likely to agree with these beliefs than were respondents who were more acculturated to the United States.

- *Women's Influence on Condom Use.* Although cultural consensus modeling failed to confirm consensus on the circumstances in which women have a greater perceived power to convince her partner to use a condom. Respondents perceive that it is the power of sexuality and motherhood that allow the woman to convince her partner to use condoms.

- *Power in Heterosexual Relationships.* Qualitative analysis revealed that power is perceived by Mexican immigrant couples in two predominant ways: control over the partner and the ability to make decisions. Women are believed to feel more powerful in a relationship when they are able to make decisions and have economic independence. In contrast, respondents believe men's feelings of power are derived from having control over one's partner, and working and bringing home money. Cultural consensus modeling revealed that the statements from the Phase IV structured interviews appear to tap into a set of widely shared beliefs among Mexican men and women on the topics of what makes women feel more powerful and what makes men feel more powerful. Women showed greater agreement with the underlying model (set of beliefs) than did men. Data provide limited, preliminary support for the conclusion that power differentials among Mexican immigrant partners are related to their communications about sexual and reproductive matters and their contraceptive use. Domain-specific power variables, compared to a general power variable, appear to be more related to the communication and contraceptive use variables.

- *Experiences of Violence, Fear, and Unwanted Sexual Behavior.* Over half the respondents reported that they have felt fear in their relationships. Three themes that emerged from qualitative data were: fear of abandonment, fear of infidelity, and concern about physical violence. One-third of the women and four male respondents stated that their partners had asked them to participate in unwanted sexual behavior, and one women and three men responded that the man had forced his partner to do something sexually when she did not want to.

Despite the major methodological strengths of the project, several limitations must be considered when interpreting and applying these results. Among these are: limited generalizability of the samples; use of English translations of qualitative transcripts; lack of concordance in responses of partners; and possible underreporting of sensitive information. This report concludes by discussing recommendations for additional data analysis, future research, and design of interventions. Preliminary recommendations for interventions in the Latino community are based on study findings as well as previous literature and include:

providing separate but tailored interventions for the man and woman in the couple; integrating AIDS and STD prevention efforts with family planning and reproductive health programs; facilitating couple communication regarding sexual wants and STD-prevention-changing aspects of the social environment to promote condom use; designing strategies to involve men in health programs at primary care clinics; and teaching effective, culturally appropriate influencing techniques to women.

In conclusion, Latina women as individuals may or may not share their groups beliefs and values. Likewise, their health practices, including use of traditional healing methods, cannot be determined a priority, but only on obtaining accurate information based on a relationship of trust created in a climate of respect.

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THE HEALTH OF SPECIAL POPULATIONS OF WOMEN: IMPLICATIONS FOR RESEARCH

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The purpose of this workshop is to examine the health status and health outcomes of special populations of women across the life span — in the broadest sense. “Special populations” includes women of different racial, ethnic, and cultural origins; women with disabilities; lesbians; women living in urban and rural settings; and immigrants, among others. Although I will use as examples primarily studies dealing with different racial, cultural, and ethnic groups, health issues for women in the other categories should not be forgotten.

One needs to look at any one of several data books to know that differences in health status and health outcomes exist among different populations of women. While heart disease and cancer are the two leading causes of death for all American women, cancer is the leading cause of death for Asian women. Cerebrovascular disease is the third leading cause of death for white, black, Asian, and Hispanic women; however, for Native American women, accidents and unintentional injuries is the third leading cause. Deaths due to cancer vary among the different populations. For example, the death rate from breast cancer reported for black women is 31 per 100,000 while American Indian women in New Mexico have been reported to have the lowest incidence with the death rate at nine per 100,000.

It is clear that to properly interpret data from many of the source books, epidemiology, and other types of research, there has to be an understanding of how these subgroups are defined. It is not clear that such an understanding exists.

For example, although beginning in 1976, the Federal Government data systems classified individuals into the following groups: American Indian or Alaskan Native, Asian or Pacific Island, black and white; some source books classify Pacific Islanders with Native Americans.

Prior to 1980, race of newborn infants was determined by race of the father, but if the parents were of different races, and one parent was white, the child was classified according to the race of the other parent. Since 1980, the race of newborn infants has been tabulated according to the race of the mother. Persons of Hispanic origin are defined as persons speaking Spanish or persons with Spanish surnames, and may be of any race.

Given the variables associated with designation of race, culture, or ethnicity, one might question whether using these designations to examine different populations for study is wise. Should individuals be assigned to certain study groups based on such designations, or should they be assigned based upon self description? What would be helpful is an agreement among researchers on a uniform method, so appropriate comparisons can be made. We will look toward the panel to help us with this issue.

It is known that differences in health status and health outcomes among the different populations may reflect educational, cultural, and behavioral variables; individual preference; availability of services; differences in treatment of disease; and differences in supplementary services; but the fact that there may be physiologic and pharmacokinetic differences and predisposition to certain disorders to explain some of the differences must be explored.

I would like to provide several examples. Cervical cancer among Hispanic women in the southwest is almost twice that for non-Hispanic white women. Although risk factors including lower income, low education level, and infections with multiple human Pappiloma virus (HPV) types were similar for both groups, for Hispanic women infection with BPV types 16-18 was strongly associated with cervical dysplasia. The odds ratio for a cervical lesion for non-Hispanic white women was 18, whereas for Hispanic women the odds ratio for developing cervical dysplasia was 171. This disparity may suggest that environmental and immunologic or genetic co-factors may play a part in the development of cervical dysplasia pathology and progression to invasive cancer.

In humans, a specific class of human leukocyte antigen regions have been associated with a variety of diseases, including some cancers. This prompted a group at the University of New Mexico to look for an association of an phenotype with invasive cervical carcinoma among a group of New Mexico Hispanic women. The investigators found that DR-13 haplotypes are associated with a strong protective effect against developing invasive cervical carcinoma. On the other hand, a group of DRDQ haplotypes was associated with a strong susceptibility to develop invasive cervical carcinoma in association with HPV-16 infection. These results suggest that the immune response to HPV-16 may be determined in part by specific HLA class II haplotypes and influence a risk of cervical neoplasia. In other words, specific host genotypes or phenotypes may predispose some populations to certain cancers. A similar explanation may prove to be the case for other disorders. The panel dealing with cancer genetics will enlighten us on this topic.

Virtually all comparative black/white studies in North America have shown that black women have 5 to 10 percent greater bone mass and 5 percent greater bone density than white women when matched for age. This is the case in spite of the fact that African Americans, when studied, have been shown to have a significantly lower calcium intake throughout the life cycle. Two possible explanations have been put forth to explain the black/white differences in bone mass. One deals with calcium and bone metabolism and the other with reproductive hormones. A study showed a lower urinary calcium excretion among black children when compared to white children of the same age. The same, lower urinary calcium excretion, was found among a population in older black women when compared to white. Though not fully explained, the concept is that there may be lower bone turnover among blacks which contributes to an accumulation of a greater bone mass. The implications of the differences in steroid hormone levels are not entirely clear, but there is some feeling that higher estrogen levels among black pubertal girls favor the retention of minerals by the skeleton, and it's particularly beneficial because of the lifetime priming of bone estrogen receptors. Thus, in this instance, there appears to be a physiologic explanation for some of the differences, although genetic determinants which increase bone mineral density — independent of dietary intake of calcium — may be a factor as well.

It's been a commonly held belief that incontinence and pelvic organ prolapse among black women occurs less frequently than it does among white women. Up until the NIH consensus development panel on urinary incontinence in adults in 1989 emphasized the importance of gathering data regarding incontinence in non-white ethnic groups most studies of incontinence were done on white women. In 1993, a group of black women with incontinence were studied and the findings were compared with a group of white women. Urodynamic assessments showed that African-American women were more likely to have motor instability as a cause of their incontinence and less likely to have an anatomic defect for stress incontinence than whites. Thus, black women presenting with incontinence require more accurate and sophisticated urodynamic diagnostic testing before they undergo treatment. Continued study of a larger population and of different subgroups is needed.

The fact that African Americans have a greater prevalence of hypertension than whites is well known but they also have increased morbidity. Obesity is more common among black women than Caucasian women; 20 percent of African-American women over the age of 18 are smokers, and African-American women are less likely to engage in regular physical activity which puts them at greater risk. But there are physiologic reasons that increase the risk for serious sequellae. Fifty-one percent of African-American women have undesirably high serum cholesterol and lipoprotein-A levels, which correlate with an increased risk of coronary heart disease. Diabetes is more prevalent among black women. African Americans are more sensitive to sodium loading and exhibit a less marked reduction in blood pressure at night. The constant increased pressure load has obvious implications for the development of organ damage and, thus, increased morbidity.

Differences in infant mortality rates have been known for a long time. The elevated infant mortality rates have been attributed to adverse sociologic factors, including poverty, alcoholism, inadequate parenting skills, and inadequate prenatal care. But, even correcting for the socioeconomic risk factors, African Americans still are at a greater risk for infant mortality. Alternatively, favorable birthweight and low infant mortality rates have been reported more consistently for Hispanics of Mexican descent, despite the lower socioeconomic status. To explain these favorable outcomes, it was proposed that Hispanics of Mexican origin have a higher rate of fetal loss, which eliminates the biologically weaker fetuses. However, this does not seem to be the case. A study evaluating fetal deaths in Mexican-American, black, and white non-Hispanic women who receive government-funded prenatal care did not substantiate an increased fetal death rate among Mexican-American women. The traditional family attitudes of Mexican-American women have been thought by many to influence their health and the health of their newborn infants.

To prevent disease, we have to maintain health. The roles of traditional cultural values, sociologic, and behavioral factors in maintaining health must be recognized and investigated.

Among a group of women studied at Denver General Hospital, the major reason for lack of prenatal care was attitudinal. The most common reasons given were feelings of depression, ambivalence about the pregnancy, and having to deal with other problems (most of the pregnancies were unplanned). Among the Hispanic women, a common reason for not getting prenatal care was, “I was getting good advice from family and friends.” Among blacks, the reasons were “I didn’t think it was important,” and “I didn’t want to think about being pregnant.” White women were more likely to identify financial reasons and problems with access than black and Hispanic women. Nearly all women (88 percent) thought they were pregnant within 4 months, but by the end of 6 months, one-third still had not seen a professional.

An analysis of 19,027 females (56 percent black, 44 percent white), living in rural and urban settings, showed that black women are less likely to exercise, are overweight, and are less likely to be nonsmokers. Explanations include lack of personal control over their lives and having to deal with a myriad of other issues. On the other hand, black women were more likely to have a Pap test and breast exam than white women, which may be explained by the fact they commonly live in an urban setting with a higher availability of medical services.

Alternatively, Hispanic women are less likely to utilize Pap smears or to have had a mammogram in the past 3 years. Access to care, the importance of a family member to accompany them to a hospital setting, transportation, etc. play a role. The effects of acculturation on health-seeking behavior has been examined. A group of Mexican-American women age 40 or older, living in El Paso, were studied to determine the effects of acculturation in cancer screening behavior. Acculturation was measured by assessing English proficiency, English use in the family setting, value placed on culture, traditional family attitudes, and social interaction. Although the strongest independent factor affecting mammogram screening was insurance, after adjusting for socioeconomic factors, a woman with a positive attitude toward traditional family values was more likely to have undergone a mammogram.

One cannot examine differences in health outcomes among special populations of women without addressing physician and provider attitudes and practice. Several studies indicate that less than 50 percent of primary care physicians take a sexual history from patients. Frequently there is failure to inquire about the possibility of abuse — physical or sexual. There is ample evidence in the literature that many lesbians avoid medical care because of fear of discriminatory practice, thus decreasing the likelihood of obtaining routine screening. Culturally insensitive providers have been implicated as reasons for women of color to fail to receive health-promoting care. Attitudinal barriers toward individuals with disabilities remain. Women with developmental disabilities frequently are treated as children — because of an incorrect assumption that they cannot understand.

And there are differing practice patterns. The association of race with likelihood of screening for diagnosis of hypercholesterolemia in an office-based, family medicine residency training program in Rochester, New York was studied. Of the group of patients with identified race or ethnicity, approximately 23 percent were minorities, of whom 80 percent were African American. Female sex, less than 45 years of age, receiving Medicaid, not having insurance, and being a minority, were associated with reduced likelihood of screening. Minorities were less likely to have a diagnosis of hypercholesterolemia on the medical record even though cholesterol levels were comparable among whites and minorities.

It was the authors' own conclusion that the underdiagnosis of hypercholesterolemia in minority patients suggests a difference in the behavior of health care providers toward white patients compared to African-American patients.

Recently, a review of the effects of race and income on mortality and use of services among a group of Medicare beneficiaries, including 24 million whites and 2 million blacks, indicated black beneficiaries and low-income beneficiaries had fewer visits, fewer mammograms, and fewer immunizations against influenza but were hospitalized more often and had higher mortality rates. They also had higher rates of amputation of the lower limbs suggesting that black beneficiaries were less likely than whites to have leg-sparing surgery and more likely to undergo amputation. The rates for angioplasty and coronary artery bypass surgery were substantially higher among white beneficiaries than for black beneficiaries.

Although the authors invoked many of the same reasons for these differences including educational, cultural, and behavioral variables, individual preference, and differences in treatment of disease, the likelihood that other barriers to elective health maintenance care (i.e., race, low income, physician attitude) may exist.

In summary, differences in the health status and health outcomes exist among different populations of women. The purpose of this workshop is to develop a research agenda to explore the reasons for the differences, to lend an understanding for why the differences exist, and utilize this knowledge to influence the health of women.

If physiologic or pharmacokinetic differences of genetic predisposition prove to exist, screening, diagnostic, and therapeutic regimens should be modified. If economic, social, and behavioral factors prove to be the reason for less than ideal health status and outcomes, it is imperative that these factors be addressed so that health is maintained. If provider attitudes and practice prove to be the reason, then, an appreciation for differences among populations should be taught in medical schools. After all, the reason for all research is to improve the health of mankind, and in this instance the health of all women.

BREAST CANCER EPIDEMIOLOGY: CANCER GENETICS AND ITS IMPLICATIONS FOR DIFFERENT POPULATIONS OF WOMEN

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Today I would like to discuss the genetic epidemiology of breast cancer using examples of what we have learned studying mutations in the BRCA1 and BRCA2 genes from populations around the world. Since the United States is a country comprised of people whose ancestors came from every part of the globe, it is critical to study the genetics of different populations in order to understand our own heritage and how it influences our unique population genetics. The data that I will discuss with you comes both from our group in the laboratory of Professor Mary-Claire King at the University of Washington as well as from our colleagues around the world. Most of the research on the population genetics of breast cancer to date has been done on Caucasian women in North America and in Europe, which leaves great holes in our knowledge of many ethnic groups. However, we can make some epidemiological observations with the knowledge that we currently have, and hope that more work is done in the future in all ethnic groups.

There are a number of factors which influence breast cancer incidence, some of which are environmental and some of which are inherited. At this time, we have an imperfect understanding of how multiple factors interact to cause breast cancer. One strategy to increase our knowledge of the primary causes of breast cancer is to study high-risk families — ones which have multiple, often early-onset, cases of breast cancer. These families are likely to have inherited a predisposition to breast cancer and by understanding what that predisposition is, we hope to eventually learn how to intervene to stop cancer development. Mutations in the BRCA1 and BRCA2 genes are the most common inherited predisposing factors which we currently know to exist. However, not all women who inherit a mutation in either BRCA1 or BRCA2 develop breast cancer, leading us to ask how those lucky ones escape cancer. Is it the co-inheritance of protective genetic factors, the benefit of some environmental influence, or perhaps the combination of both?

The incidence of mutations in BRCA1 and BRCA2, and therefore their influence on breast cancer predisposition, varies between populations around the world. There are a certain number of founder mutations in BRCA1 or BRCA2 which have been shown to be present in a significant percentage of individuals from particular ethnic groups. Some of these mutations have made their way to the United States via immigration. Other BRCA1 and BRCA2 mutations that have been identified are unique to one or a few families in the United States and have not been seen in other countries. By studying all mutations, we seek to understand the influence of both common and rare inherited mutations on breast cancer incidence in the United States. By studying common mutations, we can learn how these have traveled to and around this country, and potentially use their prevalence to assist with the genetic testing of at-risk individuals from particular ethnic groups. In addition, by examining cancer incidence in different places between individuals with the same mutation, we can look for environmental and other genetic factors which may influence cancer development.

One example of a population which has inherited founder mutations in BRCA1 and BRCA2 is the Ashkenazi Jewish. It has been shown that nearly 2 percent of Ashkenazi Jewish individuals in the general population have inherited one of three common mutations in the BRCA1 and BRCA2 genes. The inheritance of the same mutations worldwide presents us with the unique opportunity to examine the cancer incidence in carrier individuals in different areas of the world, people who have inherited the same mutation but who are exposed to different environmental influences and have different secondary genetic factors. Although these three mutations are common in the Ashkenazi Jewish population, however, approximately half of the high-risk Ashkenazi Jewish families do not have one of these mutations. Other predisposing factors, either in BRCA1, BRCA2, or unidentified genes, are likely to be responsible for the remainder. Given the number of novel mutations in BRCA1 and BRCA2, it is unlikely that even fairly common mutations are entirely responsible for all of the inherited predisposition to breast cancer in any ethnic group.

In contrast to the Ashkenazi Jewish population, we know relatively little about inherited predisposition to breast cancer in the African-American population. A few studies have been done that have identified mutations in BRCA1 which are inherited in more than one high-risk breast cancer family, but these studies should be expanded to better represent the African-American population as a whole. Only by expanding our studies to include all ethnic groups will we be able to fully understand inherited predisposition to breast cancer in the United States.

In summary, I would like to leave you with the knowledge that the tools of genetic epidemiology can be very powerful in understanding the causes of breast cancer. From such studies, we can make appropriate risk profiles for the United States as a whole as well as the variety of groups within it. Knowledge of specific mutations in BRCA1 and BRCA2, and their frequency, can also be useful in targeted genetic testing; however, some mutations are private to one or a few families. We can take advantage of common BRCA1 and BRCA2 to investigate the existence of secondary factors, either genetic or environmental, which influence breast cancer risk. Ultimately, we seek to understand the factors which initiate breast cancer so that early intervention treatments can be developed.

TRADITIONAL MEXICAN FOLK MEDICINE AND FOLK BELIEFS: THEIR INFLUENCE IN THE SOUTHWEST

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Even as a Hispanic child growing up in a small community in the Southwest, I was fascinated by the practice *of curanderismo*, or folk healing. I vividly remember the ritual to cure *mal de ojo* (the evil eye) with its prayers and the use of an egg. There were days that I would have a mild *colico* (stomach ache) and would get the treatment for that. Also, there were many times that I would experience a bad fright and suffer from *susto* (magical fright) and have to be cleansed with a broom or *ruda*. Still, though I grew up with it, it is difficult to explain, not so much the rituals of curanderismo, but the love and the faith associated with it. Nonetheless, I wanted to try. I felt it was very important to keep *curanderismo*, the art of Mexican folk healing, alive, and to acquaint the general public with its importance in the Mexican and Mexican-American culture.

At first I concentrated on the herbs. It was natural to begin here, remembering as I did that for every illness and with every ritual there would always be a freshly brewed cup of tea — perhaps *manzanilla* (chamomile) or *canela* (cinnamon).

However, it became clear that interest in *curanderismo* was high, and yet works available on the subject, particularly works aimed at the average person, were few and far between. I felt I had to expand my lecture notes into something more substantial to fill this need.

Curanderismo, the art of folk medicine and folk beliefs, has played an important role in the history of Hispanic traditional medicine. In order to discuss Hispanic traditional medicine, it is important that we understand the role of the folk healer, *Curandero. Curanderismo* has always embraced three levels, though certain *curanderos* may choose to emphasize one above or even to the exclusion of the others. These are the material (the most common, with its emphasis on objects such as candles, oils, herbs), the spiritual (here the *curandero* is often a medium), and the mental (psychic healers, for example). Rituals — formulaic or patterned ways of treating the various illnesses of those who come to see the *curandero* — are present on all three levels.

It is the state of consciousness that distinguishes the *curandero* working on the material level: he is awake rather than in a trance and is himself — that is, has not assumed the being of another.

Is belief in *curanderismo* a religious belief or is it a belief in the supernatural? Well, it is often both. The belief that all healing power comes from God makes it religious, as does the very prevalent idea that a *curandero* can only bring about God's will. The belief that certain rituals or practices can affect a certain outcome is, however, a belief in the supernatural — that is, a belief that outside forces can be changed and controlled. In this way, *curanderismo* partakes of both the religious and the supernatural.

Many ailments in Mexican folk healing *curanderismo* require that the patient eat, drink, or otherwise use a specific substance such as an herb. The cure also involves rituals and the use of what an anthropologist would call "symbolic objects" and folk healing practices.

Some of the most common folk ailments, especially with traditional Hispanics in the Southwest including those along the Mexico/Texas border, include *mal de ojo* (the evil eye), sometimes referred to as *mal ojo,* or just plain *susto* (magical fright), and *caida de mollera* (fallen fontanelle).

There are also a number of ailments less frequently encountered, and these would be found in Mexico more often than in the United States. These are *bilis, muina, and latido.* These three unusual and exotic rituals can be correlated to modern illnesses and are the theme of this paper.

A curandero might be called upon to treat any of these three ailments — *bilis, muina, or latido.* On the other hand, a member of the family, such as a grandmother, mother, or aunt, might administer the remedy for these illnesses. If a family member tried to remedy the ill, however, and it persisted, it is likely that a *curandero* would be consulted.

Definitions of the various ailments and their causes differ, but those which follow are generally accepted for *bilis, muina, and latido. Bilis, muina*, and *latido* are rituals in folk healing that have been around for hundreds of years. In folk healing, these three rituals are very beneficial. Are the rituals psychosomatic, where the power of the mind affects the body? I truly believe that it is mind control.

Many rituals in folk healing, including *bilis, muina, and latido,* can be traced back not to the Native American but to the Spaniards who brought them to the New World. The natives practiced other rituals in the New World that were different from *mal de ojo, susto, caida de mollera, bilis, muina, and latido.*

Where did the Spaniards learn these rituals? They borrowed them from the Moors, who lived in Spain for more than 700 years. Where did the Moors learn these rituals? Probably from the Chinese who are well known throughout the world for their folk medicine and folk-healing practices.

Bilis is an illness best described as having excessive bile in the system. It is thought to be brought about by suppressed anger. Symptoms include gas, constipation, a pasty-looking tongue, and sour taste in the mouth. Treatment for *bilis* is far less exotic. Epsom salts or some other laxative would be given once each week for 3 weeks.

Dolores Latorre reports that *muina* is sometimes called “anger sickness,” but it differs from *bilis* in that it results from a show of rage rather than its suppression. The victim, Latorre writes, “becomes tied up in knots, trembles, and may lose the ability to talk or may become momentarily paralyzed. The jaws may lock, or hearing may stop.” Like *bilis, muina* can result in a discharge of bile throughout the body. Latorre says that it can lead to jaundice. The treatment for *muina* — the other illness caused by anger — is formulaic. As Dolores Latorre reports: “The affected person is swept with three red flowers on three consecutive days — Wednesday, Thursday, and Friday — and afterward is given a decoction made with flowers and leaves of the orange tree or other citrus. This will calm the patient. If it does not, the person is struck, shaken, or addressed with unkind words in order to break the fit of anger.” Interestingly, the symptoms which Latorre attributes to *muina* are much like those of someone suffering from hysteria. For a long time, and even today, an hysterical person is slapped or shaken, much the way the victim of *muina* would be if he didn’t respond to the ritual of the flowers.

Originally, the symptoms of *latido,* which translates as “palpitation” or “throb,” were a feeling of weakness and a throbbing, jumpy feeling in the pit of the stomach. Now, however, the term *latido* is often used to describe a stomach ache. Both forms of *latido* tend to strike those who are weak and thin.

Some liken *latido* to a nervous stomach, though others, probably describing the original ailment, say it is like the condition which medical authorities call hypoglycemia or even anorexia in more severe cases. Indeed, symptoms of *latido* usually occur when a person has not eaten for a long period of time. *Latido* is usually treated by administering nourishment. Some suggest that a patient take, for 9 consecutive days, a mixture of raw egg, salt, pepper, and lemon juice. A more appetizing cure requires that the patient eat bean soup with onion, coriander, and garlic. Latorre describes a *comfortative* made of a hard roll which is split, sprinkled with alcohol, filled with peppermint leaves, nasturtiums, some cinnamon, cloves, and onions. After this is done, the roll is closed, wrapped in white cloth, and bandaged over the pit of the patient's stomach. The fact is, as farfetched as some of these rituals may sound to those of us accustomed to the cold, sterile administration of medical aid, they work!

Perhaps most importantly, the *curandero,* if used in these rituals, focuses his attention 100 percent on his patient. This cannot but be an important component of the healing process. Then, too, touch figures largely in the healing rituals. Only recently has the medical establishment come to admit the therapeutic importance of touch. The rituals often involve other members of the patient's family, too, and many are done in the patient's own home. The person who is ill thus has a very deep sense of belonging while the rituals are performed.

Some think that *bilis and muina,* the anger illnesses, are ridiculous and superstitious, but if one thinks about it, the rituals play an important role. Researchers have concluded that chronic anger ranks with, or even exceeds, cigarette smoking, obesity, and high-fat diets as a powerful risk factor for early death. For women, constant suppressed anger seems to be a strong risk for early death. Therefore, prolonged anger can kill you. In earlier years, people had practiced cures for illnesses that modern medicine has just recently recognized such as gastric indigestion in *bilis,* hysteria in *muina*, and anorexia in *latido.*

There are several factors that may allow the U.S. medical system to study a dual system which could integrate Western and traditional medicine concepts. The factors that are leading toward this dual concept are:

- the constant influx of immigrants into the United States with traditional medicine values;
- a greater understanding and appreciation of holistic, herbal, and preventive medicine by the general public;
- the increasing costs of modem medicine; and
- the forthcoming health reform changes in the U.S. health system.

This possible dual health system, similar to China's health care approach, would allow the consumer to make a choice in treating either modem gastric indigestion or traditional *bilis;* modem hysteria or traditional *muina;* and modem anorexia or traditional *latido*.

Traditional medicine treats many ailments not even recognized as such by the formal medical establishment. In many cases, these ailments reflect the patient's psychological state. As Ari Kiev, an author and psychiatrist, has pointed out, *curanderismo* is a traditional system of medicine which recognizes the profound effect the emotions can have on health. It takes into account the physical manifestations of such feelings as anger, sorrow, shame, rejection, fear, desire, and disillusionment. When one considers that the holistic movement is one arm of formal medicine which has finally begun to recognize this, the centuries-old practice of traditional medicine seems advanced indeed.

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INHERITED BREAST CANCER

Approximately 7 percent of breast cancer and 10 percent of ovarian cancer in the United States is thought to be due to the presence of an autosomal dominant susceptibility allele. Two breast cancer susceptibility genes (BRCA1 and BRCA2) now have been identified[1–3] and a third (BRCA3) is being actively sought. Breast cancer susceptibility in families with mutations in these genes appears as an autosomal dominant trait, with breast cancer affecting as many as half of the women in each generation. Thus, both of these genes are considered high penetrance genes, as the majority of individuals with these alterations will ultimately develop breast cancer. Mutations in several other high penetrance genes, such as p53 (associated with Li-Fraumeni Syndrome) and MSM (associated with hereditary non-polyposis colon cancer), also have been identified as causes of hereditary breast cancer but are very rare in the general population. It is very likely that many other genes contribute to inherited breast cancer susceptibility in families where the incidence of breast cancer is elevated, but where the appearance of breast cancer is more scattered, because fewer numbers of carriers will develop breast cancer as a result of these lower penetrance genes. These genetic alterations are complex and what little is known about candidates for low-penetrance cancer susceptibility genes is not yet of clinical use.

The isolation and study of BRCA1 and BRCA2[1,4] have greatly expanded our knowledge of inherited breast cancer. Utilizing direct mutation screening, recent epidemiological studies are providing increasingly accurate estimates of the fraction of hereditary breast cancer attributable to gene mutations in BRCA1 and BRCA2. These studies also calculate the penetrance — the disease risk — of inherited mutations more accurately than could be accomplished prior to the isolation of the genes. At the same time, functional studies are beginning to identify several mechanisms of cellular growth control with which the breast cancer susceptibility genes interact. Finally, families and individuals can be accurately classified using genetic testing, facilitating studies of tumor type and outcome.

How Much Breast Cancer is Due to BRCA1 and BRCA2?

BRCA1, the first early-onset breast cancer susceptibility gene, was initially mapped to chromosome 17 in 1990.[4] Linkage — an association between breast cancer and a specific genetic marker on this chromosome — was subsequently demonstrated in families of both breast and ovarian cancers.[5] These early studies estimated that 90 percent of breast-ovarian cancer families — those with four or more cases of early-onset breast cancer and at least one case of ovarian cancer — were linked to this locus. Forty-five percent of specific breast cancer families — those characterized by the occurrence of breast cancer alone — were linked to 17q21.[6] The second breast cancer susceptibility gene, BRCA2, was linked to chromosome 13 in 1994[7] and isolated in 1995.[2] Early estimates suggested that BRCA2 might be responsible for 25 to 30 percent of site-specific breast cancer. However, data derived from linkage studies tend to overestimate the true fraction of heredity breast cancer due to mutations in BRCA1 and BRCA2, as has been shown by more recent studies performed on families that may not be suitable for age analysis, but who are more typical of the spectrum of breast cancer families seen by practicing physicians. These studies suggest that BRCA1 mutations account for only 11 to 17 percent of inherited breast cancer, with BRCA2 mutations probably responsible for a similar fraction of families. However, as many as 45 percent of families with both breast and ovarian cancer may carry BRCA1 mutations.[8–10]

Several groups have begun work on models using individual and familial factors to predict the probability of finding germline mutations in BRCA1.[9–11] These studies, despite methodological differences, have identified several factors which predict for increased likelihood of finding a BRCA1 mutation in an individual. These traits include ovarian cancer, particularly an individual with both breast and ovarian cancer in the family, an early age of breast cancer diagnosis, and Ashkenazi Jewish ancestry (because of the increased mutation frequency in this population). These models, and others under development, were all designed to help guide clinicians in identifying those patients in whom BRCA1 and BRCA2 mutation testing is most likely to be informative. As information about the functions of the BRCA1 and BRCA2 proteins accumulate, it may also become possible to correlate mutations in specific functional domains of the protein with the pattern of cancer incidence in families.

Do All BRCA1 and BRCA2 Mutation Carriers Develop Cancer?

As noted above, the penetrance of BRCA1 and BRCA2 mutations is high, but like estimates of the contribution of BRCA1 and BRCA2 to inherited breast cancer, the early estimates may be exaggerated due to the peculiarities of the families commonly used for genetic research studies.

Female mutation carriers were initially estimated to have an 87 percent lifetime risk of developing breast cancer, and a 40 to 60 percent lifetime risk of developing ovarian cancer.[12] The cumulative risk of developing a second breast cancer was estimated to be 65 percent for affected mutation carriers who lived to age 70.[12,13] The risk profile of BRCA2 was thought to be similar, but with a lower risk of ovarian cancer. Initially, linkage studies estimated the lifetime breast cancer risk to BRCA2 mutation carriers to be 85 percent, and the lifetime ovarian cancer risk to be 10 to 20 percent.

More recent estimates from a population-based study of ovarian cancer suggest a penetrance of 70 to 75 percent for breast cancer and 25 to 30 percent for ovarian cancer. Using a similar approach, Streuwing and colleagues have recently addressed the question of the penetrance of common BRCA1 and BRCA2 mutations in a large population-based study of Ashkenazi Jews, suggesting that the estimated lifetime breast cancer risk to carriers of any of the three mutations is 56 percent, with an ovarian cancer risk of 16.5 percent.[14] Of additional interest, this study did not support previous suggestions that the location of a mutation within the gene was associated with the variations in the degree of risk for ovarian cancer.

Probable reasons for the discrepancy between recent data and the earlier linkage studies include: 1) only the most severely affected families were used for linkage studies; 2) even the most sensitive mutation detection techniques fail to identify mutations which do not fall within the region of the gene that encodes the BRCA1 and BRCA2 protein products (estimated to account for over 10 to 20 percent mutations), but linkage analysis will detect these families; and 3) lower sensitivity mutation screening techniques for coding region mutations have been used, again missing families that will be detected by linkage analysis.

BRCA1 and BRCA2 Mutation Spectrum

BRCA1 is a very large gene, making the possible number of mutations enormous and the technical aspects of finding them daunting. Since the identification of BRCA1 in 1994, more than 300 sequence variants have been detected. These variants are distributed along the entire coding region of the gene, and over 50 percent of them have been identified only once. This means that in most settings, a BRCA1 mutation test must evaluate the entire coding region of the gene. Most mutations described so far generate stop codons, truncating the protein, but others result from mutations in the signals that allow proper splicing of the mRNA, or from single base substitutions that destroy a functional region of the protein.

Controversy exists over whether the location of a mutation within BRCA1 plays a role in the clinical appearance of the family or individual. Two studies[15,16] suggested that mutations in the 5′ half of BRCA1 predispose to both breast and ovarian cancer, while mutations closer to the 3′ portion of the gene are predominantly associated with only breast cancer. However, several recent and larger studies have failed to reproduce this finding. As noted previously, it has also been suggested that mutations occurring in the terminal regions of BRCA1 may be associated with a more severe phenotype, as defined by high breast tumor grade.[17]

Somewhat surprisingly, all breast cancer-related BRCA1 mutations identified to date are germline mutations,[18] meaning they are present in all cells in the body, including egg or sperm, and therefore can be passed on to the next generation. Acquired mutations — those that occur after birth in a single cell — are not passed on unless that cell happens to be a sperm or egg, but may give rise to cell clones that become cancerous. Acquired (somatic) BRCA1 mutations have not been described in human breast cancers, and only rarely are found in human ovarian cancers.[19–21] This finding has led to speculation that BRCA1 may not be an important component of the development of most breast and ovarian cancers, yet it is possible that the function of BRCA1 may be disrupted in other ways in sporadic (non-inherited) breast cancer.

BRCA2 is almost twice as large as BRCA1, thus is even more complex to fully screen for mutations. More than 100 BRCA2 mutations have already been described,[2,3,22–28] and several similarities with the mutation spectrum of BRCA1 are apparent. First, BRCA2 mutations span the entire coding region of the gene. Second, most mutations reported to date result in premature termination of the protein product. Finally, few mutations have been identified in the BRCA2 gene in sporadic breast or ovarian cancers. These data suggest that, as is the case for BRCA1, BRCA2 mutation testing requires evaluation of the full coding region of the gene. Present BRCA2 mutation coding techniques also fail to identify noncoding mutations, thus false negative mutation test results occur and test results must be interpreted in the context of the predicted probability of finding a mutation.

A few common mutations have been identified in BRCA1 and BRCA2, particularly in specific subpopulations. 185delAG and 5382insC in BRCAl and the 6174delT in BRCA2 have been identified as common mutations in the Ashkenazi (Eastern European) Jewish population, with a combined frequency of these mutations estimated at 2.0 to 2.5 percent.[29–33] This is strikingly increased compared to the overall mutation frequency in an unselected Caucasian population of about 1 in 1,000. This phenomenon is most likely to occur in populations that have historically been geographically or politically isolated from surrounding populations, where reproduction occurs solely within the group. An additional factor is the absence of selection bias before childbearing age, so that most mutation carriers would be expected to reproduce before succumbing to breast or ovarian cancer. The common ancestry of a mutation may be demonstrated by genetic techniques (haplotyping), revealing, in this case, a founder effect in the Ashkenazi Jewish population.[34,35] Using haplotyping, it is estimated that the 185delAG mutation in BRCA1 entered the Eastern European Jewish population in a single individual (the founder) in approximately the 12th century, and has been propagated throughout that population to the present.[34] The high frequency of BRCA1 and BRCA2 mutations in this population has a significant impact on clinical estimates of the probability of finding a mutation in certain individuals — recent reports have taken this into consideration and generated separate models for Ashkenazi Jewish families.[10] One additional consideration that arises when population frequencies are high is the likelihood of finding more than one mutation segregating independently in a family. Several group have reported individuals who carry mutations in both BRCA1 and BRCA2, and these individuals have relatives that may have either mutation or neither of them. These findings underscore the importance of full pedigree evaluation, of mutation testing for both genes in families' bilinear cancer histories, and the need to evaluate all Ashkenazi Jewish individuals for all three common mutations, even when one of the three mutations has been identified in another family member. Finally, as the effect of population genetics is apparent in the Jewish population, it is important to bear in mind that virtually all of the mutation estimates derive from Caucasians of Northern European ancestry and may not be applicable to African Americans, Asians, Hispanics, or other population groups with differing genetic backgrounds.

Direct sequence is thought to be the most sensitive and specific BRCA1 mutation testing method available; however, because sequencing is labor intensive, it is the most expensive mutation detection technique. Gel shift assays, including multiplex heteroduplex analysis[36] and single strand conformation-sensitive polymorphism,[37,38] can reduce the number of samples that must be sequenced, but the sensitivity of these assays is highly dependent on the experience of the laboratory. Other assays including allele-specific oligonucleotide hybridization and the protein mutation assay[39,40] are also available, but have the limitation of identifying only specific types of mutations. Now technologies are being developed, including those using computer-based analysis, to fully automate completed gene sequence analysis. These techniques should significantly improve the efficiency of mutation detection, decrease the price of clinical testing, and enable population-based studies of mutation prevalence and disease penetrance.

In the setting of clinical testing, two categories of mutation test results may be difficult to interpret. First, single base pair changes — missense mutations — do not always result in an altered function of a gene's protein product. Thus, missense mutations not located within critical functional domains, or those that make only minimal changes in the surrounding protein structure, are not likely to be disease associated. For this reason, determination of the functional significance of newly identified missense mutations outside of the RING finger of BRCAl requires clear correlation with disease status in multiple affected families and individuals. Second, negative test results, particularly from an affected member of a family with a high predicted probability of carrying a breast cancer susceptibility gene mutation, may be difficult to interpret. In interpreting these results, it is important to remember that all routinely available tests fail to identify a minimum of 10 percent of mutations in both BRCA1 and BRCA2 that occur in noncoding regions, resulting in a false-negative test result.

Clinical Implications and Directions for Future Research

While proven preventive interventions specific to the hereditary breast cancer population are still not available, several important clinical questions are currently being investigated. Because of the high rate of second primary breast tumors in BRCA1 and BRCA2 mutation carriers, and because of uncertainty with regard to radiation risks in this population, the appropriateness of breast-conserving therapy in known mutation carriers is evaluated. Data need to be developed with respect to appropriate breast cancer screening among schedules for mutation carriers, and information about the effectiveness of ovarian cancer screening, generally not thought to be effective, will need to be obtained in these mutation carriers. Prophylactic surgery is also controversial, and both families and physicians raise questions about the effectiveness of this aggressive approach in mutation carriers. Although the degree of risk reduction resulting from prophylactic surgery is not presently known, both retrospective and long-term followup studies of mutation carriers are underway to address these questions. More specific information about disease penetrance will be an important element in both the development of screening protocols and the evaluation of prophylactic surgical interventions. Finally, additional information about the mechanisms of BRCA1 action is needed in order to identify specific preventive and/or therapeutic strategies. While early BRCA1 gene therapy trials have not yielded significant responses, further definition of disease mechanisms may facilitate the identification of appropriate molecular targets.

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INFLUENCE OF TRADITIONAL AND CULTURAL HEALTH PRACTICES AMONG ASIAN WOMEN

I would like to thank Dr. Vivian Pinn for this opportunity to discuss the diversity of Asian traditions and cultural practices that impact the health of Asian women. I was glad to see that the needs of my Pacific Islander sisters, Native Hawaiians, will be presented separately because when data for Asians and Pacific Islanders (API) are disaggregated, the health differences are great.

I would like to dedicate this presentation and my work for improvement of health outcomes for minority women to my mother, Florence L. Yee, who died on June 18, 1997, at the age of 69, of nasopharyngeal carcinoma. She died of a disease that is rare among Caucasian Americans, but is epidemic among Chinese, immigrants, and their descendants from Southern China. She suffered for 2.5 years from ineffectual and painful cancer treatments for nasopharyngeal cancer in its last stages because poor screening and diagnostic tools, as well as effective therapies, are lacking for this type of cancer. My mother also suffered from radiation and chemotherapy treatments and their iatrogenic effects that produced poor quality of life during her last years of her life. Mom, this presentation is dedicated to you.

During the past two decades, much biomedical research has been devoted to examining the universal precursors of health and disease. What is currently lacking is our understanding of the unique contributions that traditions and cultural practices have upon health outcomes for minority populations. In an examination of risks and protective factors in health and disease, after controlling for intervening variables such as key demographic factors including social class and education, and universal contributors such as genetic factors, diet and exercise, or environmental exposure, we are still left with much variance to be accounted for. I suggest that culture and acculturation may be several critical intervening variable that could explain much variance, perhaps not alone, but in their dramatic influence upon precursors to health and disease.

Several caveats must be stated before any discussion of Asian traditions and cultural practices can be made. First, there is great diversity across the 28 Asian ethnicities designated in the 1990 Census in culture, acculturation, and Westernization; immigration and personal history; cultural health beliefs; and lifestyle practices that impact health outcomes for Asian women in the United States (Table 1, Figure 1).

Currently, there is problematic aggregation of data across API ethnicities in national databases because they are very heterogeneous across health status, health risk, and protective factors, and may be contradicted by localized state surveys that are API-ethnic specific. For example, the monograph entitled “Racial/Ethnic Patterns of Cancer in the United States, 1988-1992,” published by National Cancer Institute’s Surveillance, Epidemiology, and End Results program, reports that Asian women span extreme ends. From the lowest breast cancer incidence for Korean-American women to second highest incidence in Hawaiian women across all women. Or, the highest incidence of cervical cancer among Vietnamese-American women across ethnic groups to the lowest for Japanese-American women. Therefore, the aggregate rate across these heterogeneous API groups becomes meaningless, and portray incorrect health status. Population-based statistics suffer from errors in undercounting API populations and accounting for the rapid growth in API populations between the 1970, 1980, and 1990 censuses.

TABLE 1. 1990 Census Codes for 28 Asian and 19 Pacific Islander Ethnicities in the United States

Asian		Pacific Islander	
Chinese	Ceram	Hawaiian	Palauan
Filipino	Indochinese	Samoan	Ponapean (Pohnpeian)
Japanese	Indonesian	Guamanian	Polynesian
Asian Indian	Iwo Jiman	Carolinian	Solomon Islander
Korean	Javanese	Fujian	Tahitian
Vietnamese	Malayan	Kosraean	Tarawa Islander
Cambodian	Maldivian	Melanesian	Tongan
Hmong	Nepali	Micronesian	Trukese (Chuukese)
Laotian	Okinawan	Northern Mariana Islander	Yapese
Thai	Pakistani		
Bangladeshi	Sikkim		
Bhutanese	Singaporean		
Borneo	SriLankan		
Celebesian	Sumatran		

Given these numerous research caveats and indications that these data are seriously flawed, we cannot use them to generate health policy because they underestimate negative health status among certain API populations or tend to provide poor, at best, estimates of API health status. They must be taken with a healthy degree of skepticism when used to shape national health policy for API populations.

Not only is there a serious methodological flaw of aggregation across widely diverse Asian ethnicities, but an equally serious problem is the lack of valid national data on Asian women. This error of omission, total lack of or

FIGURE 1. Life Span Development Model: Understanding Asian and Pacific Islanders Across the Life Cycle

Age-related or Normative Changes

Biological
Psychological
Social

Personal Characteristics

Personality – Self Efficacy
Health and Mental Health Status
Skills: Physical, Cognitive, Social,
  Cultural Competence
Personal Beliefs

Present Environment

Ethnic Density Support
Cultural Competence of Social Context
Social Support and Networks
Economic and Social Opportunities
Presence of High-Risk and Protective Factors
Current Stressors

History

Generational and Cohort History
Ethnic Group History in the United States
Personal History in the United States

Source: (Yee, 1976; Yee, 1977; Yee, 1992; Yee, 1993; Yee, 1995.)

inaccuracy of national health status information on API populations, is often justified by saying that this population is small and that the little data we have appears to indicate that API may be healthier than even the white population. The perpetuation of the model minority myth is problematic from several perspectives. There is clear evidence that there are significant and problematic errors which produce a significant underestimation of API mortality. For instance, Sorlie, Rogot, and Johnson (1992) found that the Census Bureau underestimated Asian death rates by 12 percent because they were reported as white on death certificates. Another clear example of underestimating API mortality occurs among infants. According to Hahn, Mulinare, and Teutsch (1992), the National Linked Birth and Death Files revealed miscoding of 33.3 percent Chinese, 48.8 percent Japanese, and 78.7 percent Filipino American infants, typically included as white infant deaths. In contrast, the errors for white infants was only 1.2 percent. These two examples suggest that there is a significant underestimation of API mortality, therefore, current baseline data of API health could be suspect; more adequate and sound data must be gathered.

A third caveat is that the correlation of health status between generations of Asian women may be lower than the prediction across generations for the more established ethnicities in the United States. For instance, the impact of acculturation to American health habits occurs most rapidly among children to young adults because they have less established health habits than among middle aged to elderly Asian immigrants. Therefore, conducting research of health among young Asian women is not helpful for predicting health among older generations of Asian women. With acculturation to American ways, serious health risks are generated for certain diseases such as cardiovascular diseases and cancers, while lessening of risks for others such as strokes or nasopharyngeal cancers. While the health risk among American-born Asian women approach rates approximating those found among Caucasian women, such as breast cancer in Japanese-American women.

Asian Traditions and Cultural Practices that Impact Health Outcomes

In such a short time, I cannot outline all the health beliefs and lifestyle practices, across each of the Asian ethnicities, which impact health outcomes for Asian women, but only highlight important ones. We have just started linking key cultural health beliefs and lifestyle practices among Asian women and much more research is necessary to help us understand how culture and acculturation intervene to produce better or poorer health outcomes for Asian women.

Health Beliefs and Practices for Asians

There are clear differences between Asian and Western concepts of health and wellness. The Chinese health belief system is the basis of beliefs held by many traditional Japanese, Korean, and Southeast Asians. Health results from a state of equilibrium between man, society, and the cosmic forces of the universe (Yu and Cypress, 1982). Health is achieved if one can balance Yin and Yan energy forces. Yin represents forces in the body described as darkness, cold, and emptiness. Yan represents light, warmth, and fulness. Eating certain foods can bring about the balance or imbalance between Yin and Yan. For instance, since elderly people are predisposed to Yin, or cold energy forces, they should avoid eating too many cold foods such as leafy green vegetables (Chen-Louie, 1983). These beliefs, then would discourage elderly Asians, holding this belief, to eat enough leafy green vegetables, a practice not conducive to good health by Western standards.

Disease and illness is a disturbance of the balance of Yin and Yan. Illness is also created by imbalances of *chi* or blood. Since blood is a source of human vitality and difficult to replenish, any medical procedure that loses blood or lowers the body's ability to make blood is avoided. As a result, many elderly Chinese who have these beliefs may decide not to have the needed surgery or wait until a crisis develops. This has serious implications for those who were dependent upon the surgery to survive. Delaying the needed surgery may have serious negative ramifications and even death for these Asians.

Chi, a form of energy, circulates in the body and moves along pathways called meridians. In order to achieve balance, the flow of chi must be directed at focal points on the meridians. Stimulating the flow of chi can be achieved with acupuncture through needles, and acupressure or shiatsu through pressure. Wind or "feng" is an external force that causes disease. This noxious substance invades the body and produces symptoms such a bloating, flatulence, depression, and joint pain (Kunz, Lam, Siu, and Young, 1981). These Asian assumptions about health, disease, and illness are so different from Western beliefs of health that health care professionals treating elderly Asians must have some training about these beliefs in order to understand their clients behaviors and be more effective in helping these patients.

Traditional Asians believe that Western medicines are too strong for their Asian bodies, therefore, may halve the standard dosages prescribed for them. This may have serious implications for efficacy of certain medicines such as TB drugs or antibiotics. Or, this may have life-saving implications for other medications such as psychotropics, known to have serious overdose implications for Asians (Lin, Poland, and Nakasaki, 1993). Add gender and age differences to this Asian belief, and you may have serious iatrogenic health implications for Asian women.

Asians are also susceptible to drug interaction and toxic substance because of their use of herbs and Chinese patent medications. Substances such as herbal remedies may interact with their prescription or over-the-counter medications and create serious side effects. Certain medications may contain toxic substances, such as arsenic or mercury, or are medicines with unproven treatment claims that may endanger Asian elders. Use of unproven treatment medicines may divert elderly consumers from proper medical attention on a timely basis (California Department of Health Services, 1988).

Two indigenous belief systems have developed for the Japanese elders. Shinto religion regards humans as inherently good. Humans become evil because they have succumbed to temptation and the spirits are taking their revenge on this human. Purification rites, such as cleanliness and use of herbal purgatives, come from these rites.

The second Japanese belief system is the "Kampo" medical system which encourages maintenance of harmonious relationship with the universe. Kampo practitioners help the Asian client cure illness by restoring a stopped or slowed flow of energy. Treatment methods include use of herbs, acupuncture, acupressure, massage, and moxibustion. Moxibustion is the practice of burning small cones of mugwort leaves at specified points on the skin surface and is thought to be particularly effective for treatment of ailments of the joints, muscles, bones, and back.

Several Japanese cultural values have implications for delivery of health care services to Japanese elders. For instance, fear of being in an embarrassing or shameful situation could discourage Japanese elders from pursuing health care or coming back for treatment if they could not afford to pay the physician on a timely basis. Many Japanese elders passively accept events thought to be beyond their own control. This passivity endangers the elders' life because after hearing the news of their illness, they may not pursue a treatment regimen because they thought that this illness was their "fate" and not something under their control. Deference to authority can mean that Asian elders will appear to agree with their physician by nodding their head or not ask questions about the information provided or instructions about the treatment regimen. The appearance of agreement may not indicate that they really agree or fully understand instructions or what was said. Rather, cultural norms that encourage deference to authority may produce this behavior and health care professionals should make sure that Asian elders really understand what was said by having them repeat the information. "Gaman" or self-control could make

Japanese patients very stoic about pain and suffering, or make them reluctant to use community services to alleviate their problems (see Hashizume and Takano, 1983; and Yee and Hennessey, 1982, for review of cultural values and behavior).

Common Cultural Characteristics

Understanding of an ethnic group's history is critical. A brief summary of the common cultural characteristics might be helpful in understanding API elderly. A caveat is that there is great diversity in the extent to which an elder integrates traditional and American ways, but some common cultural threads can be seen (see Yee and Hennessey for review, 1982). Understanding these traditional cultural threads can help us understand how we can improve our research on, and services to, API elderly.

Confucian philosophy created the framework for the traditional Asian family and society. Every person has a definite place in society and a prescribed status. If everyone knows her or his place and acts accordingly, social order is assured. Almost all relationships are of the "subordinate-superordinate" type, and complementary roles are of the leader-follower, teacher-pupil, and father-son variety. As a result, all interactions within the family and society are based upon clearly prescribed roles, duties, and responsibilities rather than on personal affection. Conflicts for traditional Asians come when the Americanized members of the family no longer abide by the prescribed roles, duties, and responsibilities (Yee, 1989). Service delivery systems that do not take these prescribed roles into account will often not be utilized by traditional Asians because there are too many unknowns for these elderly. For example, physicians must often be more authoritarian because these traditional elders expect this of authority figures.

Needs of the family always take precedence over the needs of any given individual. The survival and success of the family is more important than the success of the individual. For traditional Asians, individuals learn to suppress their own needs if these conflict with the needs of the group. Approval-seeking from authority figures come from this value. Traditional Asians learn to act cautiously because any deviation from appropriate behavior reflects negatively upon the individual and her or his family and thereby producing shame, embarrassment, and disgrace for all concerned. Service delivery that does not consider the needs of the entire family, along with the needs of an elderly patient, may find that they have lost this patient.

In traditional Asian families, elders are the authority figures and keep younger members in line with threats of shame to the family if indiscretion occurred. In traditional Asian families, elders are looked up to, have control over the family's purse strings, and have the final authority to make decisions for each younger member of the family (Yee and Hennessey, 1982). This is a very different situation from reality in the United States. Traditional Asian elders living in the United States often find themselves with less control, experience role reversal, and no longer control financial resources — they find themselves totally dependent upon their adult children for support.

Maintenance of family harmony and cohesiveness is critical. This traditional Asian value comes from agricultural Asians where a certain degree of harmony was necessary to make that economic unit function effectively and smoothly. In order to maintain harmony interactions, there is an avoidance of direct confrontation, disagreement, and criticism. Straightforwardness is considered to be impolite and a lack of intelligence. Once Asian families come to the United States, younger family members rapidly adopt American ways and may offend their elderly relatives. Awareness of this need for family harmony and cohesiveness should be recognized when prescribed interventions and services for the elderly are suggested.

Another distinctive feature of the traditional Asian family is group loyalty and dependence. Loyalty to the family is a long-term commitment and is maintained through a system of obligations. Obligations are especially strong within the family because many exchanges of favors are made between parents and children, siblings, and extended family members. Family obligations must be repaid by other family members if the person incurring the obligation cannot or fails to repay the obligation. Family obligation may take precedence over the needs of a given individual, so service providers must take this into account when suggesting possible family interventions.

Spirits of dead relatives are at the heart of the family and they guide the behavior of each family member. Each member of the family forms a link with past and future generations. The family must be held together to maintain this historical continuity. Filial piety is paid to older members of the family because they gave life to younger family members and will soon be joining the family ancestors after death. Filial piety is no longer the major focus of the relationship between generations of Asian-American families.

As suggested above, several traditional Asian cultural characteristics may influence the behavior and attitudes of the elderly and their families. These cultural attitudes and behaviors systematically influence physical and mental health status, as well as social relationships and networks in later life of API elderly. However, the extent to which each individual Asian elderly and their family members prescribe to these traditional values and beliefs varies widely in the API population.

A few examples are warranted to understand the interaction of cultural, genetic, environmental, and behavioral factors on the health of Asian women. A clear example is the Southern Chinese tradition of weaning babies off mother's breast by giving them salted fish, eating this salted fish especially in early life and over a lifetime. The carcinogens in this Chinese salted fish is one of three critical factor implicated in nasopharyngeal cancers. Two other factors implicated are Epstein Barr virus that triggers the cancer, and underlying genetic cancer vulnerability. Yet, salted fish is currently widely available in Asia and the United States. There are no U.S. bans on this dangerous food product, nor widespread health promotion efforts to discourage use of this carcinogenic food.

In 1985, we conducted (Yee and Thu, 1987) a mental health needs assessment of Southeast Asian refugees in Houston, Texas. We found that these Vietnamese refugees were using alcohol and smoking as coping mechanisms to deal with their problems. Although this was more prevalent among the males, the gender gap in poorer health habits were closer among younger refugees. The acculturation of Southeast Asian refugees produced poorer health outcomes for younger Vietnamese refugees because they glamorized and adopted Western, sometimes poorer, American health habits.

In a pilot study (Yee, in press; Yee, in progress), I found that Vietnamese women have less knowledge about the risk factors that put one at higher risk of stroke; coronary heart disease; diabetes; chronic obstructive pulmonary disease; chronic liver disease; and lung, breast, cervical, and colorectal cancers. Older Vietnamese women had the least knowledge about risk and symptoms, tests, and treatments of these diseases than younger Vietnamese women, and much less knowledge than their Caucasian counterparts. Although, in examination of their health practices, these older Vietnamese women engaged in healthier health habits than their younger counterparts, such as less smoking, drinking, and had better overall diets.

Another example is that environmental and behavioral risk factors for one ethnic group may not necessarily have the same impact on another ethnic group (Croft, 1995). Susceptibility to lung cancer is influenced by genetic polymorphisms in human cytochrome P450lAl gene (CYPlAl) that produces an enzyme to metabolize carcinogens found in cigarette smoke. Asians are found to have more of this type of genetic susceptibility than Caucasians. African Americans have a higher polymorphism not associated with total lung cancer, but significantly associated with adenocarcinoma of the lung and prostate cancer in smokers. Smoking and environmental exposure to carcinogens produces quite different health outcomes across racial groups because they may lack, in higher proportions, the enzyme to neutralize these carcinogens.

Le Marchand, Sivaraman, Franke, and Wilkens (1995) found that the rates of colorectal cancer among Japanese Americans has surpassed those of whites. A population case-controlled study found that Japanese Americans living in Hawaii had a 50 percent greater intake of red meat and processed meat, and genetic polymorphism in NAT2 and CYPlAl genes involved in metabolism of carcinogens in red meat. This genetic susceptibility puts Japanese Americans at higher risk of colorectal cancer with acculturation to Western diets.

A third example from a population-based case-controlled study of prostate cancer among blacks, whites, and Asian Americans in Los Angeles, San Francisco, Hawaii, Vancouver, and Toronto (Whittemore, Kolonel, Wu, et al., 1995) found a significant relationship between high total fat intake and prostate cancer risk for all ethnic groups. However, saturated fat intake was associated with higher risks for Asian Americans than for blacks and whites. This study suggests that saturated fats in the diets of Asian Americans had a more negative impact for this group than other ethnic groups in the study. We may find the same results if we examine the impact of fat intake among acculturated women and its health implications. We just do not have the data yet. Acculturation to American culture through American health practices such as diet, exercise, and stress management may have both positive and negative implications for Asian women.

Challenges to Determine Risks and Protective Factors for Improvement of Asian Women's Health Status

The first and most basic challenge is to fund an epidemiological health study of Asian populations from birth to death on a longitudinal basis that is broken down by gender, age, and cohort, and clusters of Asian ethnicities by key variables to provide proxies that reflect Asian population heterogeneity. A clear example of this type of research effort is Hispanic HANES. This baseline data will allow accurate *Healthy People 2000* goals to be generated for Asian populations. Today, I challenge federal agencies across the National Institutes of Health, CDC, and other health data gathering agencies, to pool their monies and fund special research initiatives on the life span developmental health status of Asian populations and to fund research scientists partnered with community health organizations. Yu (1996) clearly outlined ten specific recommendations to improve the accuracy of health data on APIs and fill numerous gaps in this baseline data.

A second challenge is to create Asian Centers of Excellence to examine Asian health status with the intent of developing research methodologies such as sampling rare populations and cross-cultural research with Asian populations tackling issues such as health assessment and survey instrumentation, while training a generation of health researchers focused specifically on conducting culturally competent research on Asian populations. A clear example is the UCLA/MEDTEP for Asians, funded by AHCPR but broader in its mandated research and training mission. Another is the UCLA-Harborview Center for Ethnicity and Psychobiology funded by NIMH to examine Asian ethnic variations in use of psychotropic drugs. This center could expand its mission through funding by other federal agencies to examine medical outcomes in drug therapeutics in treatment of cancers, heart disease, strokes, diabetes, and other health conditions across Asian populations. Another collaborative effort across federal agencies is the Cultural Competence Series on Asian Substance Abuse Prevention and Evaluation by CSAP and the Bureau of Primary Health Care. More collaboration across federal and state lines help pool necessary resources to fund projects that will help fill needed Asian data gaps and programmatic health services in Asian communities.

A third challenge is to implement recommendations generated by the Delegates to the First National Health Summit of Asian American and Pacific Islander Health Organization Leaders in San Francisco in 1995 (February, 1996) and the Pacific Islander and Asian American Health Research Training Conference in Honolulu in 1996. These recommendations provide specific suggestions for improving the health of Asian girls and women.

Four things must occur if we wish to plan, implement, and evaluate our health interventions for maximum effectiveness among Asian and Pacific Islander communities.

Holistic Approach

First, we take a more holistic approach to people, a yin-yang approach to explore the healthy-unhealthy behaviors or strength-weaknesses of individuals and their social context (Pachuta, 1993; Ramaswami and Sheikh, 1993). The body, mind, and spirit are integrated. Imbalance in one area systematically affects the other aspects. This holistic world view is held by many ethnic communities across this country and around the world, and is being recognized among white ethnic communities and across segments of our medical community. There is a secular trend in the revitalization of the human spirit. The fragmentation of how we deliver health care and services must move toward integration of the body-mind-spirit health concerns at the primary, secondary, and tertiary prevention (rehabilitation) levels.

In the late 1970s, the mental health community said that Southeast Asian refugees did not come to mental health services. At the Asian Pacific Development Center in Denver, Colorado, many Southeast Asian refugees used mental health services because ESL, job training, cultural orientation classes, clothing, housing, furniture, or anything else that refugees needed, facilitated usage of mental health services as needed. The lesson learned at this first Southeast Asian mental health center in this country, high-risk groups typically required multiple services, rather than only health or mental health services. Multiple services, broader than health and mental health, offered at a single point of contact, with case management that was culturally competent, was more likely to be used and more effective than our fragmented services. The alleviation of stress in one aspect of life helped to create a sense of stability, and energy to tackle problem solving in the other aspects that needed attention.

Although difficult, the very nature of this task is painstakingly slow; fraught with pitfalls and traps for research and evaluation of such prevention programs. In our efforts to improve prevention strategies we must conduct ethnic-specific needs assessment, research, and evaluations to incorporate cultural competence models for high-risk populations that focus on health-destructive, as well as health-promoting, mechanisms and use theories of human development to guide and test these interventions. Lorion (1991) stated that theory may enhance our risk estimates for targeting prevention interventions but we have an additional responsibility to measure our intervention's possible iatrogenic risks, such as social labeling, that may lead to a downward spiral of social breakdown or social incompetence (Kuypers and Bengston, 1973). Lorion and Jason (1995) call attention to an opportunity that awaits psychology in the area of health and high-risk populations. He illustrates this opportunity by reminding us of psychology's contribution to identification of behavioral risk factors in AIDS, DePaul University's psychological research on chronic fatigue syndrome, and substance abuse.

Comprehensive: Multidimensional and Multidisciplinary Approaches

Second, since we know that clusters of risk factors occur across many health conditions, for the poor, inner city urban residents, and the elderly (Yee, Castro, Hammond, et al., 1995), multidisciplinary research, planning, programming, and interventions must be implemented. Let's not miss this opportunity to make behavioral sciences and cultural competence advisors essential members of the health research and Health Maintenance Organization teams. Congress has recognized the importance of behavioral risk factors in health and the NIH mandated Office of Behavioral Sciences and Social Research. Norman Anderson, a psychologist and colleague from Duke, was appointed to lead this critical office and needs our assistance to integrate behavioral sciences and community-based psychology into NIH's research mission.

This shift towards identifying important behavioral risks in health is not the only philosophical shift that is required. There needs to be a balance in our research efforts to study the yin and the yang of each health condition and our possible interventions. What is interesting is that major researchers who have studied animals and people who are depressed and have learned helplessness, the yin (Seligman, 1977; Seligman, 1990), are now working upon the concept of learned optimism, the yang, and prevention of learned helplessness. From their research on learned helplessness, these researchers have discovered how organisms learn to become helpless and then become depressed. In their discussion of learned helplessness, Seligman and colleagues have come up with an "inoculation or prevention" plan that can teach organisms and people how to overcome negative outcomes, bounce back, and become resilient in their efforts to successfully cope with life's setbacks. Resilient and competent individuals come from all segments of our society, even from the most deplorable of circumstances. Therefore, these multiple profiles of survival and successful adaptive strategies must be examined in the context of multiple ecological niches (e.g., sociocultural context). Our current challenge is to determine what these survival profiles and patterns of human competence may look like within specific cultural and ecological perspectives (Ogbu, 1981). A particular behavior or comment taken out of context may appear to be maladaptive at first glance. When the context is taken into consideration, the behavior of concern could be viewed as adaptive for the particular set of environmental conditions.

In a recent article, Millar and Millar (1995) argued that there may be negative affective consequences of thinking about disease detection behaviors rather than health promotion. For these authors, disease detection behaviors provide opportunities to detect precursors to disease and illness, and may generate negative affective consequences if an actual disease is found. Whereas, health promotion behaviors provide behavioral plans of action to promote health. Growing health behavioral literature suggests that rational-cognitive considerations may be less important than considerations of emotional-affective issues (see review in Millar and Millar 1995). Similar trends are found concerning the growing predictive power of emotional intelligence as compared to IQ, upon competence and life span adaptation (Goleman, 1995). It appears that how one feels about health and health interventions may be more critical than how one thinks about health. Health decisions appear to be based upon the emotional overtones that are influenced by cultural scripts (Kitayama and Markus, 1994). These findings suggest a shift toward health promotion and prevention, rather than disease detection and illness, while recognizing the equally important contributions of cognitive and emotional-affective mediators of people's behavior to engage in health-promoting behavior and cessation of health-damaging behaviors.

In a recent article, Munoz, Ying, Bernal, et al. (1995) found that depressive symptoms and disorders could be lessened by cognitive-behavioral interventions. They looked at a sample of ethnic minority persons visiting primary care clinics in California (10.1 percent Asian with 67 percent Filipino; 23.7 percent African American; 24.3 percent Latino with 39 percent from Nicaragua and 39 percent from El Salvador; 35.1 percent white; and 6.8 percent other). The Depression Prevention Course consisted of an introduction to depression, use of social learning theory, and other self-control approaches such as learning to monitor daily mood levels; examined how thoughts, activities, and interpersonal interactions affected moods; learning to identify situations that most affect mood levels; and learning to monitor whether and under what conditions mood changes occurred; relaxation training; and realistically plan life's goals to decrease likely of future depression. It appears that there was some decrease in depression by using cognitive-behavioral techniques for preventing future depressive episodes among ethnic minority clients at a primary care clinics.

Cultural Competence

The third essential ingredient for effective prevention interventions is cultural competence. This focus requires a close examination of the sociocultural context of urban environments that produce adaptive behaviors and is rooted in ethnic and family, class and minority, storehouses of adaptive strategies to deal with the stressors of urban life. We must be creative and broaden our acceptance of possible solutions from third world and developing countries, to help shape our prevention efforts with limited resources. The barefoot doctor programs in the PRC helped to provide massive immunizations to millions of Chinese people, even in rural areas. These health paraprofessionals served as health educators, nurses, and physician assistants and referred serious cases to physicians in acute care settings; improving primary and secondary prevention in the PRC.

In a recent Commonwealth study (1995), Chinese, Korean, and Vietnamese, 18 years and older, said lack of insurance, health care costs, having a regular doctor, and less satisfaction with health care services prevented them from receiving adequate health and preventative care. Forty-seven percent of the Vietnamese group who had visited the doctor in the last year, did not receive preventive care services such as blood pressure tests, Pap smears, or cholesterol, compared to white adults (25 percent). The literature cited above suggests that we have much health and mental health prevention work to do in API communities, especially among poorer and non-English-speaking API communities, because they are not currently receiving adequate health and preventive care.

According to Frye (1995), the cultural themes of kin solidarity and search for equilibrium can be used across Southeast Asian refugee groups: Vietnamese, Cambodian, and Hmong. Cultural themes inherent in kin solidarity can be used as cultural motivators in our prevention interventions. For instance, use of the Vietnamese women's dominance in the management of the home (i.e., household and finances) by providing health strategies to these women. In our TB grant in Houston, we used the grandmothers and mothers as health educators to disseminate TB health promotion to the six Vietnamese villages. The search for equilibrium across all aspects of life, is a world view that captures the essence of Buddhist roots, traditional Southeast Asians, and other ethnic minority populations. Unlike those of us acculturated to Western ways — we can put too much energy into work — at the expense of family issues. Balance across emotions, relationships, work, leisure, food intake, and spiritual life is the goal, but if disequilibrium occurs, suffering results. Suffering could be caused by the spiritual disharmony.

One mechanism to get around such linguistic and cultural barriers is to utilize the natural support systems within families and communities to encourage effective health maintenance practices. The critical role of the family and social support system for adaptive aging among traditional Vietnamese refugee elderly should be examined. We must understand how the natural social supports in these populations work, how to measure them, and learn to access them in order to create effective intervention strategies to improve the health and mental health of these high-risk groups.

A critical piece of these prevention interventions is one of cultural competence. Kagawa-Singer and Chung (1994) argue that there are three basic human needs: safety and security, integrity, and a sense of belonging; but each culture provides prescriptions for the most appropriate means to meet these needs. Culture then, has an imprint upon development of the self or identity, and prescribes normative rules for social interaction. Thus, culture provides the framework and behavioral scripts for prevention and any therapeutic interventions. In a study of help seeking among Southeast Asian refugees in California, Chung and Lin (1994) found that Chinese herbs were used as self treatment and health promoting to prevent negative health conditions. After controlling for confounding variables (age, gender, educational level, and English proficiency), use of Western medicine in the home country were: Vietnamese (68 percent), Lao (53 percent), Cambodian (44 percent), Chinese Vietnamese (44 percent), and Hmong (11 percent). This trend was not mirrored in the United States: Cambodian (88 percent), Lao (86 percent), Vietnamese (76 percent), Chinese Vietnamese (69 percent), and Hmong (56 percent). The authors attributed these help-seeking differences to degree of exposure to Westernization, and availability of Western medicine. In addition, a gender difference found in Asia and the United States indicated that female Southeast Asian refugees used more traditional medicine over Western methods and attributed this difference to lower educational levels and literacy, coupled with higher distress levels. The unanswered question then becomes, does the content arena of mental or emotional distress create a different help-seeking pattern for females versus males. Or did educational and literacy wipe out gender differences? One could argue that there are cultural differences inherent in gender that may produce different behavioral strategies for health promotion and prevention, as well as prescriptions for remedying health problems or health access.

Improvement in Prevention Research Methodology and Instrumentation

The fourth issue is improvement of prevention methodology and instrumentation to generate adequate databases to facilitate effective prevention interventions for API communities. According to LaViest (1995), the API elder population (50 and older) is troubled by inadequate attention to estimating a population prevalence rate due to small sizes of the Asian population and limitations or disagreements about appropriate rate sampling techniques. In an analysis of federal agencies, LaViest (1995) found, among 44 national data sets, only 23 included Asian respondents, only one was large enough to estimate a 0.005 prevalence, and only ten were large enough to estimate a 0.1 prevalence. As you can see, these national data sets are a problem for estimating aging-health prevalence rates for Asian. The problem is probably quite similar for all age groups of Asian. The Asian data is scanty and, when you aggregate across diverse Asian populations such as Japanese, Hmong or Hawaiians, you are likely to get poor, at best, or wrong estimates of health status, at worst. The outgrowth of this dismal data situation is that federal policy has chosen to direct only eight of 336 *Healthy People 2000* goals to Asians — another federal policy that has served to maintain the myth of healthy Asian populations.

Another critical prevention issue to be tackled is reliability and validity of instruments normed on white, middle-class populations. In the areas of health, this could mean the difference between life or death. Just recently, Walter Reed Hospital found that the prostate-specific antigen test and its normative values for determination of prostate cancers failed to pick up 40 percent of these cancers in African-American men sampled. These types of errors can be attributable to the use of inappropriate norms for detection and determination of disease and health in ethnic minorities. Another example is one of using calcium channel blockers to control hypertension and is used more frequently among African Americans because it is viewed to “work better,” but puts the user at higher risk of fatal heart attacks. There are clearly efficacy and outcome studies that must be done to insure that “gold standard” treatments work equally as well among ethnic minority and female-gender populations as the white/male populations where standards had been developed.

Surely, an adequate national database on health and mental health status is needed for the API population; 95 percent live in metropolitan areas of which 45 percent live in central city sections of urban metroplexes (Bennett, 1992). Inherent in this fourth issue is one of developing adequate methodological techniques and instruments that are reliable and valid with Asian and Pacific Islander populations.

Adequate Partnerships with Asian Communities

Adequate tuberculosis prevention among Southeast Asian refugees is an example. This Texas state-funded Vietnamese tuberculosis (TB) prevention project in Houston, Texas, was designed to provide health education, screening, and improvement in compliance with TB treatment protocols. It appears that non-compliance with the treatment regimen is the most important barrier to TB prevention and control. Elderly Vietnamese, who lived in the six Vietnamese villages to be targeted for intervention, were recruited to become TB outreach workers and paraprofessionals. These Vietnamese elders were recruited because they lived in the villages, knew the people, were not as likely to be employed, and were integral to the communities that were being targeted. These elderly outreach workers were trained in TB education and prevention by county health department and state TB units. Over 3 months, the project coordinator and five outreach workers provided 325 home visits, made 213 telephone calls, delivered medicine 82 times, provided community TB education sessions, and provided education for 109 clients at home, provided transportation 121 times, and scheduled appointments for 289 clients and provided interpretation for 39 people. This project turned a 100 percent noncompliant group (failures from the county TB control program) into a 97 percent medication-compliant patient population. A TB health education videotape will be produced for training health professionals about TB stigma and cultural differences. Another videotape will be produced for the Southeast Asian consumer that could be disseminated over the Vietnamese television channels. This project demonstrated that partnership between a community-based organization, a health researcher, and state and local providers, could turn around the TB rates among refugee populations.

As suggested in the *Research Agenda for Psychosocial and Behavioral Factors in Women's Health*, there is much work to be done to improve the health of all women. Key psychosocial and behavioral factors work in the context of culture to impact health status and quality of life for Asian women.

Join me in this journey of a thousand miles. Together, in our explorations to discover a clearer health profile and an examination of the critical cultural factors that impinge upon the health outcomes for Asian women across our communities, we may also gather knowledge to improve the health of our Pacific Islander sisters, all women, and their families. Only through partnership and teamwork across federal and state health boundaries and across Asian communities, together with researchers, health advocates, and health service providers, can we generate accurate data and evoke programmatic changes to improve the health of Asian women. Focus upon health in the context of culture and behavioral factors will help provide enlightenment.

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PUBLIC TESTIMONY

INTRODUCTION TO THE PUBLIC TESTIMONY

Vivian W. Pinn, M.D.
Associate Director for Research on Women's Health
Director, Office of Research on Women's Health
National Institutes of Health

This is the third regional public hearing sponsored by the Office of Research on Women's Health (ORWH), of the National Institutes of Health (NIH), to receive public testimony on the Women's Health Research Agenda for the 21st Century.

We express our gratitude to our regional hosts for their enthusiasm, hard work, and invaluable assistance in bringing this facet of NIH's fact-finding process, to elicit public views of important issues for research on women's health to beautiful and historic Santa Fe. Our regional hosts were the University of New Mexico School of Medicine, represented by Dr. Gloria Sarto as cochair, professor of OB/GYN and immediate past chair of that department, and the University of Iowa College of Pharmacy, represented by Dr. Mary Berg, the first woman to attain the promotion to full professor at that institution.

ORWH looked to the broad community of scientists, health care providers, and women's health advocates, across the United States and beyond, to ensure that our research and our priorities for research are addressing continuing, as well as emerging, concerns that confront women in preserving their health and well being, and to provide the scientific information that can permit us to overcome adverse health consequences from conditions or diseases that affect them.

ORWH was established within the Office of the Director of NIH in September 1990, and was charged with the critical objective to give a central NIH focus to women's health through NIH-supported biomedical and behavioral research.

The major objectives of our office are:

- to strengthen, develop, and increase research into diseases, disorders, and conditions that affect women, determining gaps in knowledge about such conditions and diseases, and then establish a national research agenda for NIH for future directions in women's health research;
- to ensure that women are appropriately represented in biomedical and biobehavioral research studies, especially clinical trials, that are supported by NIH; and
- to direct initiatives to increase the numbers of women who are participants in biomedical research careers.

In determining directions for these objectives, we look for guidance and input from the scientific, public health, and advocacy communities. One of the most effective ways for us to accomplish this is through public hearings such as this.

Because NIH is the primary agency within the Department of Health and Human Services that performs, promotes, and supports biomedical and behavioral research, our focus, and that of this public hearing, is on that research which should be initiated, expanded, or enhanced to add to our existing knowledge about women's health, as well as to consider innovative programmatic and collaborative efforts to promote career opportunities for research on women's health, and especially that of women in biomedical careers.

From the time of the establishment of ORWH and the structuring of our first NIH research agenda on women's health, we have held public hearings to receive testimony from public representatives, and to build upon that testimony through scientific meetings and workshops to construct priorities for women's health research. The report of that first undertaking, *National Institutes of Health: Opportunities for Research on Women's Health*, is based on public testimony and a scientific meeting held in Hunt Valley, Maryland, in 1991.

Beginning in September 1996, at our first regional meeting in Philadelphia, we began our process of re-examining our research agenda to ensure that it is relevant as we move towards the next century, thus, the name of this series of meetings is, "Beyond Hunt Valley: Research on Women's Health for the 21st Century."

During our public hearing and scientific workshop in New Orleans, we invited discussion on aspects of the research agenda based upon sex and gender issues, e.g., physiological, psychosocial, and pharmacologic differences between women and men. This was our third and last regional meeting, which we designed to focus on factors that contribute to differences in health status and health outcomes among different populations of women.

Finally, on November 17, 1997, we brought together the results of all three regional meetings in a workshop in Bethesda, Maryland. Our Task Force is using this information as a guide in developing recommendations for the NIH research agenda for the beginning of the 21st century.

During this public hearing, we specifically requested perspectives about:

- Continuing or emerging gaps in knowledge about women's health across their life span.
- Population differences: race, culture, ethnicity, and other factors and their influence on women's health.
- Women with special health concerns: recommendations for future research.
- Career issues for women scientists and how to overcome barriers.

Testimony was received and reviewed by our Task Force on the NIH Women's Health Research Agenda for the 21st Century. We are fortunate to have members of the NIH scientific community, as well as women's health advocates, scientists, and health professionals from across the country who are serving as members of this important Task Force.

We are grateful for the dedicated leadership of this Task Force by the cochairs, Dr. Marianne Legato, a distinguished cardiologist and expert on women's health of Columbia University, who is a member of our Federal Advisory Committee, and Dr. Donna Dean, acting chief of the Referral and Review Branch, Division of Research Grants at NIH, who serves as a member of our NIH Coordinating Committee and chair of our NIH Research Subcommittee, which provides advice to our office about priorities and funding programs.

On behalf of NIH ORWH, I thank participants for their role in reassessing our research agenda so that we can continue to make progress in women's health status as we enter the next century.

PUBLIC TESTIMONY
SANTA FE, NEW MEXICO
JULY 21, 1997

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The Overtreatment of Normal Childbirth in America

Each year in the United States, some 3.9 million babies are born. The clear majority of these are born to healthy women, that is, women without medical problems which either precede pregnancy or arise during the course of pregnancy. For historical reasons (which have more to do with professional and economic factors than safety concerns), about 99 percent of all babies are delivered in U.S. hospitals. As such, normal childbearing accounts for a very large portion of the total U.S. health budget. In fact, "normal pregnancy, delivered" is one of the most common discharge diagnoses from U.S. hospitals.

American childbearing women receive more technical procedures during labor, and are more frequently delivered by surgical methods than are women in any other developed country in the world. The excess use of technology and surgery is problematic for two reasons: 1) it is extremely expensive. These financial resources could be better directed elsewhere, to the potential benefit of all childbearing women and their infants, and 2) it engenders excess morbidity, in terms of both unnecessary medical complications and adverse psychological outcomes. In the important transition to motherhood, none of these can be considered insignificant.

Many examples of the overtreatment of childbirth in America are available. One is the continued high rate of cesarean delivery in the United States. Although the C-section rate has declined from its all-time high in 1988 of 24.8 percent, it now stands at 21 percent, approximately twice that of countries in western Europe. Some 30 percent of women delivered by cesarean are known to have significant postoperative morbidity (as measured by infection, blood loss, anesthesia complications, and extended hospital stay), and breast-feeding failure is higher in these women as well. The World Health organization has repeatedly stated that no country, and no population, can justify a cesarean rate of over 15 percent. The U.S. Public Health Services' goal for the year 2000 was set at 15 percent, a rate which is very unlikely to be met.

During labor, the use of four technical procedures in the United States can be legitimately described as excessive: electronic fetal monitoring, labor augmentation with oxytocin, epidural analgesia, and episiotomy. Use of electronic fetal monitoring has risen from 45 percent of all U.S. births in 1980 to 81 percent of all births in 1995. It is a screening test for fetal asphyxia in labor which has a very high rate of false positive diagnoses for fetal distress. Randomized trial data for over 50,000 women in seven countries have shown remarkably consistent results: electronic fetal monitoring doubles the risk of operative delivery with no clear benefit to the baby. Clinicians and institutions, however, are not changing this practice pattern and still heavily rely on a poor screening tool which probably does more harm than good.

Augmentation of labor with intravenous oxytocin for "failure to progress" in labor is becoming mainstream care. Oxytocin is a potent drug with potential negative effects. In 1995, it was used to stimulate 16 percent of all labors in the United States, a rise of 48 percent since 1989. Clearly the operational definition of normal labor progress needs reevaluation when one in six labors are defined as "too slow." This frequent diagnosis of abnormal labor indicates that clinicians too often fail to wait. Furthermore, when women are asked what they think, something we do too infrequently in American obstetrics, they say that oxytocin makes their labors more painful, and they do not like it!

Epidural analgesia has been termed the “twilight sleep of the 1990s.” In 1981 it was used for 16 percent of all U.S. births. Since, then, no national estimates are available, but large institutions report rates of 30 to 60 percent, and occasionally higher. Epidurals require the simultaneous use of several other technologic procedures, and they increase the rate of operative delivery. The research on epidurals is primarily concerned with which drugs to give and how to give them, and the long-term effects on mother and baby have not been thoughtfully considered. Further, the ethical dimensions and legal imperatives of informed consent for epidural analgesia are commonly trivialized in clinical practice.

Episiotomy remains a common practice largely based on historical assumptions. It still accompanies 50 percent of vaginal births in the United States. Numerous studies, including randomized trials, show that no short- or long-term benefits accompany routine episiotomy at birth. Serious trauma to the perineum (third and fourth degree lacerations) almost never occurs except in conjunction with episiotomy. Importantly, perineal trauma is problematic for new mothers, impairing physical functioning in 20 percent of these women for 2 to 3 months, and in 10 percent for up to 1 year after delivery.

So, what is the bottom line? In obstetrical care in the United States we clearly have a very big problem: we are doing too much of the wrong things and not enough of the right things. NIH is encouraged to place the proper treatment of normal pregnancy and childbirth (including appropriate technology) on the national research agenda. The following questions are examples of those which need to be addressed:

- How can childbearing women be effectively prepared for labor?
- How should labor be managed to increase the proportion of normal deliveries?
- How should labor be managed to reduce postpartum morbidity?
- How does the style of care during labor relate to long-term health issues: mother-infant interaction, breast feeding, etc.?
- How can clinicians be encouraged to re-examine the science base for their practice?
- How can medical educators redefine teaching priorities around normal childbirth?

American Heart Association
Kathleen Blake, M.D. *New Mexico and Arizona Affiliate*

I am Kathleen Blake, a cardiologist with the New Mexico Heart Institute and chair of the Committee on Women and Heart Health of the New Mexico and Arizona American Heart Association (AHA) affiliate. This committee was established in 1990 by the American Heart Association and the Department of Health of the State of New Mexico with a mission to promote awareness, in the professional and lay communities, about the problem of heart disease in women. Our professional educational objectives were addressed first, and we have now shifted our focus to community programs for prevention and early heart disease detection. My comments address the information needs of organizations such as ours as we design programs and educational materials for women.

Cardiovascular disease will kill 450,000 American women this year. Yet when asked, most women will not know this fact. They will cite breast cancer as their number one health concern, although this disease takes the lives of just over 40,000 women in the United States per year. Women are, therefore, unlikely to seek out information about heart health for themselves. They will be less motivated to adopt heart-healthy behaviors. And, unfortunately, they will also be slower to seek medical attention at the time of a first heart attack because the disease is not one that they expect to have.

It is in this context that we want to see research on successful health education strategies for women. We must know what motivates a woman to seek information about heart health. Does she want it because of concerns she has for her own health, or is it best coupled to information for the whole family? Where and when do women get health information that they believe in and will incorporate into their daily lives? In the managed care era, we suspect that physicians provide less education to their patients during office visits that are shorter than ever. What are the best or better substitutes? Will it be other health care providers, or the media or volunteer organizations such as the AHA? Women who participate in cardiovascular clinical trials represent a readily available group of women who can help answer these questions. Acquisition by each funded trial of information about what motivated each subject to participate may give us the insight we need to then target subgroups of women with similar characteristics for community programs.

New Mexico and Arizona are states with large populations of Native American and Hispanic women. Very little is known about the best strategies for heart disease prevention in these women. Ethnic differences exist in dietary habits, diabetes incidence, smoking, and obesity. These differences must be understood if successful prevention efforts are to be implemented. Specific issues related to childbearing need to be addressed. There is limited teratogenicity data available about cardiac drugs that may be needed for specific situations during pregnancy. There is minimal prospective controlled data to guide anticoagulation decisions during pregnancy. A randomized controlled trial of heparin, low-molecular-weight heparin, and coumadin should be designed and funded.

Basic research to further elucidate gender differences in vasomotor tone and endothelial function should be supported. Comparison of the effects on endothelium of estrogen, tamoxifen, and extreme cholesterol lowering by HMG CoA reductase inhibitors is needed to enable the clinician to make informed therapy decisions with women who may not be able to take estrogen after menopause.

In summary, we need to know who wants heart health information, how they want to get it, and what format works best to promote behavioral change. The best strategies for prevention in Native American and Hispanic women are unknown. Childbearing needs to become safer for women with heart disease who need drugs, especially anticoagulation. The endothelium will be final common target of what we suggest for women; we need to know how to achieve, if possible, the same benefits seen with hormone replacement therapy in women who cannot or will not take estrogen.

Jeanne Carritt, M.A., M.Ed.
Lois Grey Long, R.N., M.S.N. *Selves*

Age and Aging: Women's Health Issues

> *"Old age" is ten years beyond your own chronological age.*
> *Kay Seidell*

The particular way in which this conference has been organized seems to preclude input from elderly women. Once women leave the workforce, few have access to fax or email. The registration form calls for titles and affiliations. These represent serious roadblocks for elderly women. Input about the elderly is, therefore, coming from younger people. There is little first-hand observation from the population coping with specific problems of the elderly. In response, listed below are some concerns of elderly women:

- In the agenda for this conference, elderly and frail elderly women have been combined. Issues for women who are 65 or 70 and 85 or 90 years of age are enormously different. Since this is the fastest-growing segment of our population, it can only be ignored at the peril of society as well as of the women whose problems we hope to address. This is particularly a women's health issue because in the over-65 age group, women outnumber men 2 to 1.

- There has been considerable research done on aging issues, much of it on men. In addition, generally the research has been divided by disciplines (e.g., one group working on housing and another on cardiovascular disorders). There is real need to integrate these data and make information available between disciplines. We must find ways to provide reliable, easy-to-understand information based on this knowledge to the general public and to the elderly and their families.

- In this population, one cannot separate physical health issues from economic problems and from those components which make up psychosocial well being. Some of these are loss, depression, poverty, etc., with losses including those of mobility, friends, health, and general physical self confidence. Another part of the loss issue has to do with societal attitudes toward women, a major concern which applies uniquely to women. All of these factors affect physical and mental health along with longevity and quality of life.

An example of a related economic concern is the cost of drugs. The current emphasis on the treatment of osteoporosis in older women with the new medication Fosamax costs about $55 per month, putting it beyond the reach of many women without prescription coverage and without insurance coverage. The new sleeping medication, Ambien, costs about $2 per tablet.

An example of maladaptive approaches to some of the losses is the increasing use of alcohol and mind-altering prescription drugs to help cope with disturbed self concept and body image and the related stresses unique to women. Elderly women are more likely to be prescribed drugs which affect judgment and safety, leading to even greater health-related problems.

- There are many basic questions having to do with activities of daily living for which guidelines have not been established in the context of prevention for elderly women at any age. Available information is currently not geared to this age group.

In the parameters of "normal aging," for example:

- How should diets be altered to accommodate metabolic changes and meet daily nutrition needs.
- Should older women use the same aerobic parameters currently standard for younger women?
- To what extent are dietary supplements and nutritional additives helpful or relevant?

Peripheral, but related to women's health, is the change in living conditions brought about by women working outside the home. This social change is creating change in the caretaking role, geographic disruption, and the demise of the extended family, all of which have changed the whole pattern of intergenerational living. These factors have created housing problems of large proportions. Agencies which have attempted to address this issue are divided among city, state, and federal governments.

How can these services be integrated to best serve all ages and economic levels? As we become much older and energies fail, they presently must attempt to navigate these various systems to get their needs met.

In addressing these problems, there must also be an understanding that chronological age has little to do with functional status and thus with the kinds of support systems needed. There is a danger in standardizing services based on age alone

Our current knowledge includes the information that each woman who reaches a certain age plateau can expect to live x-number of years and be reasonably healthy. There is a lack of information about changes in services and support systems needed as these women become more frail.

With regard to the research focus of this conference, and in light of our original comment about obtaining information on perceptions of needs from this most-advanced age group, *perhaps the greatest challenge is simply finding ways to elicit accurate information.*

With regard to this particular forum, many of the issues raised in this commentary may seem simplistic; in the context of the lives of aging women, these concerns are very real. Hopefully women's health research in the 21st century will include and reach beyond the disciplines of medicine and pharmacy.

Jean Charles-Azure, M.P.H., R.D.

Director of the Nutrition and Dietetics Training Program
Indian Health Service

I am a member of the Lummi Tribe in Washington State. I also have Omaha, Ponca, and Sioux heritage. Accompanying me is Carolyn Lofgren, Coordinator of the HQW Women's Wellness Initiative and member of the National Indian Women's Health Steering Committee. Our discussion focuses on nutritional issues related to Native American women's health.

As a Native American woman, I have long been interested in health care and health promotion for American Indian/Alaska Native (AI/AN) women. Native American women are concerned about their nutritional health throughout the life cycle, especially in the childbearing, perimenopausal, and postmenopausal years. Many tribes are interested in resuming healthy nutrition and food traditions, such as breast feeding, lower-fat cooking, becoming more physically active, reducing risk for diabetes and osteoporosis, and achieving and maintaining healthy weights.

Native American women, often the decisionmakers regarding food selection and preparation, are committed to improving the nutritional health of their families and communities. They can be found leading community efforts to provide healthy meals and physical activity for children and adults. They play a key role in improving nutritional health through their active participation as parents and community members on advisory groups for day care centers, schools, Head Start, and elderly meals programs. Nutrition during recovery from substance abuse is stressed in the concept of a grassroots group, Gathering of Native Americans (GONA) "Indian Women in Action," support efforts. The community concept is making an impact in all areas of women's health, but particularly in EtOH/Substance Abuse. Continued support for "community mobilization" interventions are essential for lifestyle changes and long-term outcomes.

The strategies developed to address the health problems of AI/AN populations need to consider the characteristics of the population. Over the past three decades, the nutritional health of AI/AN has changed dramatically from morbidity and mortality associated with infectious diseases to chronic diseases associated with obesity. An American Indian School Children Height and Weight Survey found that 40 percent of this population were obese. Obesity has long been known as a major risk factor for cardiovascular disease, the number one killer of American Indians and Alaska Natives. Another major consequence of obesity in children is the increasing incidence of Type II Diabetes Mellitus, as early as age 14. Native infants who were breastfed have been found to have lower rates of diabetes than bottlefed infants. Native infants whose mother's were obese during pregnancy have higher rates of diabetes. Some American Indian tribes have diabetes rates ten times the rate of the U.S. population, virtually all in Type II Diabetes or diabetes in pregnancy.

Throughout the history of the United States, AI/AN peoples have been an integral part of the American character. Tribal America has provided certain values and ideas, as well as many native foods, that have become a part of the general American culture. Today, however, we see the health challenges facing American Indians. The research agenda for American Indians and Alaska Native women should consider these components:

- Community-directed pilot projects that rely on the public health model and foster partnerships between community members and program staff to develop and implement nutrition and physical activity interventions. For the Indian Health Service (IHS), partnerships could include IHS, Tribal Programs, Urban Indian Programs, Indian Community Colleges and Tribal Schools, Head Start, Food Distribution Programs on Indian Reservations, Women and Children's Supplementary Food Program, Housing Programs, Treatment Programs, and Youth Programs, university research programs, and so on.
- Information is needed to learn the most effective public health strategies for reducing rates of chronic disease (diabetes, obesity, and cardiovascular) among Native women and in their communities. We need to know the key characteristics of successful strategies for community mobilization, school interventions, worksite interventions, family interventions, multigenerational interventions, and nutritional interventions while respecting traditions, culture, and values.
- Information dissemination to translate and transfer what is learned about successful interventions to other Native communities is an essential component of research projects.

Col. Laurie Davis, Ph.D.

Project Director for Women's Health Coordination
Nursing Consultant to the Surgeon General on
Advanced Practice Nursing and Women's Health

Until 1994, the vast majority of research conducted within the military population had focused solely on military men with little to no research aimed at the female soldier. With the increase in numbers of military women (340,000) and the expanded roles women are assuming within this predominantly male environment, it is vital that increased research emphasis be exerted towards this group. This need for increased research focus on military women resulted in a 1994 Congressional directive which mandated that women be included in all DoD-sponsored research. This directive was backed with a $40 million appropriation bill that enabled the establishment of the Defense Women's Health Research Center (DWHRC) for "multidisciplinary and multi-institutional research" on military women's health issues (Institute of Medicine, 1995). While this is a substantial initial step, much more remains to be done in addressing the multitude and variety of military women's needs. This brief will present demographics of military women, along with current research endeavors, and ongoing issues in need of continued and/or future research.

Jane L. Delgado, Ph.D.

National Coalition of Hispanic Health and Human Services Organizations (COSSMHO)

Hispanic Women and Research Issues

I am pleased to have this opportunity to provide the perspective of the National Coalition of Hispanic Health and Human Services Organizations (COSSMHO) on the funding priorities for women's health programs. Before providing our perspective on this issue, I would like to provide you with some background on COSSMHO.

COSSMHO is a private nonprofit organization representing the needs and concerns of 1,500 health provider members and the people they serve. COSSMHO is the only national organization with a primary mission in Hispanic health. As a national organization, COSSMHO is unique in three major ways:

- *Diversity is Our Strength.* Founded in 1974 in Los Angeles by two Mexican American social workers and one Puerto Rican social worker, COSSMHO's founding goal was to represent the needs of all Hispanic communities. The COSSMHO symbol represents the Mexican American, Puerto Rican, Cuban, and Central American and South American communities joining hands to work together.

- *Commitment to Funding Local Programs.* COSSMHO obtains funds for implementing model programs with local determination being the hallmark of our activities. Today, 80 percent of COSSMHO's budget is allocated to implementing multisite community programs. Approximately 50 percent of COSSMHO's program dollars are awarded locally in the communities we serve. Our commitment to local determination is reflected in the positions we take as a national voice on Hispanic health policy issues.

- *No Funds from Tobacco or Alcohol Companies.* As the only national Hispanic organization with a primary mission to improve the health and well being of Hispanic communities, COSSMHO does not accept any funds from tobacco or alcohol companies or their subsidiaries. COSSMHO is the only national Hispanic organization to have adopted this policy.

COSSMHO's President and CEO, Dr. Jane Delgado, in association with the National Hispanic Women's Health Initiative, has authored the first comprehensive compendium on Hispanic women's health. The book, *¡SALUD!: A Latina's Guide to Total Health — Body, Mind, and Spirit*, will be released by Harper Collins Publishers in September of this year. In addition, COSSMHO has sponsored a university-based research consortium on Hispanic women's health issues, in particular issues of chronic illness and access to health services for Hispanic women. COSSMHO also sponsors a number of efforts in the area of breast and cervical cancer early detection and treatment. These efforts include the development of the Salud para Todas Breast and Cervical Cancer Resource Kit and a model outreach program for community educators. In addition, Unidos por la Salud, a research network of comprehensive cancer centers, is completing a landmark study of the treatment experiences of Hispanic women diagnosed with breast cancer. This network is coordinated by COSSMHO with funding from the National Cancer Institute and the NIH Office of Research on Minority Health. As you can see, women's health has been a long-standing priority for COSSMHO.

Based on COSSMHO's efforts in the area of women's health and a 25-year record of leadership in Hispanic health, COSSMHO makes the following recommendations on priorities in women's health research.

- Women's health study priorities should include areas of particular concern to Hispanic women, including diabetes mellitus, cervical cancer, depression, and mental health.
- By the year 2000, the number of Hispanic women will equal the number of non-Hispanic black women. Women's health research must collect, analyze, and report data by Hispanic and, preferably, by Hispanic subgroups.
- Criteria for participation in studies should not be based solely on general population norms, but account for health status indicators for Hispanic women.
- A research emphasis should be placed on developing culturally and linguistically competent health strategies for Hispanic women and their health care providers, including clinical trial recruitment and retention.

These are the priorities which must guide the development of health research. Hispanic health data, which break many of the stereotypes that we have about health, can no longer be set aside as noise or outlier data. By understanding Hispanic women's health, there are lessons to be gained to both understand and improve the health of all women.

Women's health study priorities should include areas of concern to Hispanic women, including diabetes mellitus, cervical cancer, depression, and mental health.

Without understanding the diversity of women, it is impossible to have an accurate picture of women's health. Certain health conditions are more prevalent or have a differential impact among Hispanic women than for other groups of women. These issues need to be addressed to understand and foster the health of all women.

Diabetes is one of the six major contributors to the disparity in health status between ethnic groups.[1] The incidence of diabetes among Mexican American and Puerto Rican women is two to three times greater than the rate found among non-Hispanic white women. Indeed, 15.2 percent of Mexican American and 16.2 percent of Puerto Rican women 45 to 74 years of age have diabetes compared to 5.8 percent of non-Hispanic white and 11.4 percent of non-Hispanic black women.[2] This disease appears to be a more common cause of death among Hispanic women (27.6/per 100,000 women) than among the general U.S. population (16.3).[3] Despite the importance of understanding diabetes in Hispanic communities, the General Accounting Office found that in FY '91, although the NIDDK funded 612 diabetes research projects, less than 1 percent of clinical research and 2 percent of prevention or behavioral research projects were targeted to Hispanic communities.[4] Furthermore, in the Diabetes Prevention Program launched by NIDDK last year, while data is being coded for Hispanic subgroups, the design of the study is such that scientifically valid analysis will be possible only for white and non-white categories. The lack of information on diabetes and Hispanics extends to the Human Genome project which does not collect information on the race or ethnicity of the individuals from whom the human cells are derived in their basic research. This, despite the fact that a genetic marker (DS125) related to diabetes mellitus has been found.

Cervical cancer is more prevalent among Hispanic women than it is among non-Hispanic white women; however, it is an area that is not adequately studied or understood. Indeed, issues of women and cancer are often thought of only in terms of breast cancer. However, cervical cancer is a major concern for Hispanic women. The rate of cervical cancer per 100,000 women is 16.2 for Mexican Americans compared to 7.5 for white and 13.2 for black women.[5] In addition, half of all women newly diagnosed with cervical cancer have never had a Pap test and another 10 percent have not been screened in the last 5 years.[6] Often times, the disease can be prevented with proper screening. It is crucial that outreach, education, and research efforts are directed to the prevention and treatment of cervical cancer in Hispanic women.

Depression and mental health are significant health concerns for Hispanic women. The rate of attempted suicide among Hispanic girls (34.1 percent) is higher than that of white (31.6 percent) and black (22.2 percent) girls 13 to 18 years of age.[7] However, measures and treatment options for Hispanic women have not been given the scientific attention needed to develop a baseline understanding of mental health issues for Hispanic women or the cultural dimensions of care. In addition, the differential metabolization and effect of antidepressant medications has not been adequately studied. Environmental, cultural, and/or psychosocial factors may also affect the efficacy of a treatment. Pharmacogenetic studies investigating genetically determined variation in response to medicines resulting from inherited metabolic defects or specific enzyme deficiencies are minimal for Hispanics. However, one of the few available studies found that Hispanics required less antidepressant medication and report more side effects at lower dosages than whites.[8] Further studies must be conducted to determine appropriate treatment of depression in Hispanic women.

By the year 2000, the number of Hispanic women will equal the number of non-Hispanic black women. Women's health research must collect, analyze, and report data by Hispanic and, preferably, by Hispanic subgroups.

While there is coding for Hispanics, the design of the Women's Health Initiative (WHI) is such that scientifically valid findings will not be available for Hispanic women. The WHI Protocol (Volume 1, Section 1, pages 1–25) states, "Social/ethnic minority women will be represented in the overall sample with a target of at least the proportion that they are found in the general population of women age 50 to 79 (17 percent according to the 1990 census) with a specific target of 20 percent minority women in the CT/OS." This categorization leaves Hispanic women to be an undetermined portion of the 20 percent "minority" target. Furthermore, the WHI National Program Office reports that while minority clinical centers, including four identified in Hispanic population centers, have a goal of 60 percent minority recruitment, "specific subpopulations are not specified" for recruitment. Following standards under Office of Management and Budget Directive 15, WHI should be developing data collection protocols to allow the reporting of data by: non-Hispanic white, non-Hispanic black, Hispanic, non-Hispanic Asian or Pacific Islander, and non-Hispanic American Indian/Eskimo/Aleut.

Ethnic consideration in most health studies is critical because the concerns related to health and illness vary widely within and across ethnic populations.[9] However, as currently formulated, many studies call for analyses based on a white and non-white or minority comparison, with the non-white category representing all racial/ethnic minority groups including Hispanics. This approach effectively eliminates the usefulness of such a study for increasing the knowledge base on Hispanic women's health or for providing a full understanding of women's health in general.

The myth that a "minority model" exists for treatment of all racial/ethnic communities is perhaps the most damaging misconception in health. There simply is no design that can be used to understand health in racial/ethnic communities that are conglomerated statistically. Hispanic communities differ significantly from other racial/ethnic communities in terms of income, education, median age, access to health care, and factors of language and culture, all of which have an impact on health status and services. For example, one of the key tenets of a minority model is that minority communities have a shorter life expectancy than white communities. The fact is that Hispanics live longer than white communities.[10] Furthermore, some of the poorest Hispanic populations, newly arrived immigrants, have the best health profile in terms of birth outcomes, diet, and substance abuse.[11] Consequently, health care issues and research findings about African-American women cannot be extrapolated to Hispanic women. It is of primary importance that research design and findings be reformulated to collect data specific to Hispanic populations, including oversampling when necessary.

Although the present policy of NIH states that women and members of minority groups and their subgroups must be included in all NIH-supported biomedical and behavioral research projects, the implementation of the directive is questionable. Clustering of all minorities into one group, or only coding and not analyzing data separately for racial and ethnic groups, does not give integrity to the directive. Funding should be dependent on a research design that allows reporting of scientifically valid data for different racial and ethnic groups.

Criteria for participation in studies should not be based solely on general population norms, but must account for health status indicators for Hispanic women.

Criteria for inclusion in studies and clinical trials do not adequately account for the health status of Hispanic women. Disqualification criteria, such as overweight, height standards, and diabetes in women, make it difficult for Hispanic women to be included in research projects and clinical trials. For example, the diet study portion of the WHI, which assesses the effect of low-fat diet on breast and colon cancer, excludes women diagnosed with diabetes. This practice means that data available from the study will not reflect the status of Hispanic women or provide an accurate picture of women in general. Furthermore, identifying breast and colon cancer as a primary aim, and diabetes as a secondary study aim, is an inappropriate prioritization of health concerns for the Hispanic community. It does not give appropriate weight to the higher incidence of diabetes among Mexican and Puerto Rican women and the results from undiagnosed diabetes among those women, including blindness, kidney failure, limb amputation, and death.

Furthermore, standards for weight that determine obesity based on Body Mass Index (BMI) often constitute exclusion from studies as Hispanic women tend to exceed the recommended limits as determined by the BMI. Data shows that 41.6 percent of Mexican American, 40.2 percent of Puerto Rican, and 31.6 percent of Cuban American women are overweight compared to 23.9 percent of non-Hispanic white and 44.4 percent of non-Hispanic black women 20 to 74 years of age.[12] In order to reflect a true picture of women's heath, participant inclusion standards related to weight need to be modified to be inclusive of Hispanic women. The ideal weight of Hispanic women cannot be determined from the present weight charts. Indeed, some research has indicated that the torso of Mexican American women is proportionately longer than other women and may indicate a higher ideal weight than for non-Hispanic women.[13] The physical differences between population groups are not deficits and should not be treated as such by research, services, or care.

A research emphasis should be placed on developing culturally and linguistically competent health strategies for Hispanic women and their health care providers, including clinical trial recruitment and retention.

Effective communication between a patient and provider is central to competent health services. Currently, 83 percent of Hispanics report a preference for speaking Spanish in the home.[14] Pilot data from a NCI-sponsored interview study being conducted by COSSMHO with older Hispanic women, have found that 78 percent of interviews were conducted in Spanish.[15] These factors are frequently not taken into account in the development of studies on women's health. A number of major research instruments have never been tested in Hispanic communities and the cultural competency of research methodologies and interviewers is rarely addressed. For example, although the WHI interview instruments have been translated into Spanish, there are concerns about the cultural competency of the recruiters, informed consent of low acculturated Hispanic women, and cultural variations in language usage which have not been accounted for under the WHI protocol and procedures. It is especially vital to every woman's study to include Spanish-speaking women as part of the participants in order to reflect the current demographics of the nation and not to skew the findings of the study.

In the selection of strategies, programs, and materials for health services interventions under research efforts, the cultural competency of those strategies, programs, and materials must be a critical part of the review and final score of research proposals. Furthermore, in the recruitment of Hispanic women for clinical trials, care must be taken to ensure that information is provided in a culturally competent manner. To ensure cultural and linguistic appropriateness of all research, clinical trials, and treatment assessments, it is vital that NIH enforce the Guidelines on the inclusion of women and minorities in a manner that supports cultural competency of research.

Furthermore, all research and service delivery teams should have Hispanic staff, including projects with Hispanics as principal investigators. However, available data shows that between 1982 and 1991, the proportion of NIH grant awards to Hispanic researchers was flat compared to a 10 percent increase in the proportion of awards given to non-Hispanic white researchers. In 1992, only 1.9 percent of NIH research awards were made for Hispanic-focused research.[16]

Finally, any research effort to understand health in Hispanic communities must be undertaken by an organization with the trust and history of the community it is seeking to serve. Furthermore, any program strategies that are used as a part of a research effort must be appropriate for the racial/ethnic community which is being served by the program. To this end, Hispanic community-based organizations must be partners in the development and operation of research projects. Hispanic interviewers, principal investigators, and recruiters are critical to ensure Hispanic participation in research. However, data for fiscal year 1995 show that there were no Hispanic senior science/professional members of the Senior Executive Service.[17]

Conclusion

Hispanic women must be a part of the planning and development of national health concerns; yet, they are rarely found on advisory boards, planning committees, grant review panels, or national task forces. In the scientific community, few Hispanic women researchers are principal investigators. Funding rarely encourages the research community to address specific concerns of the Hispanic community. Hispanic women are underrepresented in professional staff of NIH. Without fair representation, Hispanic women's health issues will remain an after-thought. To address the needs of Hispanic women in research, the following priorities must be addressed:

- Women's health study priorities should include areas of particular concern to Hispanic women, including diabetes mellitus, cervical cancer, depression, and mental health.
- By the year 2000, the number of Hispanic women will equal the number of non-Hispanic black women. Women's health research must collect, analyze, and report data by Hispanic and, preferably, by Hispanic subgroups.
- Criteria for participation in studies should not be based solely on general population norms, but account for health status indicators for Hispanic women.
- A research emphasis should be placed on developing culturally and linguistically competent health strategies for Hispanic women and their health care providers, including clinical trial recruitment and retention.

Hispanic health concerns are not addressed by general population programs or a "minority model" program. Hispanics are unique communities with specific needs and concerns which must now become a part of our nation's health research agenda. COSSMHO looks forward to the Office of Women's Health taking up the challenge of an effort to understand the health of Hispanic women.

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Director
Sally Esposito *Department of Services for Persons with Disabilities*

Continuing or Emerging Gaps in Knowledge about Women's Health Across the Life Span

Good afternoon. My name is Sally Esposito. I am here today representing the City of New Haven, Connecticut, although I learned of this conference through my colleagues at DES Action USA. I am the director of the city's Department of Services for Persons with Disabilities and the Americans with Disabilities Act (ADA) Coordinator. I am also a consumer and an advocate, and sometimes even an activist.

The first part of my testimony will consist of selected demographic information on New Haven. Next will be a discussion of general women's health issues in New Haven. Lastly, I will share some observations and thoughts about women with disabilities in the New Haven community.

My department is located within the division of city government known as the Human Resources Administration, or HRA as it is commonly called. HRA includes other departments such as Health, Elderly Services, Children and Family Services, the Fighting Back Initiative, and the Welfare Department. Among other functions within the Health Department are Healthy Start and the Maternal and Child Health Outreach Program, the Mayor's Task Force on AIDS, and the Ryan White Title II Program. The common denominator among us is that we have a role in the provision or facilitation of services that impact the social and health needs of all New Haven residents. The Ryan White and the Healthy Start programs also serve persons who live outside the city.

I would like to tell you a little about New Haven. From downtown to West Rock to East Shore to the Hill, New Haven is rich in its diversity. People of many different races, ages, cultural backgrounds, languages, sexual orientations, and physical abilities, comprise the many unique neighborhoods of New Haven. The city is known for its educational, cultural, and artistic activities and resources, and especially for its medical and health facilities and services, along with a steadily growing biomedical technology industry.

It is known that the population of New Haven is declining. In 1995, the State of Connecticut's Office of Policy and Management estimated the population of New Haven to be 123,770, although the U.S. Census Bureau estimated the 1995 population to be as low as 118,000. Although Connecticut had only 5 percent of its population living below the poverty level in 1989, New Haven's rate is four times higher at 21 percent. The distribution of that poverty is particularly hard on female-headed households — in some of the city's poorest neighborhoods, 85 to 95 percent of all families with children living below the 1989 poverty level were headed by single females. In general, 65 percent of New Haven families are headed by women who live in poverty. These women also make up the group with the greatest lack of access transportation and telephones, without which scheduling and attending medical appointments become extremely difficult tasks.

In 1994, the most recent year for which statistics are available, the leading cause of death for female New Haven residents was diseases of the heart. The next most prevalent cause of death was cerebrovascular disease, followed by diabetes mellitus (Table 1).

TABLE 1. Ten Leading Causes of Death in New Haven Residents, 1994

Cause of Death	Rank	Female Deaths	Male Deaths	Total Deaths	Percent of Total	Crude Death Rate
Diseases of the Heart	1	229	185	414	32.7	317.3/100,000
Malignant Neoplasms	2	116	139	258	20.3	197.7/100,000
AIDS	3	33	72	105	8.3	80.5/100,000
Cerebrovascular Disease	4	42	22	64	5.1	49.1/100,000
Accidents	5	20	38	58	4.6	44.5/100,000
Pneumonia	6	17	19	36	2.8	27.6/100,000
Chronic Obstructive Pulmonary Disease	7	17	14	31	2.4	23.8/100,000
Homicide	7	9	22	31	2.4	23.8/100,000
Diabetes Mellitus	8	13	11	24	1.9	18.4/100,000
Suicide	9	4	16	20	1.6	15.3/100,000
Septicemia	10	7	10	17	1.3	13.0/100,000

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Accidents	5	20	38	58
Pneumonia	6	17	19	36
Chronic Obstructive Pulmonary Disease	6	17	14	31
Diabetes Mellitus	7	13	11	24
Homicide	8	9	22	31
Septicemia	9	7	10	17
Suicide	10	4	16	20

New Haven is home to a large number of health resources including two major hospitals; three free-standing community health clinics including one women's clinic; two community health care vans, one of which targets women; a public health clinic; two public outreach programs targeting women and children; several low-cost health care facilities; a medical school; residency programs, nursing programs, nurse practitioner programs, physician assistant programs, dental hygiene programs, and dental programs; a community mental health center; and two schools of public health.

Over the last week, as I was contacting numerous individuals to collect information for this testimony, I learned a number of things about New Haven and women's health. First, as a community, New Haven does not have a comprehensive, planned, and identifiable public health policy on women's health; nor do we have an informal priority to identify gaps in services and specific strategies for women's health or for research on women's health issues. There is a great deal of anecdotal information available, but very little information of a more formal nature because the human or financial resources have not been available to study women's health needs in New Haven. Sometimes though, statistics on women become available when required for grants or when requested by funding sources or agencies. For example, New Haven has the highest seroprevalence rate of childbearing women statewide, with an overall rate of 14.7/1,000 in the city compared to 3.1/1,000 in Connecticut. African-American women are disproportionately affected, with a prevalence rate of 1/80 in this population as compared to 1/150 for Latinas and 1/1,000 for white women.

During the past week, I also learned that the existing network of health care providers does collaborate on many issues. In fact, the Greater New Haven Partnership for a Healthy Community is in the process of disseminating a survey to 3,000 individuals in greater New Haven. Although some of the information being collected will address women's needs, the survey is very basic, and does not aim to draw out specific women's issues. Clearly, there is a need to do more.

I did learn too, that there is tremendous interest within the city government to explore the development of a women's health agenda starting with a formal assessment of New Haven women and their health needs. In addition, there is much interest in capitalizing on existing successful grassroots efforts to reach women in their respective environments. The Maternal and Child Health Outreach Program successfully accomplishes this task. That model could be expanded upon to reach other underserved groups of women in New Haven. To do this, the city hopes to take advantage of opportunities provided by NIH, in general, and the Office of Research on Women's Health, in particular.

Recently, some graduate students contacted me to find out how many women with disabilities are victims of domestic violence in New Haven. They were interested in studying the group to learn more about causes of such abuse and whether or not they were connected to available resources. My first response was that those in positions to estimate can't even agree on the number of people with disabilities. I am often asked by funders, legislators, media, and others how many people with disabilities live in New Haven. Do we use the Census Bureau's definition, or the definition of a person with a disability included in the Americans with Disabilities Act, the Social Security Administration's definition, or self-identification by an individual? I referred the students to several sources and ultimately, they connected with the local independent living center and the center's consumers. As I listened to their final presentation, their frustration by the lack of available data was clear. No surprise to me — we just do not have good information on the numbers of people with disabilities or even a commonly understood definition of disability.

Therefore, in lieu of statistics, I would like to spend a few minutes introducing you to some New Haven women who have disabilities: Dorothy, Vivian, Lakeisha, Brenda, Renee, Elaine, Debbie, Kim, Charese, Hannah, Stella, Mary, Deborah, Linda, and Maria. The following paragraphs describe some of their collective experiences, and detail some of the circumstances which caused me to meet them through my work. These circumstances include physical confinement to home; domestic violence; need for dental care; inaccessible transportation; physical barriers to independence; need for affordable, accessible, and safe housing; substance abuse; psychological abuse; emergency shelter; stairs; the judicial system; lack of effective communication including the use of a TTY; poverty; mental health services; deafness, hearing loss; police; welfare reform; sexuality/lesbian partners; health insurance; aging; employment; supporting children; playgrounds; interpreter services; stereotypes of women with disabilities; self defense; educational opportunities; hidden disabilities; exercise; murder; cancer; managed care; loss of benefits; and unemployment. Some of these women are young and some are old. Some are African American, some Latino, some white. Some are lesbian and some are straight. Some of these women are empowered and fight the system. Some struggle to make it through the day. Some of these women are no longer with us, having ended their struggles without resolution. However, their environments and life experiences have all contributed to the status of their health. Given the lack of formal data, I would like to share one story, Lakeisha's story.

Lakeisha, an African-American woman in her 20s, has a psychiatric disability. She has two children who have been in foster care since her last major hospitalization. While she was hospitalized, her name was removed from the Section 8 list because she did not return a card. Before her hospitalization, she lived in public housing with her two children where she chased drug dealers off the ramp that made the apartment accessible to her 8-year-old son who has multiple disabilities. She is now eligible for a Section 8 certificate but needs to wait for the state to tell her when her children will be returned to her so the public housing authority can determine the bedroom size for her certificate. The Department of Social Services refuses to tell her when the children will be returned until the mental health agency sends a clearance. Her first mental health counselor died and her new counselor is retiring early. She is asked to ferry the paperwork from agency to agency. She wants only to create a good, safe home for her children and for them to be together once again. Lakeisha is dealing with the mental health treatment, judicial, medical, public housing, and child protective/social service systems all at once. With the exception of some very limited support from me, she is essentially on her own to coordinate with all of these entities. As a professional, I would have a hard time meeting the requirements of these entities. What are we asking of her and what toll are these demands taking on her health? I admire Lakeisha for her tenacity and perseverance and I worry, too. How many other women are there in New Haven who know Lakeisha's struggles but who are not connected?

We need to find out who these women are and where they are located. While we need to do this on the national level, it is even more urgent to do it on the local level where those in need can seek and find us first. Thank you for your efforts to assist those of us who work with women and their health issues on a daily basis. We look forward to working with you in the future and we thank you for this opportunity to speak with you today.

The Endometriosis Association
Cordelia Gilkyson *St. Francis Birth and Family Center*

What can I speak of as a young woman? What do I know something about based on my life? I know the joys of growing, the love of family and friends. I have also known a lot of physical pain. This pain was not something that I chose, but a result of a condition that affects millions, or approximately one in six women that we know of in North America and countless others all over the world.

I have been living with endometriosis since I was 15 years old, nearly 9 years now, with very little help available until very recently. For what I had a minor laparoscopy and laser surgery for, some doctors are still prescribing hysterectomies and extreme hormone therapy treatments which often create more side effects than the endometriosis itself. There are no known causes for endometriosis, only theories and pontifications mostly made by the women who have experienced it in their own lives. I do know that it is greatly affected by diet, lifestyle, and state of mind like so many health issues are, but one often wonders about the affects of our environment on the sensitive reproductive systems of women.

Treatment options are limited. It must become a more illuminated issue as it is affecting more women every day. It is a topic that should be discussed within the school system's health programs, required continuing education for M.D.s and OB/GYNs, and readily available information for the public. Right now it is not. There are thousands of women walking around in pain today not knowing why, and very often being misdiagnosed or mistreated by their doctors, for lack of information on causes and treatments. Today, the only lead that I have to a possible understanding of my having developed endometriosis is a letter that my mother found, written by her mother to their housekeeper in 1952. She was leaving on a trip, and instructed the housekeeper to spray my mother's crib every day with DDT, a pesticide we recognize today as highly toxic, but in the 1950s was used like air freshener. DDT genetically affects the person who is overexposed by mimicking the hormone estrogen, which in turn would have affected her future children, myself in this case. Ironically, though restricted in the United States and Europe, DDT is still prevalent and is being used a great deal in the developing world.

I would like to see more research into the effects of our environment on women's health, primarily chemical exposures, household and cosmetic product ingredients, foods, pesticides, and all potentially toxic or hazardous compounds. Despite limited scientific information, there is solid evidence of the reproductive toxicity of some substances in wide commercial use. Some studies have shown dioxins and PCBs to be directly linked to endometriosis and infertility, as well as some 45 chemicals widely distributed to the U.S. government, including 35 pesticides and ten industrial chemicals, as shown by a study done by the University of Wisconsin. There is also conclusive evidence that these same chemicals can damage one's body by imitating natural hormones, binding to receptors on fetal cells, and altering the genetic instructions. These imitations can then potentially "derail" human development, permanently distorting it's reproductive system.

Knowledge is the first step here. Educating our doctors. Continued research on causes and treatments. The Endometriosis Association reports that 70 percent of women diagnosed with endometriosis were initially told by their doctors that there was no physical reason for their pain. Forty percent of colored women diagnosed were told they had a sexually transmitted disease. I myself was told by several physicians to "have a baby."

Today, we recognize the prevalence of endometriosis rising in younger women, but it is surprising how few of them actually even know what they're dealing with or how to even begin to treat it. Though we recognize it as affecting millions and millions of people, it does not garner the resources that some more lethal diseases do, even though they may affect a lot less people. Between 30 and 40 percent of women who are treated for infertility have endometriosis. As a 24-year-old woman who is planning to have children, and knowing that endometriosis is one of the leading causes of infertility, I would like to see more funding allotted towards research that I may more safely ensure my future.

As some of you are aware, there is a gap of knowledge in the area of fertility, environment, and women's health because of inadequate attention to the relationship between humanity and the environment. A comprehensive awareness of that relationship is required if we are to begin to create solutions for ourselves and for future generations.

Linda A. Gonzales *Consultant*
New Mexico Disability and Health Program

Health Issues for Women with Disabilities

Health issues for women with disabilities are the same as those for women in general.

- Concerns about pregnancy, breast and cervical cancer, diabetes, aging and osteoporosis, high blood pressure, stress, and heart disease.
- The need to be concerned about weight, nutrition, and exercise.

The difference is the ongoing presence of a major disability around which these health concerns constantly revolve. If these health concerns become health conditions — they are, in fact, secondary to the primary disability.

Secondary conditions — this is a term that is still relatively new to a person with a disability. The list of health concerns now expands to include:

- Conditions that may be a direct result of the disability.

  - Dicubitus ulcers, spasticity, and urinary tract infections in women with spinal cord injury, or
  - Memory loss or disorientation in a woman with a head injury.
- Conditions that may be exacerbated or are more likely to occur as a result of the primary disability.
  - weight gain, high blood pressure, and poor circulation with mobility impairments that invite a more sedentary lifestyle.
  - blindness, amputation, kidney failure would all be considered secondary conditions in a woman with diabetes.
- Conditions that extend to environmental factors:
  - a woman with a severe hearing impairment or deafness who cannot adequately communicate with her doctor.
  - a woman who skips her annual Pap tests because she can no longer get up on the examining table.
  - physicians who no longer weigh their patients in wheelchairs.

- Conditions that occur as a result of living with a disability in an able-bodied world. Being different and often feeling devalued.
  - potential for greater stress, depression, isolation, and feelings of loss, anger, and resentment.
  - issues of attractiveness, self esteem, and social interaction.
  - strain on relationships — changing roles, sexuality, and child rearing.

Research Issues for the Future

Baseline data on secondary conditions in women with disabilities:

- Women who use wheelchairs, are they receiving primary and preventive care and screenings at the same rate as the general population of women? A 1993 DHP survey indicates that they are not.
- What are the risk factors related to common secondary conditions in women (i.e., dicubiti, UTI)?
- Research needs to provide information on alternative methods of preventing the recurrence of these conditions.
- What are the reproductive and aging issues for women with disabilities?
- What impact do lifestyle changes have on women who become disabled over a period of time? (i.e., sedentary, inactive, less mobile). Are these women more predisposed to acquiring chronic conditions due to these changes?

- Identify areas of collaboration and work with scientists/researchers in other areas of disability rehabilitation (NIDRR, RSA) and disability and health. (DHHS/CDC grants to 15 states to develop a scientific base of information for the disability population. Women's health issues are a priority in many states.) And any other areas where research efforts may overlap.
- Conduct policy research on health services/providers and public recreational/physical fitness facilities that readily accommodate people with disabilities. What impact do these factors have on the overall health and wellness of women in particular (i.e., gynecology clinics and women's fitness programs)?

Conclusion

Are you involving women with disabilities in all aspects of research planning and implementation? The disability rights and independent-living movements stress the value and importance of consumer involvement. Be aware that people with disabilities are proactively concerned about and involved in the future of their health care. This future includes managed care and health advocacy movements such as the right to die, organ donor priorities, assisted suicide, and other women's health issues.

Janet Greenwald *Citizens for Alternatives of Radioactive Dumping*

Since the beginning of the nuclear age, over 50 years ago, women and children and veterans have paid a heavy price in terms of health for whatever security we gained through the development of the bomb. Though the plutonium experiments were brought to the nation's attention by the *Albuquerque Tribune*, the stories of the survivors of uranium mining, workers at Los Alamos, atomic veterans, and downwinders are little known. Through my 17 years of experience in dealing with these survivors, along with my association with researchers and health professionals concerned about this issue, I have what I believe is interesting information, both scientific and anecdotal.

Barry Halber *Wilbar Health Productions*

Hysterectomy — Women's Choices for the 21st Century

I am Barry Halber and I appreciate the opportunity to appear before you today with the same focus and commitment of my training in health care research and the cable T.V. program I produced which identified and presented personal, family, and community health topics for public review and discussion.

For over 30 years, research dollars have been spent in the United States and other countries concerning the problems associated with choosing hysterectomies (i.e., cancer — 10 percent uterine, cervical, ovarian; benign fibroids, endometriosis, heavy bleeding, hormonal imbalances, unexplained pelvic disorders, etc.); the physical and emotional issues associated with this procedure (i.e., hormonal response and production, blood clotting, cardiovascular problems, hypertension, bladder and bowel dysfunction, sexual function, and pleasure); their options (i.e., drugs/side effects, surgical procedures, physician skills/experience); risks; and self-help programs (i.e., nutritional lifestyle, stress reduction, and exercise). However, by age 60, one in three American women have had their uterus removed (Italy–one in six; France–one in 18); that's 560,000 women a year at a cost of $3 billion.

My concern is that women today are not fully informed concerning these problems and options; that the public health (physical and emotional) and economic impact of these decisions are staggering with enormous quality-of-life implications for the 21st century woman in the United States.

Women's decisions may reflect a gap in knowledge due to a lack of easily understood information, population differences, race, culture, ethnicity, and economic factors that impact their interaction with physicians. Someone should pull together the various reports and findings and make them available (i.e., annotated bibliography) on a continuing basis to women of all ages (reproductive years/middle years; perimenopausal/postmenopausal years) through regional and local organizations (i.e., educational, social, health care, and professional).

More importantly, information should be widely disseminated to all women in an easily understood format so that these basic comparative charts will illustrate differentiated symptoms, diagnostic techniques, assessments, risks, treatment options, and self-help programs. Each woman can utilize these charts to reflect more carefully, openly and privately, with their physicians and family members.

A toll free telephone number should be activated by the NIH Office of Research on Women's Health (ORWH). This informational and educational effort should encourage the participation of the College of Obstetrics and Gynecology and the American Academy of Family Practice.

Local physicians should be encouraged to participate in local and regional seminars and discussions with interested and concerned women and family members. This might coincide with the ten regional HHS Offices (Boston, New York, Philadelphia, Atlanta, Chicago, Dallas, Kansas City, Denver, San Francisco, and Seattle). If possible, a collaborative effort should include the involvement of national foundations that share these interests (i.e., The Robert Wood Johnson Foundation and The Henry J. Kaiser Foundation).

Dissemination of information should include community organizations, corporate employers, colleges/universities, hospitals/medical centers, medical schools, primary health care centers, local medical societies, physician offices, and public health organizations. New research findings should be updated annually and made part of this continuing effort.

Ladies and gentlemen, we are accountable as individuals and through our organizations for both our commissions and omissions. With this cooperative and focused approach our efforts can be both feasible and successfully implemented so that women can make truly informed choices.

Albert C. Hergenroeder, M.D. *Baylor College of Medicine*

There are gaps in our current understanding of prevention of osteoporosis with respect to young women and hypothalamic amenorrhea/oligomenorrhea, including women with eating disorders and athletes. These include:

- The vast majority of bone mineralization in females occurs by the middle of the second decade; however, the normal acquisition of peak bone mass in late-maturing and minority females has not been established.
- Even though osteoporosis is not as great a problem in the African-American female population as it is in the European-American population, it is nonetheless a problem and there is no research addressing the natural history of bone mineral acquisition in young African-American women who are at risk for premature bone mineral loss.
- Premature bone demineralization occurs in women with hypothalamic dysfunction and manifests as amenorrhea and oligomenorrhea, associated with athletics, dancing, and eating disorders. Bone demineralization will be occurring soon after the amenorrhea develops. Treatment to prevent premature bone loss and promote bone mineral accretion should begin soon, probably within 6 months after amenorrhea occurs. However, the criteria to commence estrogen replacement therapy in young women are not established. The information available is from European-American women receiving short-term therapy.
- Women who recover from anorexia nervosa at a young age (<15 years) can have normal total body bone mineralization; but regional (lumbar spine and femoral neck) bone mineralization may remain low. The longer the anorexia nervosa persists, the less likely it is that the bone mineral will return to normal. Females with anorexia nervosa need to be rehabilitated early in the disease to maximize bone mineral accretion. Currently, a gap exists in available knowledge and its application in practice. Physicians and other health care providers need more training in recognizing women at risk for premature bone loss and advising them accordingly.
- Conjugated estrogen, in doses that improve bone mineralization in postmenopausal women and in combination with medroxyprogesterone, has not been shown to consistently improve BMD in young women with hypothalamic amenorrhea. Treatment with oral contraceptive pills has been demonstrated to have a beneficial effect on bone mineralization in young females with hypothalamic amenorrhea; however, long studies with amenorrheic and oligomenorrheic subjects are needed.
- Osteoporosis is a major cause of morbidity and mortality. Peak bone mass is a major determinant of the risk of osteoporosis and the second decade is the critical period of peak bone mass acquisition. Thus, those who provide health care for adolescents and those concerned about preventing osteoprosis need to join forces to understand the factors which affect bone mineralization during this period and develop long-term treatment strategies.

Penelope Kegel-Flom, Ph.D.

Past President, Association for Women in Science
Associate Professor, University of Houston

Addressing Barriers to Women Scientists: Research and Strategies

As immediate Past President of the Association for Women in Science and as a psychologist in a health professions College of the University of Houston, I am pleased to present testimony at this public hearing as part of ORWH's plan to update and advance the national agenda for women's health research. I will speak specifically to the ORWH mandate to take initiatives to increase the number and advance the careers of women in biomedical science.[1] To this end, I will focus on the findings of the recently completed study by the national Association for Women in Science, *Cultivating Academic Careers.*[1] This study, along with others, outlines models that institutions and government agencies such as NIH can adopt to warm up the often "chilly climate" for women in science.

Founded in 1971, the Association for Women in Science (AWIS) is a nonprofit professional society dedicated to achieving equity and full participation for women in all areas of science and technology. Currently in its 25th year, AWIS has over 5,000 members and 74 chapters in 40 states. AWIS members represent a wide range of scientific and technical fields spanning the life and physical sciences, mathematics, social sciences, and engineering. AWIS serves as a catalyst for change by investigating and articulating strategies for increasing numbers of girls and women entering the sciences and advancing in their careers.

AWIS firmly believes that a climate in academe that is supportive of women, particularly in terms of balancing career and family issues, benefits everyone. Yet, the current climate for women scientists in academe is often a chilly one. Although improvements are sometimes made through personal interventions such as mentoring, we believe that there will be no permanent change until there is systemic institutional change. The AWIS project on *Academic Climate*, funded by the Alfred P. Sloan Foundation, was designed to identify strategies which could enable institutions, both public and private, to effect significant and permanent change in the academic climate for women, and, ultimately, to benefit all scientists.

Barriers

All women in science, whether students, new tenure-track hires, or women in established careers, face obstacles: the question is whether they have the institutional, personal, and professional resources to contend with and overcome — or go around — these obstacles. Identifying what the barriers are can help; even better is understanding how our institutions and we as individual scientists can eliminate them.

While in recent decades considerable attention has been focused on attracting women and people of color to science and to engineering, retaining and promoting women in these areas has received much less attention. Indeed, many people and organizations sought to document and understand the complicated and seemingly arcane workings of the academic workplace. What factors, they ask, contribute to the success of academic scientists? Are the factors different for women and men? Or, are the criteria for advancement applied differently to male and female scientists? It would appear so; according to the Ecological Society of America which concluded, in a recent study (1993), that male and female ecologists do fare differently in the academic environment.[2] The report states:

> In comparison with women, men publish more papers, have higher salaries, reach higher academic positions, have greater job security, and feel more successful in their professional lives. At all stages of their careers women face a constant low-level disadvantage that prevents their competing successfully in the academic environment (Primack and O'Leary, 1993).[2]

And, there is ample documentation that women in science, including medicine, are paid less than men, more likely to be unemployed or underemployed, receive fewer prestigious awards and honors for scientific achievement, appear far less often on advisory panels making decisions on national science policy and funding, and are, overall, largely absent at the top.[3]

That women in academic medicine — and at the National Institutes of Health — are promoted more slowly than men is well documented.[4,5] In a national sample of women and men employed in academic medicine for at least 11 years, women were less likely than men to be promoted to associate or full professor; further, these gender differences were not explained either by differences in productivity or by differential attrition in the workplace.[4] Even when quality and quantity of scholarly work appear to equal or exceed that of male colleagues, promotion and tenure decisions are often delayed and/or denied women.[6,7] Possible reasons for the difference in promotions for women and men have been proposed: lack of proper mentoring from senior scientists; exclusion from the inner circles of departmental politics and influence; isolation within the department and the discipline; conflicts between professional and personal lives; and outright gender bias.[7,8] Women in academic medicine, for example, were less likely to be nominated for promotion by their departments, suggesting not only departmental "overlook," but possible lack of networking and mentoring for women.[3]

Cultivating Academic Careers: The AWIS Project on Academic Climate[2]

Briefly, the protocol of the AWIS Academic Climate study was this: three departments at each of three different types of institutions (large public research university, small liberal arts college, and historically black university) were selected from "applicants" based upon excellent academic reputation, awareness and commitment to improve the overall climate for women, and the ability to assign resources to the study. The three disciplines of study on each campus were biology, chemistry, and mathematics.

Method. Central to the study were site visits to the biology, chemistry, and mathematics departments on each campus. Site visits, modeled after the earlier research by the American Physics Society,[8] were preceded by gathering institutional information relevant to women faculty, including policies on recruitment, hiring, and promotion and by in-depth survey via questionnaire of faculty and students.

Results. Nine central issues for women scientists emerged in the AWIS study. The AWIS report, *Cultivating Academic Careers*,[2] details these issues and presents strategies for addressing them. Here I will cite several strategies for addressing each issue.

Recruitment and Hiring

- Establish a departmental hiring plan with specific goals and timetables for recruitment and hiring of women. Make this a departmental priority; obtain designated funds.
- Seek ways to designate slots for women, e.g., the National Science Foundation Visiting Professorship for Women could be used to replace a faculty member on sabbatical. Pledge slots for women in anticipation of retirements.
- Advance the visibility of women scientists at all levels: place women on significant departmental and university committees; invite distinguished women to present their work to the department, the university.
- Target administrative officials who support — and expect — departments to undertake equity initiatives. Require departments to document their recruitment and retention of young women faculty. Reward successful efforts.
- Establish institutional policies that improve the environment for women and people of color including:
  - adequate child care services; flex time; family leave; and extended time to tenure;
  - dual career and joint position options; and
  - spousal hiring policy and procedures.
- Offer women salary and benefit packages equal to that of their male colleagues.

Tenure and Promotion

- Create and communicate a written, formal policy outlining the criteria for advancement, promotion and/or tenure, and the procedures involved.
- Ensure equitable policies regarding salary increases, annual review, and feedback.
- Create flexible timelines for tenure and promotion (for all employees) and ensure that penalties do not ensue when a flex time or extended tenure path is used.
- Include at least one woman faculty member on every tenure review committee. Two is better.
- Appoint women to leadership positions such as department chair, dean, and policymaking committees.

Mentoring Faculty

- Develop written guidelines for formal mentoring; reward mentors for time and effect.
- Actively monitor current, informal mentoring programs for new tenure-track faculty.

- Encourage faculty to seek mentors in professional science organizations.
- Give junior faculty assistance in prioritizing teaching, grant writing and research, and service.
- Make substantial efforts to decrease the isolation of women faculty and postdoctoral research associates by encouraging them to interact with graduate students, postdoctorates, and women faculty.

Family and Work

The AWIS study, *Mentoring Means Future Scientists*, found that a key factor in a woman's willingness to enter and continue in science is her ability to picture herself as both a woman and as a scientist.[7] A central concern of graduate students, in particular, was how to merge — and be successful in — a career in science and a commitment to home and family. Meeting women who had "made it" in science and in their personal lives helped these young women realize that "being a woman and a scientist is possible."[7] Policies and practices in the workplace can do even more to help women and men balance career and family priorities. Here are some strategies:

- Specify and clarify policies on parental leave, extended tenure, and child care. Post these policies in public space in the departments. Ensure that penalties do not ensue when they are used.
- Provide for flexible work hours, including part-time schedules and extended leaves to care for sick relatives.
- Offer quality, affordable health care that extends to families and to domestic partners.

Communication Between Faculty and Administration

- Encourage the university administration, in consultation with the faculty, to articulate the goals, mission, and future direction (vision) of the departments vis a vis the recruitment, retention, and advancement of women scientists.
- Sponsor a reception at the beginning of the year for women in the departments to meet, consult each other, develop a network, and make contacts with people in the administration who value and support equity in the advancement of women.
- Have an annual development workshop for junior faculty on policies, regulations, and other issues such as allocating time among research, teaching, and service. Include women faculty who understand the informal "system" leading to promotion and tenure.

Informal Networking

- Encourage women science faculty to join with a campuswide group for women science faculty, or create one if one does not already exist.
- Provide space and facilities for encouraging informal conversation.

University Initiatives

It became clear as the AWIS site visits progressed that rules and policies in themselves were insufficient to change the climate and advance equity for women in academic science. The crucial element was public endorsement and promotion by the college/university administration and accountability for the exercise of the policies by departments. Some specific administrative strategies:

- Provide a model of equity for increasing the number of women in high-level positions — make it a high priority throughout your college or university.
- Disseminate information on the status and climate for women in science on your campus. Publicize your strategies for improvement of the climate.
- Create (or activate) a committee on the status of women to inform and advise administrators on strategies to help women scientists achieve and advance.
- Establish meetings of deans, department heads, and faculty to discuss the status of women faculty.
- Perform assessments of departments and communicate to deans and chairs that one criterion for their evaluation is the appointment of more women.
- Consider the benefit of an external, third-party evaluation of the climate for women in the science departments. A professional and objective assessment can give the department ideas for strategies that need to be implemented in order to create an environment in which all faculty flourish.

Conclusion and Recommendations

Much of what I have reported may sound familiar, perhaps too familiar, to many of you. The issues raised by the women in the AWIS study — and the barriers to equity and advancement for women scientists and graduate students in the biology, chemistry, and mathematics departments we visited — have been found in other studies in other venues.[3–5,7,10] Taken together, the message is resoundingly clear: equity for women in science does not exist. Further, it is in the best interest of institutions, whether public or private, to actively change the environment in order to obtain some of the best scientific minds to carry on science in the 21st century. Thanks to studies such as “Cultivating Academic Careers,”[2] “Improving the Climate for Women in Physics,”[10] and consensus papers like “Advancing Women’s Leadership in Science,”[4] we now know how to do it.

The National Institutes of Health

Let us return to NIH and the purpose of this meeting. We look to NIH to set the agenda for our nation’s health research; to set policy for the conduct of that research; and as a role model for equity in the science enterprise. We have eagerly watched, and many of us participated in, the development of ORWH. We cheered when, in 1993, NIH policy mandating the use of female and minority subjects in clinical research, regardless of potential increase in design complexity or cost. As a role model, NIH must ensure that: (1) its intramural research programs create and maintain an environment of equity for all scientists and staff; (2) women and minority scientists are recruited, hired, and advance in increasing numbers; (3) its external training programs for young scientists and health professional in training are expanded, ensuring that increasing numbers of young women and minorities are targeted; and (4) that women continue to serve, in increasing numbers, in top-level positions of NIH and on its review boards. Finally, NIH must continue to monitor compliance with policies such as the inclusion of women and minorities in clinical research. And to ensure not only the inclusion of women as research subjects, but that data be analyzed and presented in gender-specific ways. That most researchers still do not discuss differential responses to treatment protocols has recently been documented by Charney and Morgan.[11] As NIH pursues equity in its research agenda, policy, and intra- and extramural programs, others will follow, just as others have followed NIH's lead in research on women's health.

Needless to say, when the climate for women scientists and students of science changes in ways suggested by the AWIS study, all will benefit. As the Director of NSF, Walter Massey, said in 1992, ". . . increasing numbers of male scientists with working spouses and young children, as well as changing mores about the father's role in child rearing, has made issues of child care, flexible time, and parental leave a concern for men" (Ginoria, 1995).

As the NIH Office of Research on Women's Health meets to update and revise its national agenda for research on women's health, emphasis on prevention and the behavioral aspects of disease will hold a prominent place at the table. It is believed that behavioral and lifestyle changes such as smoking cessation, exercise, good nutrition, and safer sex would eliminate at least one-half the disease mortality in this country. In order to address an agenda focused increasingly on behavioral change, women in the social and behavioral sciences will be needed in greater numbers. Strategies described in the AWIS (and other) studies for removing barriers and increasing opportunities for women in biomedical and physical sciences can be used likewise to increase numbers of women in the social sciences.

Conclusion

Increased visibility of women scientists, equitable entry- (and re-entry-) level packages, absolute salary equity, "family friendly" policies in the workplace (e.g., adequate child care, family leave, extended tenure), elimination of sexual harassment and other forms of discrimination, and accountability for improving the climate for women scientists — these are strategies that can increase the numbers of women who enter the sciences and maintain productive careers throughout their lives. As role model for the nation, NIH, and especially ORWH, can make this happen.

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Note: Cultivating Academic Careers, *the complete report, is available from: AWIS Publications, 1200 New York Avenue, NW, Suite 650, Washington, D.C., 20005; Fax: 202-326-8940.*

Gwendolyn Puryear Keita, Ph.D. *American Psychological Association*

On behalf of the American Psychological Association (APA), I would like to commend Dr. Vivian Pinn for her leadership in advancing research on women's health. We would also like to convey our deep appreciation for her recognition of the importance of psychosocial and behavioral factors in women's health and the inclusion of behavioral and social scientists in the development of the new women's health research agenda.

We are the largest scientific and professional organization representing psychology in the United States. APA's membership includes more than 151,000 researchers, educators, clinicians, consultants, and students. APA's mission is to advance psychology as a means of promoting human welfare, as a science, and as a profession. APA has a long history of involvement in women's issues, in particular supporting and encouraging behavioral and social science research to address women's health.

Despite increased focus on medical and epidemiological aspects of women's health, research has not adequately addressed psychosocial and behavioral factors that contribute to health status. In May 1994, APA, in collaboration with a number of federal agencies and professional organizations, sponsored an interdisciplinary conference titled "Psychosocial and Behavioral Factors in Women's Health." The purpose of the conference was to highlight the extensive research implicating behavioral and psychosocial factors in a number of major chronic diseases and conditions that influence women's health across the life span.

The "Research Agenda for Psychosocial and Behavioral Factors in Women's Health" evolved out of the conference. It was developed by the conference advisory committee, which included experts from across disciplines, institutes, and federal agencies — including the Office of Research on Women's Health — and represented a broad range of women's health concerns. The Research Agenda builds on the growing body of knowledge in women's health and articulates a set of priorities for the next generation of research studies.

The Research Agenda defines research priorities pertaining to specific diseases and health practices that greatly affect women. The diseases included are those that show high mortality or morbidity rates for women and that may cause great physical disability, lowered financial resources, and poorer quality of life. Some of the priorities delineated support important priorities for women's health identified at the beginning of this decade in the U.S. Department of Health and Human Services' *Healthy People 2000*.

APA believes that consideration of future research and funding needs for women should be made (1) with full awareness of the issues of concern to women's health, (2) with knowledge of what research has already shown, (3) with knowledge of what questions remain unanswered, and (4) with a full appreciation of the behavioral and psychosocial factors that impact each health issue. Our Research Agenda was developed with these factors in mind. We, therefore, propose that ORWH use our Research Agenda as the foundation upon which ORWH builds its new research agenda. This would avoid duplication of efforts and enable women's health researchers, federal agency personnel, and policymakers to most effectively address women's health research and would go a long way in furthering the much-needed federal commitment to improving the health of America's girls and women. Copies of the Research Agenda are readily available for your use.

Thank you again for the opportunity to participate in this hearing and for your leadership in research on women's health.

Daniel Kerlinsky, M.D.

Self/Environment Committee
Physicians for Social Responsibility

The Environment Committee of Physicians for Social Responsibility is a national organization of 15,000 members that supports the prevention of nuclear war, reduction of violence, and the protection of the global environment. In particular, the organization is concerned with the effects of toxic environmental chemicals in the prenatal period. These children present with poor attention span, impaired impulse control, aggressive behavior, learning difficulties, communication disorders, and difficulty with complex thinking. The issue of environmental toxicity in the prenatal period is important to the Office of Research on Women's Health for the following reasons:

Toxic exposures during fetal development produce effects that last a lifetime.

Birth defects, mental retardation, and impaired reproductive ability are some of the lifelong effects of in utero exposure to toxins. Each of these has profound impacts on self esteem, social functioning, vocational abilities, and family life. The more subtle toxic effects on information processing, emotional relatedness, attention, and aggressive behavior may be difficult to study. Having a single handicapped child changes every aspect of family life. However, toxic environmental exposures are likely to produce multiple lifelong impairments in several children in the same family.

Sensitivities during this period are orders of magnitude greater than in later life.

The developing fetus is much more sensitive to toxic chemicals than adults are. Dioxin exposure shows that regulatory genes, growth factors, protein transcription, and multiple hormone systems can be affected by these chemicals. These effects can occur at very low concentrations. Hypoplasia, a decrease in cell numbers, occurs in lymphoid tissue; dysplasia, the abnormal growth or development of an organ, occurs in ectodermal tissue in humans. It is not necessary to kill a cell during fetal development to affect brain development; an impaired energy metabolism in a cell may be sufficient to lead to altered connections. These sort of effects appear functionally years later when complex functions, such as sustained voluntary attention, require the coordination of many brain areas.

Multiple organ systems are affected by prenatal toxins.

Many organ systems are affected by exposure to toxic chemicals in utero. This leads to more complex illnesses, such as asthma, disorders in liver metabolism, and multiple drug sensitivities. Immune system suppression may further complicate the presentation and management of these cases.

Women bear the brunt of raising CNS and behavior disordered children.

Mothers are directly impacted by the behavior problems of their children. The increased stress that these children experience in their early years may be followed by physical traumas as they get older. Male children exposed to toxic chemicals show increased aggressive behavior as they enter their teenage years.

In utero exposure to environmental chemicals may have profound effects in wildlife populations, which may, in turn, affect human populations.

Population reductions in wildlife due to reproductive failures have been profound. Decreases of 80 percent in populations of birds and mammals over just a few years have been reported. These raise concerns about human reproduction as humans are not particularly resistant to the toxic effects of the chemicals to which these population crashes are attributed.

Proposed solutions to dealing with the threat of prenatal toxins include regulating and restricting the use of toxic chemicals; long-term research support; medical and community education efforts; and government outreach and support to women whose occupations expose them to toxic chemicals.

Senior Research Associate
Wilhelmina A. Leigh, Ph.D. *Joint Center for Political and Economic Studies*

I am Wilhelmina A. Leigh, Senior Research Associate at the Joint Center for Political and Economic Studies located in Washington, D.C. The Joint Center for Political and Economic Studies is a nonprofit, nonpartisan, research and public policy institution established in 1970, whose mission is to enhance the quality of life — broadly writ — for African Americans. Although the title of the institution does not suggest an interest in health or in women, health has been one of our areas of interest since the early 1990s, and women's health has been of interest to me ever since my rather unhealthy childhood. I am now pursuing my broad health interests at the Joint Center, where projects have been implemented on health care access, women's health, HIV/AIDS prevention education, and managed care.

My statement addresses population differences due to race/ethnicity and their influence on women's health. I will begin with some background information on the four major racial/ethnic groups of women and why it is important to be aware of differences among these populations when doing health research. One health behavior (help seeking in the managed care environment) and several health outcomes (low birthweight, hypertension, osteoporosis, and Alzheimer's disease) are the specific foci of my statement.

Background

Of the more than 265 million residents of the United States in 1996, over half (nearly 52 percent) were women and over 36 million were women of color. The phrase women of color includes women of the following racial/ethnic groups — black non-Hispanic (or African American), Hispanic, Asian, Pacific Islander, and American Indian and Alaska Native. Women of color are more than one-fourth of all women and, with population increases due to the following — fertility among women already in the United States, continued immigration, and even higher fertility among many immigrant groups — women of color as a share of the U.S. population and as a share of all U.S. women will grow.

Women of color differ from white women not only physiologically, but also psychosocially and economically. All of these differences influence the health of women of color. For example, women of color not only are more likely to be obese but also are likely to not perceive body mass in the same manner as white women. In southern African-American culture and Polynesian cultures, girth is considered desirable, a sign of prosperity, not a factor predisposing one to hypertension or diabetes. Many males outside of the dominant U.S. culture also find girth attractive and preferable in their partners, creating social pressures against tackling what could become a health problem. The economic status of women of color also may limit their ability to work against being obese — if they are unable to afford health club memberships or, more simply, lack the time, energy, and fearlessness to exercise outside in the neighborhoods in which they live.

Women of color will become the majority of household heads and health care seekers in many of the communities of this nation. Thus, as the 21st century approaches, it will become increasingly important to conduct research on the health-related behaviors and the health outcomes for women of color. It will be difficult to serve these women well (i.e., act with knowledge about them) without understanding their differences.

Health Behavior

The health behavior I will focus on — help seeking in the managed care environment — provides a ready example of how differences among women of color may influence the receipt of services and, therefore, health outcomes. In 1995, women of color were equally represented (about a fourth) among all women and among women who lacked health insurance coverage of any kind, either fee-for-service or managed care (nearly 19 million women).[1] The individual groups of women of color, however, are more likely to be uninsured than are white women. Thirteen percent of non-Hispanic white women were uninsured, compared to 17 percent of American Indian/Alaska Native women, 18 percent of non-Hispanic black women, 19 percent of Asian and Pacific Islander women, and 30 percent of Hispanic women.

Certain subpopulations of women of color also are more likely to have public insurance than white women. Also in 1995, while 24 percent of Asian and Pacific Islander women and 27 percent of white women reported having public health insurance, a third of Hispanic women and 40 percent of black women indicated that they had this coverage. Public insurance often is less generous than private insurance and sometimes limits access to needed services, either directly or through barriers encountered when trying to use public insurance in selected markets.

The managed care industry, which first made inroads in the market for private health insurance, is now focused on penetrating the public health insurance market. Most of the 50 states have sought and received waivers from the Health Care Financing Administration (HCFA) to modify their publicly funded Medicaid programs (that provide health insurance for the poor) by using managed care as the organizing mechanism. These states project that by superimposing managed care onto their Medicaid programs, they will save enough to enable them to provide health insurance coverage for all the poor (i.e., those low-income persons currently covered by Medicaid and those uninsured). Currently, the Medicaid program does not provide health insurance coverage for all persons throughout the nation with incomes below the federal poverty threshold.

In some places, private managed care networks have bought local health services facilities and are competing for the right to provide health insurance coverage for the poor, both the current Medicaid population and the currently uninsured poor, many of whom were formerly served at community clinics. If these private networks get the rights to cover local Medicaid populations, they siphon off Medicaid funding that has been a mainstay of neighborhood/community facilities and, in many cases, cause these facilities to close.

This modification of the rules by which the uninsured and those with public insurance such as Medicaid get health care is affecting women of color throughout the nation. Help-seeking behavior must change as the gatekeepers and access points to the health care system change, if quality care is to be received. For example, how will the many subpopulations of Native people (e.g., American Indians, Alaska Natives, Native Hawaiians, Samoans, and other native Pacific Islanders), whose members can be characterized as follows — strongly autonomous, non-linear thinkers, users of indirect communication and styles, and having a historical suspicion of authority — respond to the imposition of managed care in the environments where they seek health care?

Although the Indian Health Service provides free care to those living on or near reservations (and to some in urban areas where urban Indian clinics are located) and has not yet adopted managed care as the operating principle for the delivery and financing of its services, Native people ineligible for this free care will confront the challenge of managed care elsewhere in the health care marketplace, and there may be a resultant worsening of the quality of care received. In another example, Hispanic subpopulations, many of whom have religious and cultural beliefs that make it difficult to establish the importance of preventive health behaviors,[2] could encounter a deterioration in the quality of care received under managed care. Since preventive care is purportedly a centerpiece of managed care, and the ability of managed care programs to reduce costs for comparable services below the levels incurred by their fee-for-service competitors, any groups unwilling to get the preventive care provided in managed care networks may face worsened health outcomes.

In yet another example, how will populations with little education, little knowledge of English, and little knowledge of health conditions, recommended preventive tests, and the like, respond in the managed care environment? Large numbers of women of color have these characteristics and, thus, will face challenges in receiving needed health care services in the world of managed care. The closing of a community clinic may alter the ability of indigent immigrant women to get appropriate care on a timely basis. Use of preventive care may cease when the place where care is received relocates from a local neighborhood to a downtown medical center. The timely diagnosis of conditions may no longer happen (or may take place less frequently) in the managed care health environment. These changes may bring with them attendant greater morbidity and mortality. Although this may not be what is commonly thought of as a behavioral health issue, I think it clearly is important and needs both to be monitored and to be on the agenda for future research and evaluation of the health needs of women of color (who are disproportionately poor and, therefore, most likely to use local health clinics) and for all women.

Health Outcomes

The health outcomes I would like to see in the research agenda for women in the 21st century include: low birthweight of infants, hypertension, osteoporosis, and Alzheimer's disease. None of these is new, but the group of women studied for these conditions should be broadened.

Low birthweight for infants is defined as less than 1500 grams. I am, of course, interested in the elevated incidence of infants with low weight born to black women in all socioeconomic strata. Some evidence suggest that the spacing of births is an explanatory factor, given the greater frequency of short intervals between pregnancies among black women than among white women.[4] Other researchers have postulated that childhood deficiencies in the mother's nutrition and subsequent development account for the high incidence of low-weight infants born to black women.[5] I would like to see this investigated further.

I also would like to see work done to probe two other findings. The first is the increased incidence of low-weight births among Mexican-American women as their length of residence in the United States increases. What factors explain this? How can we confer the protective aspects of pregnancy among recently arrived immigrant women on later generations of similar women? The other finding I would like to see explored is the fact that although a high percentage of Asian Indian women in the United States (80 percent) begin prenatal care in the first trimester, their incidence of low-birthweight infants (10 percent of all live births) is higher than expected.[6] How is this explained? Yet another subpopulation of women that could be studied for their births of low-birthweight infants is Puerto Rican women, 9 percent of all live births to whom have low weights. (The rate of births of low-birthweight infants is 6 percent for white women and 13 percent for black women.) By focusing on these subpopulations, in addition to black and white women, the role of prenatal care and other factors in influencing birth outcomes perhaps could be elucidated.

I would like to see the issue of hypertension explored further along the lines initiated by Nancy Krieger.[7] She is researching the influence of racism on hypertension among blacks. Further work to clarify what psychosocial and physiological mechanisms underlie the high rates of hypertension, heart disease, and death among black Americans is needed. Research on the high incidence of hypertension among Native Hawaiians and Filipinos should be undertaken as well, exploring psychosocial factors along with other mechanisms that may be responsible for the condition.

The third issue is osteoporosis. Research is needed to determine the mechanisms that trigger this disease. Is it a disease influenced by childhood nutrition, as some research suggests, or is it primarily determined by the initial endowment of bone density that comes with our DNA and genes at birth and the rate at which this bone mass decreases over time? As the population of Asian American females (who are more likely to have this condition than other women of color) increases in the United States, we need to have better knowledge about osteoporosis to treat all women who may have this disease.

Finally, I would like to see more research on Alzheimer's disease. A higher incidence of Alzheimer's disease has been reported among black Americans than among other elderly populations.[8] Some hypothesize that the lower levels of education among African Americans are related to this finding. Alzheimer's disease should be explored in conjunction with the health of the oldest old, among whom some women of color tend to be well represented. The reverse survival pattern that kicks in for blacks (and perhaps for other people of color) after age 65 (i.e., black women and men are overrepresented among the oldest old, relative to their representation among other age groups) needs to be studied and understood. Is there evidence of this pattern among other racial/ethnic minority groups? Are the oldest old women of color (and white women) most likely to develop Alzheimer's disease, or is the disease more common among the younger old women of color (and white women)? The interactive mechanisms for this disease need to be researched and lain bare to benefit all members of the aging society of the United States.

Finally, I would end my statement by thanking the Office of Research on Women's Health and Dr. Vivian Pinn for holding this and the other regional meetings conducted to help them develop their research agenda for the beginning of the 21st century. There is virtue in inclusiveness, and this truly has been a virtuous process.

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Susan Lewis

Independent Living Research Center

As a woman with a spinal cord injury (quadriplegic), there are many areas or gaps in knowledge relating to health for women with disabilities. After sustaining an injury at 24 (a time when thoughts of education, careers, marriage, and families enter the picture), I entered a different world. A world where my independence and freedom were taken away from me.

The medical professionals did not provide the needed information, education, or financial resources necessary for transitioning me from the hospital back into my home. As a result, I ended up in a nursing home for 8 years of my young life. I lost control of every aspect of my life.

With the assistance, support, and encouragement from an employee of the Division of Vocational Rehabilitation, I was able to move out of the nursing home and return to school for an education.

Living in the community and regaining my independence, I have learned that the following issues affect women with disabilities:

- *Lack of information for individuals and their families.* Increasing information increases choice and individual empowerment.

- *Adaptive equipment is not always accessible and is often times very expensive.* Having access to adaptive equipment eliminates limitations.

- *More services are needed, especially at the initial phase of an injury*. Attendant services are of major importance but, in most cases, not easily accessible or affordable. They are important in maintaining quality of life and for reducing risk of developing infections and other health problems.

- *Health and auto insurance issues faced by women with disabilities.* Auto insurance increases because of being a "high risk" driver; and health insurance is not always accessible. If it is, there is no guarantee that it will assist with payment of medical assistance.

- *Women with disabilities face extreme financial issues.* The cost of living with a disability puts extra stress on individuals and families.

- *Complicating the issues of women's health is the fragmentation and underfunding of a variety of federal and state programs that pay for a range of services that people with disabilities need to become independent.* In addition, more of these programs contain disincentives to employment, which keeps women with significant disabilities out of the workforce and dependent on services and programs.

These are just a few issues that women with disabilities face living in our communities. These areas need to be addressed so those women with disabilities can live a quality life in our communities.

Rosemary Locke

Washington, D.C. Liaison
Y-ME National Breast Cancer Organization

In 1996, Y-ME National Breast Cancer Organization and other cancer patient and provider organizations filed a citizen petition urging the Food and Drug Administration (FDA) to ease its restrictions on access to silicone gel breast implants for women with breast cancer or those at high risk for the disease.[1] The petition relied on the impressive body of sound scientific evidence related to silicone gel implants that has been produced since the FDA severely limited access to these medical devices 5 years ago.

Women requiring mastectomies following a diagnosis with breast cancer face the difficult and very personal decision whether to have reconstructive surgery. Y-ME and others strongly believe that women with breast cancer have the right to choose whether they want implants and to select the product that will give the best cosmetic outcome for reconstruction. In order to make this decision, we must have as much clear and accurate information about the safety of these products as possible.

Unfortunately, women have great difficulty obtaining accurate information. Many women increasingly rely on the media to assist them in making health-related choices. But sadly, for the most part, the media has presented sensationalized stories about women with breast implants using anecdotal accounts instead of scientifically valid studies looking for a causal relationship between breast implants and illness.

FDA, the source informed consumers should normally rely on, continues to downplay the overwhelming scientific evidence that indicates no clinically relevant risks associated with these devices. Moreover, two official FDA documents send a mixed message to consumers.[2] This creates fear and confusion for women considering implants, as well as those who already have them.

FDA breast implant policies have broader implications relating to the regulation of and access to medical devices used in the treatment of other cancers. The threat of overly burdensome regulations and litigation have an intimidating effect on the research and development of potentially life-saving medical products.

Because the FDA failed to adequately address our concerns, the following cancer organizations joined Y-ME in the attached citizen petition: American Cancer Society (ACS), American Society of Clinical Oncology (ASCO), Cancer Care, Inc., Candlelighters Childhood Cancer Foundation, National Alliance of Breast Cancer Organizations (NABCO), National Coalition for Cancer Survivorship (NCCS), Society of Surgical Oncology, and US TOO International (prostate cancer organization).

We believe that this document will provide a valuable tool for the Office of Research on Women's Health as it assesses issues relevant to breast implants, other medical devices, and scientific research.

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Ann Martin-McAllen, M.S., Ph.D. (Candidate) *Self*

Fibromyalgia

My name is Ann Martin-McAllen. I am a Ph.D. candidate in Health Education and Promotion at the University of New Mexico. The topic of importance regarding women's health on which I wish to testify is the syndrome fibromyalgia. Not only am I presently researching the connection between stress, personality, and coping style in women who have been diagnosed with fibromyalgia (FMS) for my dissertation, but I am also an a FMS survivor myself. Thus, I describe first hand what it feels like to have FMS and how it compromises one's life.

Like many women with FMS, I was diagnosed many years after several traumatic life experiences. Two were automobile crashes, both of which occurred in the morning on my way to work and both of which were caused by someone else. When my life and my health did not return to normal after many years of treatment, I believed it was due to the traumatic experience of seeing the crashes coming, but of being unable to prevent them. Likewise, I believed that my health would only improve after more time elapsed. The problems I experienced in trying to get a diagnosis were considered textbook by health care professionals who understand FMS and the problems associated with being diagnosed. This difficult task consisted of seeing many doctors of various specialities, having many examinations, taking a great variety of tests, yet stubbornly refusing to believe that it was just my imagination, because I ”looked perfectly healthy.” Oh, I had gained 80 pounds; was so fatigued at times that I could hardly function; and was in tremendous pain throughout my body which, at its worst, caused me to depend on my husband to basically dress and undress me, help me to get in and out of the shower, and bathe and perform every other task of daily living. The comfort of finally having my condition being given a name is beyond words. Once diagnosed, I knew I had achieved the first step in regaining my health or at least in becoming functional again and, hopefully, would be able to recapture my life and my future. Before any of this happened, I had described myself as a super woman....a wife, mother of four girls, and career woman with goals and plans for the future which meant also being a student and continuing my education. What followed my diagnosis was a continued quest for treatment modalities that would restore my health or would at least allow me to reclaim my life and my relationships.

This testimony provides only a thumbnail sketch of my experience with FMS. For you to truly understand the significance of the effects that this syndrome can have on a woman’s life, I will paraphrase some of the information that was given to me by approximately 150 other women when they called me hoping to participate in my study which was mentioned in the *Albuquerque Journal* on May 5, 1997, in an excellent article on FMS.

Before I communicate these women’s comments, I think it is important for you to know the definition, history, epidemiology, symptoms, and diagnostic procedures as they relate to fibromyalgia.

Definition

FMS is a syndrome, indicating a specific complex of symptoms. It is defined as “a form of nonarticular rheumatism characterized by widespread musculoskeletal aching and stiffness, as well as tenderness on palpation at characteristic sites called tender points” (Rachlin, 1994, p. 3).

History

Since the 17th century, aches and pains in the muscles and joints have been described as muscular rheumatism in European literature. In the *British Medical Journal* in 1904, W.R. Gowers in “Lumbago: Its Lessons and Analogies,” first used the term fibrositis (Rachlin, 1994; Boissevain and McCain, 1991). While fibrositis was used to describe musculoskeletal aching, stiffness and fatigue, it is considered a misnomer by Boissevain and McCain (1991) because of “the lack of an underlining inflammatory mechanism” (p. 229). The term ‘fibromyalgia’ was first introduced by Hench in 1976 (Boissevain and McCain, 1991). In 1988, Holmes, et al. published the first working definition of FMS, which was also the first official recognition of this complex of symptoms.

Epidemiology

The epidemiology of FMS indicates that it occurs predominantly among females, with only 5 to 20 percent of the cases among males. FMS occurs most commonly in the age group of 30 to 50 years, but some juveniles and elderly also are afflicted. The literature describes most patients as being Caucasian, but FMS is also found among the Japanese and South African blacks. The literature shows that cases per capita vary from 1 to 10 percent of the population (Norregaard et al., 1993; Wolfe, 1993).

Of the approximately 150 phone calls I received from women who wish to be in my study, more then 50 percent were over 50 years, and many were in their 70s, with the oldest being 82 years.

Symptoms

The most common and characteristic symptoms of FMS are (Rachlin, 1994; Wolfe, 1993):

- Generalized myofascial pain at 11 to 18 tender points,
- Prominent stiffness of three anatomical areas for 3 months,
- General fatigue or tiredness,
- Poor sleep,
- Depression, mental distress, anxiety, and stress,
- Swollen feeling in soft tissue,
- Paresthesia,
- Chronic headaches,
- Irritable bowel syndrome/70 percent candidiasis,
- Dysmenorrhea,
- Female urethral syndrome,
- Hypothyroidism, and
- Dry eyes and mouth.

The literature shows other symptoms that include:

- Often thought to be an example of “mass hysteria” or “all in the head,”
- Diagnosed by exclusion/process of elimination of other diseases,
- Most patients had symptoms for years and have multiple, inclusive diagnostic tests,
- Symptoms began with flu-like symptoms, and
- Patients usually look well.

- Chronic fatigue is present in virtually all patients.
- Have neuropsychiatric abnormalities such as:
  - mood disorders,
  - major depression,
  - anxiety disorder,
  - highly stressed,
  - feelings of helplessness, hypervigilance, and increased frustration regarding health because diagnosis may be delayed for years while the patient sees multiple physicians and undergoes a battery of tests,
  - sensory and cognitive disturbances,
  - attention deficits, and
  - slow speed of information processing.

- Neurologic abnormalities are as follows:
  - paresthesia, and
  - sleep disturbances:
    1. abnormal stage IV sleep pattern,
    2. nocturnal myoclonus, and
    3. sleep apnea.

Diagnostic Process

When seeking a diagnosis of FMS, it is very important to take a thorough history of the current complaints and history of the onset of the symptoms, as described by Rachlin (1994). The possibility of contributing causes — such as tension and/or stress which is experienced in conjunction with business, personal, family, marital problems, or other traumatic experiences — should also be explored. With FMS, it is also necessary to follow the physical examination by observing the patient's movements and posture, testing range of motion and muscle strength, checking neurologic integrity, and palpation of muscles and algometry. The history should include characteristics of the pain, referred pain patterns, factors that precipitate and prolong the symptoms, previous episodes of pain, treatment, and response to treatment. The history of onset should include when the person first became aware of the pain; any history of physical or emotional trauma; any specific incident or activity which preceded it; a review of any causes which may contribute to the pain, such as prolonged muscle tension or recurring spasm; and pain related to occupational and/or athletic activities. Details may give clues to what the individual is actually experiencing (Rachlin, 1994).

Reason for Needed Research

The reason this syndrome is of such concern is that FMS dramatically affects the lives of its victims in a wide range of ways. Jacobsen, et al., (1993) and Hendriksson (1993) described the range of impairment to include:

- *Muscle Pain.* The individual has localized pain in the beginning stages that progresses to pain over the whole body in the later stages.
- *Functional Disability.* The individual has problems of mobility, muscle stiffness, and weakness.
- *Poor Physical Fitness.* The patient exercises very little because of pain, sleep disturbance, fatigue, and decreased muscular endurance.
- *Work Disability.* The patient is unable to cope with household duties, may not be able to work outside the home, changes jobs or works only part time — all resulting in documented negative work performance.
- *Psychological Distress.* Twenty to 70 percent of the individuals have problems with depression and anxiety.
- *Decreased Quality of Life.* The individual feels unable to participate in desired activities.
- *Relationship Problems.* The individual feels less supported and understood by family members and friends.

Among the calls I received from women interested in participating in my study, several were from women who had experienced the symptoms for up to 35 years, while others had never been diagnosed. Many women either could no longer work full time or had to stop working completely. Some women had been misdiagnosed and treated inappropriately for years and had experienced serious side affects from the treatment given. Their response was the same as my own when they finally received a name for the pain and suffering they had endured for so many years. Some women were even in tears, thanking me for caring enough to help them and other women find answers to the mystery of FMS.

Other things these women voiced are as follows:

- They felt like they were losing their minds.
- They were frequently told it was all in their mind.
- They were told that they are just menopausal and were being neurotic.
- They were not believed or taken seriously.
- They felt helpless because no one would listen to them or believe them.

- They were told by physicians that they didn't believe FMS really existed.
- They believed no one understood or really cared.
- Because of panic disorder, they were afraid to leave the house, try new things, or drive in traffic.
- They had major cognitive problems — memory problems, concentration.
- Told their thyroid was within normal range when in fact they had all the symptoms of FMS.
- Told Candida was not recognized even when they had the "classic" FMS symptoms.
- They are unable to support themselves financially.
- Gained tremendous weight and couldn't regain normal weight.
- They were unable to care for their children.
- They experienced flu-like symptoms much of the time.
- It was painful to have their skin touched.
- They isolated themselves and didn't understand why.
- Their quality of life had deteriorated and they felt no hope for the future.
- Because of the continuous pain and suffering, they considered suicide.

Due to the nature of FMS, the symptoms, and the lack of understanding and knowledge, it is believed that there may be an epidemic of FMS both in this country and in other parts of the world. The lack of information and understanding possessed by the public at large, as well as the health care community, has caused many women to suffering needlessly — virtually having their lived destroyed. Women have been told, and are still being told, that there is really nothing wrong with them because nothing shows up in tests and they look well. This attitude has caused many family members to doubt the seriousness of the condition and this only adds further suffering to the individual. Some women have had various surgeries such as hysterectomies, back surgery, and even one woman in her 50s was given a tonsillectomy to treat FMS. This resulted in side effects which further weakened their physical condition, causing even more problems. Other standard treatments are antidepressants and pain medication which not only cause side effects but also tend to mask the symptoms and the progress of FMS.

When I conclude my dissertation, I will complete the grant proposal now in progress which uses behavioral medicine as part of the treatment for FMS. It follows my dissertation in its hypothesis since I used the theories of behavioral medicine and psychoneuroimmunology as part of my dissertation. Many different therapies have been tried on me and my health has greatly improved. The research for my dissertation is but the first step toward testing my theories of what will improve the lives of those who suffer with FMS. While drug research is being accomplished, there are other modalities which need to be tested in a scientific manner, methods which will enable the individual to reclaim her life without the side affects of drugs because of her extraordinary sensitivity to them.

In summary, there are millions of women who are suffering from FMS. Many have been unable to obtain a diagnosis because of the confusion within the medical community regarding FMS and the stigma that still exists where women's health is concerned. Thus, we must call for a greater focus in research of the etiology and treatment of FMS. We have a responsibility to take women seriously, to believe them and trust that they know their bodies; not to dismiss their complaints as being neurotic.

This process can begin with the use of behavioral medicine; women can be taught to recognize how their behavior affects their lives and their health, especially, how our culture affects our attitudes and that we as women do have choices in our behavior.

Ann McCampbell, M.D.

Chair, Multiple Chemical Sensitivities
Task Force of New Mexico

My name is Ann McCampbell and I am a physician disabled with multiple chemical sensitivities (MCS). I am also the Chair of the Multiple Chemical Sensitivities Task Force of New Mexico, a statewide advocacy organization for people with MCS. Since this illness primarily affects women, I welcome this opportunity to encourage the Office of Research on Women's Health to make research on MCS a high priority.

In-depth research on MCS is urgently needed and long overdue. Since MCS was described in the 1950s, its prevalence has grown to near epidemic proportions, yet this illness continues to be virtually ignored by the medical and scientific communities. The fact that the vast majority of MCS sufferers are women has undoubtedly contributed to the tendency for MCS to be dismissed as hypochondriasis and hysteria. Efforts by the chemical industry, with its vested interest in maintaining doubts and controversy about MCS, have also contributed to lack of research in this area. Clearly, it is time for government to declare war on MCS, as it has on cancer, and commit to solving the mysteries of MCS, developing effective treatments, and implementing prevention programs.

What is MCS?

People with MCS experience adverse health reactions following exposures to a wide variety of chemicals, many of which are commonly encountered in everyday life. These reactions occur with low levels of chemicals which ordinarily do not affect others. Substances which frequently cause symptoms in chemically sensitive people include pesticides, perfumes, new carpets, fresh paint, tobacco smoke, vehicle exhaust, and many cleaning compounds, to name a few. The severity of symptoms ranges from mild to life threatening, and symptoms can be provoked by even minute amounts of substances that have been inhaled, ingested, or absorbed through the skin.

Many people with MCS also react to mold, dust, pollen, animals, and food. A significant percentage of people with chronic fatigue syndrome, fibromyalgia, and Gulf War syndrome also report being unusually sensitive to common chemicals.

The symptoms of MCS vary greatly and are unique to each person, but the unifying factor is that their symptoms are caused or worsened by chemical exposures. Common symptoms of MCS include, but are not limited to, headache, fatigue, rashes, heart irregularities, respiratory difficulties, joint and muscle pain, nausea, diarrhea, weakness, poor coordination, and seizures. In addition, disorientation, memory loss, poor concentration, and difficulty thinking and speaking are common.

The fact that many people develop MCS following a pesticide or other toxic exposure, or after moving into a newly built home, or working in a recently remodeled office, strongly suggests that chemical exposures are responsible for inducing this illness as well as triggering its symptoms. Abnormal brain scans (Heuser, Mena, and Alamos, l994) and neurobehavioral tests in chemically sensitive people also suggests that MCS involves a neurotoxic brain injury. At present, however, the etiology of MCS is unproven and the mechanism of the chemical sensitivities is unknown.

Scope of the Problem

Severity. The severity of MCS ranges from those who are only mildly affected to those who are severely disabled. MCS is recognized as a potentially disabling condition by the Social Security Administration, U.S. Department of Housing and Urban Development (HUD), and many other federal, state, and local government agencies. It is covered under the Americans with Disabilities Act on a case-by-case basis.

In its worst form, MCS is a devastating chronic illness which forces people to alter every aspect of their lives. Many lose their jobs, homes, careers, families, and friends. Mothers have had their children taken away because they were too sick to care for them or because they were unjustifiably declared mentally unfit by an ex-husband or social worker. Due to chemicals that are present, many chemically sensitive people are unable to go into most schools, hospitals, stores, restaurants, motels, places of worship, etc. Some people with MCS are housebound while others are homeless. Severe isolation almost always accompanies this illness.

Prevalence. MCS is a large and growing problem. According to Nicholas Ashford of M.I.T. and Dr. Claudia Miller, authors of the 1989 award-winning study of chemical sensitivity conducted for the New Jersey Department of Health, “evidence does suggest that chemical sensitivity is on the rise and could become a large problem with significant economic consequences related to the disablement of productive members of society” (Ashford, Miller, 1991).

MCS is reported worldwide (Wilson, 1995) and occurs in people of all ages, races, and socioeconomic backgrounds (Meggs, et al., 1996). It is estimated that 70 to 80 percent of MCS sufferers are women. Random population-based surveys in California (Kreutzer and Neutra, 1997) and North Carolina (Meggs, et al., 1996) found that 16 and 33 percent of the respondents, respectively, reported being chemically sensitive. Four percent said they suffered daily or almost daily symptoms (Meggs, et al., 1996), and 3.5 percent said they were chemically sensitive and had been diagnosed with MCS (Kreutzer and Neutra, 1997). Statistics from the New Mexico Department of Health indicate that MCS is probably 25 times more prevalent than AIDS in this state.

In the California study (Kreutzer and Neutra, 1997), 1.5 percent of the respondents also admitted that they had lost a job or career because of their chemical sensitivities. If this statistic is true nationwide, it would indicate that over 3 million American women have already lost their ability to earn a living because of this disease.

Research to Date

Much of the research on MCS has been presented at three federally funded conferences: Workshop on Multiple Chemical Sensitivities, National Academy of Sciences (1991); Advancing the Understanding of Multiple Chemical Sensitivity, Association of Occupational and Environmental Clinics and Agency for Toxic Substances and Disease Registry (1991); and Conference on Low-Level Exposure to Chemicals and Neurobiologic Sensitivity, Agency for Toxic Substances and Disease Registry (1994).

Unfortunately, most of these studies are small and, even when considered together, merely scratch the surface of what is needed to investigate this illness. It is clear that a large comprehensive research plan needs to be developed and implemented in order to better characterize and understand MCS. Though this has consistently been the recommendation of the conference participants (Miller, 1994), it has yet to be done. A step was taken in 1995 by the National Institute of Environmental Health Sciences which co-sponsored a conference entitled Experimental Approaches to Chemical Sensitivity. Once again, guidelines for MCS research were proposed; but unless these studies are funded, little progress can be made.

Barriers to Funding MCS Research

- *It's just hysteria.* As I am sure ORWH is aware, diseases that affect women are generally not taken as seriously as those that affect men. Consequently, it has been easy for many practitioners to dismiss women with MCS as hypochondriacs (Black, 1996), hyperventilators (Leznoff, 1997), or as having a panic disorder or depression (Black, 1996). The characterization of MCS as being a disease of neurotic housewives is also not uncommon. Recently, we have even been portrayed in the media as con artists swindling funds from the government (ABC News, “20/20,” 1-3-97). Sadly, serious interest in MCS may only come from research into Gulf War syndrome which predominantly affects men.

- *Chemical/pharmaceutical industry opposition.* The chemical industry has vowed to prevent the legitimization of MCS (Chemical Manufacturers Association, 1990). It is concerned about product liability, lawsuits, and diminished sales if MCS is conclusively proven to be caused and/or triggered by chemical exposures. Industry has organized a public relations campaign to promote the idea that chemicals are safe if used as directed and that MCS is not a “real” illness. This strategy parallels that of the tobacco industry which denied the hazards of tobacco use until very recently.

The chemical industry does extensive lobbying to block legislative efforts to help people with MCS and/or to study the illness. In the New Mexico legislature this year, lobbyists for the pesticide and fragrance industries testified against a bill that would have appropriated money to conduct a detailed prevalence and economic impact study of MCS in this state. The Greater Albuquerque Chamber of Commerce sent a "Chamber Alert" to all its members urging them to contact their legislators to defeat this and all other pro-MCS bills. It stated that "while there may be no obvious harm in simply studying the issue, the fact that MCS is gaining recognition in the Legislature could have major implications for the business community...special legislation for multiple chemical sensitivity sufferers could cost the state's businesses millions."

The chemical industry has two good reasons to promote MCS as a psychological illness. Many companies manufacture pesticides and other products, thought to cause MCS, as well as drugs used for treating psychological problems. Proof that MCS is caused by chemical exposures could hurt both markets.

Truthfully, however, business and industry would actually prefer that MCS not even be considered a psychological illness, because people with MCS would still be entitled to Social Security and Workers Compensation benefits as well as accommodations under the Americans with Disabilities Act. That is why they often use the terms "phenomenon" and "belief system" to describe MCS instead of calling it an illness. This implies that people with MCS are not really sick. Lest they appear too hardhearted, however, they also frequently add that "people with MCS are truly suffering and deserve the best in medical care." This is both insincere and inconsistent with their position that people with MCS are not ill.

- *Need for paradigm shifts.* According to what I was taught in medical school, chemical sensitivities like those found in MCS shouldn't exist. The chemical levels that cause symptoms in MCS are too low to be having a classical toxic effect and MCS cannot be explained by traditional allergic mechanisms. Clearly MCS does not fit into our current model or paradigm of disease. Therefore, it threatens the status quo.

Not long ago, an intrepid researcher had the nerve to propose that duodenal ulcers were caused by bacteria instead of stress. His theory was soundly rejected by the smug medical community that was sure that bacteria could not survive the acid environment of the stomach. Similarly, many doctors and scientists seem to have rejected the concept of chemical sensitivities because it simply conflicts with their assumption that 'it just can't happen.' It is now widely accepted that bacteria cause duodenal ulcers and it is our hope that the medical and scientific communities will open their minds to MCS as well. After all, MCS research could be viewed as an exciting new frontier that will surely further our knowledge of the human body, help us reduce morbidity and mortality, and expand our understanding of disease processes.

Thus far, however, the inquiry into MCS has not followed the normal course of science. Ordinarily, unanswered questions about an illness would stimulate research about it, but unanswered questions about MCS have ironically been used to suppress it. Our New Mexico prevalence study bill failed, at least in part, because some legislators bought the industry lobbyists' circular argument that 'we don't know enough about MCS to study it.' Similarly, a growing body of anecdotal observations should lead to the formulation and testing of hypotheses regarding those observations. But anecdotal information about MCS has been used as an excuse not to study it, some dismissing the whole subject with the comment "that's just anecdotal, it doesn't prove anything." In the normal course of science, anecdotal observations are considered an integral part of developing research — not dead ends.

The other paradigm that is challenged by MCS is the assumption that the chemical soup in which we live is safe. With the dramatic rise in the manufacture and use of synthetic chemicals, we have increased our exposure to them in our air, food, and water. Many of these chemicals have not been adequately tested for safety, and the cumulative and synergistic effects are not generally known. People with MCS are often referred to as the canaries in the coal mine, serving to warn others that our world has become dangerously polluted. But acknowledging the existence of MCS threatens almost all aspects of our current way of life. This, ultimately, may be the biggest barrier to the aggressive pursuit of research on MCS.

Goals of MCS Research

- *Validation.* Establishing that MCS is a bona fide illness will help reduce discrimination against people with MCS and help us obtain Social Security, Workers Compensation, disability, and medical insurance benefits. It will also help us obtain reasonable accommodations under the Americans with Disabilities Act and lay the groundwork for further studies.

- *Prevention.* Prevention is by far the best option for addressing the MCS problem since, at present, there is no cure. Determining the specific cause(s) of MCS will lead to more successful preventive programs. However, recommending the avoidance of chemicals and circumstances that are known to have previously led to MCS seems prudent, until further information is available.

- *Treatment.* More effective treatments are urgently needed. Hopefully, insights gained into the mechanisms of MCS will lead to the development of new treatments. But the development of effective treatments need not await the elucidation of the pathogenesis of MCS. Empirical treatments should also be researched.

- *Expand understanding of the effects of low-level chemicals.* Research on MCS will expand our knowledge of the hazards of low levels of chemicals. While genetic research abounds, chemical and environmental factors have been largely overlooked with respect to their effect on disease. Besides triggering symptoms in people with MCS, common chemical exposures may cause or worsen illnesses like allergies, asthma, breast cancer, multiple sclerosis, rheumatoid arthritis, atherosclerosis, and others. In fact, Dr. Claudia Miller postulates that chemical sensitivity should be considered a theory of disease (like the germ theory) as well as an illness, that describes a family of disorders that are caused or exacerbated by chemical exposures (Miller, 1997). In any case, it is highly likely that MCS research will advance the understanding of many diseases other than itself.

Conclusion

In summary, MCS is a big problem that is not going away. It is affecting more women every day, causing many to become jobless and homeless. People with MCS have suffered for decades while political and economic forces have delayed the comprehensive research on MCS that is so desperately needed. I, therefore, urge the Office of

Research on Women's Health to recognize MCS as the women's and human health crisis that it is, and to step forward to advocate for the research that will relieve the suffering of people with MCS and prevent the spread of this devastating illness.

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Martha A. Medrano, M.D., M.P.H.

Associate Director
Medical Hispanic Center of Excellence

We have had an opportunity to organize a Hispanic Faculty Association within our institution to identify and address issues of Hispanic Americans.

Hispanic women faculty in the early stages of their careers are heavily involved in clinical services but seldom have an opportunity to become involved in activities that will assist their tenure and promotion. Hispanic women faculty are sometimes written into grants that seek funds to research Hispanic communities but have limited influence in the project; or are written in but when the grant is funded, are not notified and therefore not involved in the project.

The solution to the above issue is the funding of postgraduate fellowship opportunities for women of color in academia. All grants targeting research in minority populations should have, at a minimum, one coinvestigator involved through the life of the grant that is representative of the population being studied.

These measures would ensure sound, culturally and gender-sensitive research design, methodology, implementation, and reporting of results. This would also ensure that female minority researchers have opportunities to be involved in research projects.

Holly J. Neckerman, Ph.D. *Navajo Division of Health*

It is my pleasure to talk with you today. I am here on behalf of Rosalyn Curtis, Director of the Navajo Division of Health, and Marla Jasperse, Director of the Office of Planning, Research, and Evaluation. The mission of the Division of Health is to develop and implement programs to enhance the mental, physical, and spiritual health and well being of the Navajo people. It is essential that the voice and concerns of Navajo women are heard today.

Before I begin, it is essential that you understand where and how many Navajo people live so you can fully appreciate the urgency of the health problems. The Navajo Nation covers over 25,000 square miles, with a population of approximately 168,000. If you drive through the Navajo Nation, you will quickly realize that it is quite a spectacular place. Yet, despite its beauty and splendor, there are many factors which place the Navajo people at increased risk for health problems and which create challenges for health care delivery. Many people are both physically and geographically isolated. While the rest of the United States is talking Internet access and the Information Super Highway, only about 25 percent of households have a working telephone, 25 percent of households do not have access to a car or truck, road conditions are poor, and public transportation is almost nonexistent. Many families lack modern facilities; 50 percent lack indoor plumbing. Education levels are low and unemployment rates are high. Depending upon the season, unemployment ranges from 35 to 50 percent. And the list goes on and on.

Women and children — they are the future of the Navajo Nation. They can not afford to walk silently any longer. Four health issues demand our attention because of the serious toll they are taking on Navajo Women, and indirectly, on children and families. I don't have time to give you a bunch of statistics, nor details on the etiology of the health problems. Instead, I want to focus on what is happening on the Navajo reservation.

The first health problem is gestational diabetes. We know that diabetes is a problem on the Navajo Nation, yet there has been little attention to the potential complications when you mix diabetes and pregnancy. A study conducted in Shiprock found that 3.4 percent of pregnant women had gestational diabetes. Many of these women will develop diabetes later in life. You should also know that only about 40 percent of women begin prenatal care in the first trimester, and followup throughout pregnancy is less than ideal.

What is being done? Currently, women with gestational diabetes receive top-notch clinical care and some education on diabetes and nutrition, yet little more. We are seeking funding to develop a coordinated, comprehensive, and multidisciplinary approach to patient education, monitoring, and treatment for women with gestational diabetes. If funded, this 5-year demonstration project will be implemented in the Chinle Service Unit, and later replicated throughout the reservation. We need your help.

The second problem is Chlamydia. Chlamydia is the most common STD among Navajo adolescents and young adults. While there has been a decrease in the number of syphilis and gonorrhea cases since 1975, the story is not so rosy when it comes to Chlamydia. The number of cases increased from 44 in 1986 to over 1,300 in 1996. Of these, 85 percent were female.

What is being done? Currently, doctors are doing their best to treat patients, yet we know that many cases go undetected and that noncompliance with medical treatment is high. The Navajo STD Program is doing its best to provide health education, counseling, and referrals for testing for the entire reservation. They are also responsible for the surveillance of all STDs, yet the program is still a paper-and-pencil operation. More resources are needed. We need your help.

The third health problem is breast and cervical cancer. While the prevalence and incidence rates may not necessarily be higher than other ethnic groups, the survival rate is much lower because of the advanced stage of the disease upon detection. The case fatality rate is much higher. Women aren't getting screened, and if they receive an abnormal test result, they are not going in for diagnostic tests and treatment.

What is being done? A year ago, the Navajo Breast and Cervical Cancer Early Detection Project got funded by the Centers for Disease Control and Prevention. Our goal is to increase breast and cervical cancer screening and followup services for older, low-income women. We have a problem, however. This project can only pay for a limited number of mammograms for this subpopulation. Since, the cost of mammograms is not automatically covered by IHS Contract Care dollars, this means that many low-income women will have to pay the bill. This is not the way to increase early detection among Navajo women. We need your help.

The fourth health problem is domestic violence. This is a new, yet devastating, problem for Navajo women. Unfortunately, we don't have very good data. We know that domestic violence is underreported in both police and hospital data. Police statistics are underestimates, in part because many women choose not to press charges once the police arrive. This is not unique to the Navajo Nation. However, recall that only about 25 percent of families have phones. In addition, there are too few police to cover such a large geographic area. So even if you have a phone to call for help, you might expect to wait hours, not minutes.

What is being done? The Division of Public Safety received a DOJ grant award to tackle the criminal enforcement aspect of the problem. Under this grant, a newly formed Advisory Council will develop training materials for police and protocol for how police should respond to domestic violence calls. At the community level, grant-funded programs are struggling to meet the immediate needs of the women by providing counseling and group sessions to victims and perpetrators. Some service units also provide shelter to battered woman and their children. Yet with only two women's shelters on the reservation, some have resorted to identifying a network of volunteer safe houses for use on an emergency basis only. The current level of services is insufficient to meet the growing problem. We need your help.

The Navajo Nation must develop comprehensive approaches for dealing with women's health issues. I'd like to suggest one recommendation for each health problem. Before I do this, I want to make two comments. First, we must realize that these health problems are not unrelated. And second, while the focus of this conference is women's health, we can not forget that women are also mothers, wives, daughters, and community members. This means that we can not discuss women's health without considering the implications for sons and daughters, husbands, mothers and fathers, and community members.

First, we need to develop a comprehensive approach to providing coordinated care for women with gestational diabetes — including both preconceptual and postpartum counseling and followup. This will require both an increase in funding and a change in attitudes about the delivery of health care and the role of prevention.

Second, we need to develop a comprehensive approach for the prevention and treatment of Chlamydia, with a special focus upon older adolescents and young adults. This age group tends to fall through the cracks when it comes to health education.

Third, we must explore options for funding mammograms for all women, not just older, low-income women. We need to increase our capacity to do mammograms and we need more bilingual personnel. Perhaps a Navajo Nation "mammovan" would be appropriate — taking much in the way of resources. However, we must be sure that we can meet the growing demand for preventive services.

And fourth, we must develop more comprehensive services for victims of domestic violence and their children. The available services must include shelters for women and children on the reservation, and specialized domestic violence counseling for women, children, and families. We can not afford to ignore the children or perpetrators, especially since most families are eventually reunited.

Yet, all our efforts will be futile if we do not increase the number of Navajo health and research professionals through some combination of scholarships, fellowships, training programs, and perhaps a Women's Health conference focused on American Indians on the Navajo Nation. I would suggest that having more Navajos trained in the health and research professions will not eliminate the need to collaborate with non-Indians in research and health-related activities. Instead, collaborations will be raised to a higher level. It is essential that we give Navajos and other American Indians a stronger voice and better tools to speak for their people.

I appreciate the opportunity to talk to you today. While the size of the population of Navajo Women does not compare to other ethnic groups, they have a very important voice that must be heard. Yet the area of women's health crosses ethnic, socioeconomic, and geographic boundaries. The collaboration of researchers from the Navajo Nation with researchers on the outside is the key to improving the health of Navajo women. Neither group can walk alone.

Electra D. Paskett, Ph.D.

Women's Health Center of Excellence
of Bowman Gray School of Medicine

Approximately one million persons in the United States are diagnosed, and over one-half million die of cancer each year. A disproportionately greater number of incident cases and deaths occur among the socioeconomically disadvantaged.

African Americans comprise about one-third of the poor and have the highest overall age-adjusted cancer incidence and mortality rates of any population group in the United States. Diseases of particular concern are breast, cervical, and colorectal cancer since screening exams, when used regularly, can reduce mortality.

Research conducted by investigators at the Women's Health Center of Excellence at the Bowman Gray School of Medicine have focused, for several years, on improving rates of screening exams among low-income, predominately African-American women. One of the most recently completed studies, the Forsyth County Cancer Screening Project, was an NCI-funded study to improve breast and cervical cancer screening among women who resided in low-income housing communities. The end-of-study survey collected information on knowledge, attitudes, and practices related to breast, cervical, and colorectal cancer. These data provide insight into differences in screening behaviors among African-American and white women who have a relatively similar low socioeconomic status.

A random sample of 424 women, stratified by city and age group (40 to 64; and 65 and older), from the housing communities was selected to participate in the end-of-study survey by simple random selection. Of the 300 women who participated in this cross-sectional survey, 79 percent (N = 237) were African-American and 21 percent (N = 63) were white. African-American women in the sample were younger (average age 66 years), compared to white women (average age 73 years) ($p<.001$).

In general, screening tests for breast, cervical, and colorectal cancer were underutilized by the women and racial differences in screening rates were observed. Only 52 percent of African-American women and 40 percent of white women had had a mammogram within recommended age-appropriate guidelines. About 60 percent had had a Clinical Breast Exam in the last year although about 80 percent had visited a physician in the last year for a regular checkup. Fewer white women had had a Pap smear in the last year, but African-American women had achieved the 80 percent goal set by the year 2000 objectives. Colorectal cancer screening test utilization rates were low among both groups of women. After adjustment for significant factors, important issues related to obtaining regular screening exams included the receipt of regular checkups and knowledge, beliefs, and barriers related to |the specific screening test, regardless of race. These data suggest that efforts to improve mortality rates from these cancers, among low-income women, should include tailored messages to improve beliefs and convey understanding of risk. These efforts will assist in bringing us closer to the Year 2000 goals for all women and help to reduce the disproportionate cancer mortality rates among low-income populations.

Sally Piscotty *National Association of Women's Health Professionals*

Gaps in Women's Health Research: Education and Alternative Health Care Practices

The National Association of Women's Health Professionals (NAWHP) is pleased to offer testimony to the Office of Research on Women's Health that will help identify gaps in women's health research. We are a professional membership organization of women's health administrators, health educators, and clinicians who reach more than 100,000 women each day through patient visits and educational programming. We have been successful in making the health care system more responsive to women over our 10 years of existence through advocacy, women's health education, and the creation of models of care that encourage women to seek preventive health care and become more informed consumers and collaborators with their health care practitioners. We promote and encourage gender-specific research that will improve health outcomes for women. We teach women, health care providers, and community leaders about meeting women's health care needs. Our members conduct market research and patient satisfaction studies in their communities to determine women's wants and needs. Given the background, expertise, and experience of our members, we welcome the opportunity to suggest new avenues of research that will improve health for all women regardless of their age, race, or socioeconomic status.

We are grateful that 7 years ago the National Institutes of Health placed women's health high on its research agenda and established the Office of Research on Women's Health (ORWH). The leadership of ORWH has helped ensure that women's health has remained a priority on our national agenda. We look forward to the results of the Women's Health Initiative that will provide us with scientifically valid information on the effects of diet, exercise, smoking, and hormones on cardiovascular disease, osteoporosis, and breast, colorectal, and lung cancers.

While this continued attention to women's health concerns is encouraging and vitally important, NAWHP has identified two important gaps in women's health research. The first is a lack of research documenting the effectiveness of gender-specific education methods in primary and secondary prevention.

Sandra Smith, editor of *Practice Development,* states that information and health education can enable a woman to avoid major risks, practice prudent self care, and seek timely medical interventions. Thus, information and education have direct and indirect effects on outcomes, quality, and costs. She further states education is like medication. It is effective when the appropriate content is given and accepted in the form, dose, and timing that is right for the patient/learner and her condition. Some medications, such as aspirin, are useful for large groups of people and can be made effective for additional groups with adjustments. So it is with health education. Still, education is now dispensed with no scientific basis and with little regard for its suitability or effectiveness for women. The potential effects and relative low cost of science-based, gender-based health information warrant research of the intensity and rigor applied to drug research. We recommend research that reviews the extent to which gender-specific health education changes behavior and improves health status.

The second area of insufficient research centers around the effectiveness of alternative and complementary health care practices. In addition to educating women about traditional care methods, we also need to educate them about alternatives. Complementary and alternative medicine has an enormous presence in the U.S. health care system. It is emerging as a significant area for scientific research and clinical care with medical, psychological, and sociocultural dimensions. Women use alternative medicine more frequently than men. Some health care professionals postulate that this may be due to the fact that women undergo more surgery and drug interventions with their accompanying risks, complications, and side effects and, therefore, seek natural, less-risky alternatives. We recommend a national survey on women's use of alternative medicine and scientific studies evaluating its effectiveness, benefits, risks, and costs. With this research, we can use effective education to inform women about *all* of their choices.

The Value of Education in Improving Health Outcomes for Women

It is a well known fact that significant reductions in death and disability are more likely to occur through risk reduction, adoption of healthy lifestyles, early disease detection, and preventive health services than through major therapeutic advances. The rapid and extensive changes in the health care system, and the growth of managed care organizations in the United States, provide us with new opportunities for prevention-oriented initiatives. Although the medical community and financing and delivery systems have increased interest in promoting health and preventing illness, counseling about health promotion and financing preventive interventions have lagged behind current scientific knowledge (Fontanerosa, 1994). Under today's productivity demands, busy clinicians cannot provide all the educational needs of their patients. One primary focus of a women's health center is to provide gender-specific education and support to encourage women to make healthy choices. Our body of knowledge about prevention is not gender specific. According to the Stone Center scholars at Wellesley College, women learn differently than men. Health promotion strategies should take this fact into account. Continued gender-specific research will be critical for the development of effective health education strategies that meet women's unique needs.

Case Studies on the Effectiveness of Health Education

Targeting education efforts to specific groups is effective. The Centers for Disease Control and Prevention (1995) cites examples of managed care organizations that have incorporated prevention practices for improved health of specific patient populations. One example was CIGNA HealthCare of Maricopa County, Arizona which improved vaccination rates of children under 24 months of age using five categories of interventions: the standardization of vaccination records, seminars for medical staffs working with children, use of incentive coupons, and *improved informational materials and programs directed at parents and care givers.* Critical to their success is that they directed their education efforts to a specific target group. As a result, their vaccination completion rate increased from 55 percent in 1992 to 73 percent in 1994.

We believe that similar outcomes can be achieved in women's health initiatives on a national scale through targeted education which incorporates values and learning strategies that work specifically for women. This premise needs to be subjected to scientific verification.

Members of the National Association of Women's Health Professionals have been effective in improving breast health screening rates and increasing the number of women diagnosed in Stage I breast cancer, decreasing preterm births, decreasing women's cardiovascular risks, and increasing the initiation and duration of breast feeding through their women's health programs of education, counseling, and support.

For example, a community project in Bend, Oregon (St. Charles Medical Center) has successfully demonstrated that education and community outreach has resulted in early diagnosis of breast cancer with a 75 percent Stage I diagnosis as compared to the state average of 51 percent and the national average of 49 percent. The benefits in terms of quality-of-life issues, for women and their families, and the cost savings are enormous. The cost of treating one early-stage breast cancer is approximately $12,000 while late-stage treatment is estimated at $145,000. A retrospective study of 1,459 women participating in a low-cost mammography screening program in a women's health center in the Capital Region of New York (Bellevue Woman's Hospital) had similar results. Using conservative cost estimates, this study demonstrated significant cost savings; more importantly, 100 percent of those with malignancies were diagnosed in Stage I.

Another example is a cardiovascular risk assessment, education, and treatment program for women in Albuquerque, New Mexico (St. Joseph's Women's Care) which has shown positive health outcomes including decreases in blood pressure, total cholesterol, LDL cholesterol, triglycerides, weight, and body mass index in a small followup study.

A Healthy Deliveries Incentive Program in Kansas City, Missouri (Health Midwest) provides a program of health assessment, education, and incentives to improve birth outcomes. They have experienced impressive results in decreasing both preterm births and employer costs for health care.

The scientific literature links specific health messages to birth outcomes. Kogan, et al. (1994) showed that having information on each of seven topics decreased the chance of having a low-birthweight infant for women of all races, ages, parity, education, and socioeconomic backgrounds. Sufficient research that will document these behavior changes and health improvements is important.

The Impact of Psychosocial Determinants on Health Behavior Change

The targeted use of educational, behavioral, and psychological interventions in a health care setting can dramatically improve health outcomes and reduce the need for more expensive medical treatments. These interventions require more than providing information to patients. Education through brochures, videos, classes, self-help groups, and/or individual counseling sessions needs to be accompanied by strategies that increase confidence, reduce isolation, and encourage patients to play an active role in their own health care (Sobel, 1995).

Much of the decision to seek medical care relates to an individual's perceptions, values, and attitudes including her knowledge of treatment options, attitudes of one's social support network, and confidence in the health care system, as well as other subjective factors. Demand-management strategists (Vickery and Lynch, 1995) find that individuals with access to self-care and self-help interventions have greater confidence in their ability to self manage and less perceived need for medical services; individuals able to exercise informed choice tend to choose less risky options, and these options tend to be less costly; and, individuals who choose healthy lifestyles tend to demand less medical care for preventable illness. Demand-management programs have achieved declines in utilization and costs as a result of education and the use of self-management support systems to enable and encourage consumers to make appropriate use of medical care. The key to success seems to be education and social support.

David Sobel, M.D., M.P.H. (1995), Kaiser's Regional Director of Patient Education and Health Promotion, relates important psychosocial factors to health in his article entitled, *Rethinking Medicine: Improving Health Outcomes With Cost-Effective Psychosocial Interventions:*

> *Thoughts, feelings, and moods can have a significant effect on the onset of some diseases, the course of many and the management of nearly all. Many visits to the doctor are occasioned by psychosocial distress. Even in those patients with organic medical disorders, functional health status is strongly influenced by mood, coping skills, and social support, yet the predominant approach in medicine is to treat people with physical and chemical treatments that neglect the mental, emotional, and behavioral dimensions of illness. This critical mismatch between the psychosocial health needs of people and the usual medical response leads to frustration, ineffectiveness, and wasted health care resources. There is emerging evidence that empowering patients and addressing their psychosocial needs can be healthy and cost effective. By helping patients manage not just their disease, but also common underlying needs for psychosocial support, coping skills, and sense of control, health outcomes can be significantly improved in a cost-effective manner. Rather than targeting specific diseases or behavioral risk factors, these psychosocial interventions may operate by influencing underlying, shared determinants of health such as attitudes, beliefs, and moods that predispose toward health in general.*

We agree with Sobel's recommendations that clinical interventions should be brought into better alignment with the emerging evidence on psychosocial determinants of health by providing services that address psychosocial needs and improve adaptation to illness. Since women's mental, emotional, and behavioral characteristics are different than men's, these variables should be considered in research studies.

A series of experiments conducted by Lorig and colleagues at the Stanford Arthritis Center (Sobel, 1995) demonstrated the link between improving health perceptions, attitudes, and beliefs through health care interventions that target the psychosocial adaptation to disease. An arthritis self-management course was designed to help patients with arthritis cope better with the pain, disability, fear, and depression often associated with arthritis. The program consisted of six weekly 2-hour sessions attended by patients and their families. They learned basic information about the pathophysiology and treatment of arthritis; strengthening and endurance exercises; relaxation techniques; joint protection; nutrition; and the interrelationship of stress, pain, and depression.

The results were impressive. Compared with a control group who had to wait 4 months before beginning the course, the participants demonstrated significantly greater knowledge, self management behavior, and less pain. In addition to increased knowledge, there was another variable that affected the outcomes. Those who improved had a positive outlook and felt an enhanced sense of control regarding their arthritis. The key difference seemed to be the person's perception of his or her own capacity to control or change arthritic symptoms. At a 4-year followup assessment, participants in the arthritis self-management program experienced a marked increase in self efficacy, a 19-percent reduction in pain, and a 43-percent decrease from baseline in physician visits. When it comes to health promotion, a confident attitude and sense of control gained through effective education may contribute as much or more to health as specific behaviors.

Another study (Fawzy, et al., 1993) provides strong evidence for the impact of psychoeducation on cancer survival. The study involved 68 patients with malignant melanoma who all had standard surgical treatment.

One-half were randomized to a control group; the other half underwent a structured psychiatric group intervention within several months of the original diagnosis and initial surgical treatment. Groups of seven to ten patients met in 90-minute sessions once a week for 6 weeks to focus on four components:

1) education about melanoma, sun protection, and healthy nutrition;

2) stress management, including personal stress awareness and relaxation techniques;

3) coping and problem-solving skills; and

4) psychological support from staff and other patients.

At 6 months, the group participants had improved coping ability, reduced psychological distress, and improved immune function. The most striking results appeared 6 years after the initial diagnosis and treatment. Only three of the 34 patients in the psychosocial groups died compared with ten of the 34 in the control group, a 60 percent reduction in the death rate. There are a number of possible explanations for these results, one of which is that group patients receive a great deal of social support. Those patients who used avoidance coping such as avoiding others, hiding feelings, or refusing to think about their illness tended to have more recurrence and lower survival rates.

Another study reported in the *Lancet* (1989) by Dr. David Spiegel, et al., showed that women with metastatic breast cancer who receive medical care as well as *psychosocial treatment,* including support group meetings and self hypnosis, live twice as long as patients who only receive medical care.

The Value of Group Education for Women

Fedele and Harrington (1990) describe the relational model of women's psychological development. They begin with the observation that women's sense of self is grounded in making and maintaining relationships with others. Participation in such relationships generates a greater sense of energy, knowledge of self and others, capacity to act, sense of self worth, and desire for further connection. This approach stresses ongoing, mutual empathic connection as central to psychological well being. Women seek such mutual relational connections as the primary and essential context for their psychological growth. In the absence of such a context, women's energy diminishes, self esteem suffers and they become increasingly disconnected from others. This relational approach used in group psychotherapy augments our understanding of the healing power of the group process. Single-sex groups allow women to focus on their unique experiences as women.

Several studies on education and preparation for childbirth programs document that increased knowledge, sense of control, and *social support* result in a decrease in preterm births, shorter labors, less use of pain medication, and increased satisfaction.

It seems that addressing the psychological and educational needs of women, from their perspective, makes sense and, therefore, its effectiveness needs to be verified. As Sobel (1995) points out, if there were a drug or surgical procedure that could reduce utilization of medical services and decrease morbidity and mortality, that intervention would be widely accepted and used with little hesitation.

Sobel attributes the effectiveness of these various group education methods to a core set of attitudes: optimism, self efficacy, sense of control, sense of connectedness, happiness, and others. These psychosocial determinants of health need further study in women's education and support groups.

In conclusion, we have anecdotal and other evidence which leads us to believe that information and health education are both medically beneficial and cost efficient. What we encourage NIH to do is to engage in research on the effects of gender-specific health education on health outcomes and cost. Such research will clarify the role of education in improving the health of all women.

Complementary and Alternative Medicine

A second area deserving of inquiry is complementary and alternative health practices. Sometimes we recognize the emergence of a trend only after it is well underway. In a study entitled, Unconventional Medicine In the United States, Eisenberg, et al., (1993), discovered that one in three persons in the U.S. adult population used unconventional therapy in 1990. The estimated number of visits made in 1990 to providers of unconventional therapy was greater than the number of visits to all primary care medical doctors nationwide, and the amount spent out of pocket on unconventional therapy was comparable to the amount spent out of pocket by Americans for all hospitalizations. Roughly one in four Americans, who see their medical doctors for a serious health problem, may be using unconventional therapy in addition to conventional medicine for that problem, and seven of ten such encounters take place without patients' telling their medical doctors that they use unconventional therapy. Furthermore, use is distributed widely across all sociodemographic groups.

Women are reported to use complementary and alternative medicine in greater numbers than do men. A study of complementary medicine in Germany (Himmel et al., 1994) found that more women than men (44 vs 32 percent) were treated with complementary medicine and more women than men preferred complementary medicine to conventional medicine (62 vs 52 percent). Our NAWHP members frequently receive requests from women for more information on alternative health methods. We have no scientific data to document the effectiveness of these alternative approaches relative to traditional medical care.

More and more, women are turning to complementary medicine to manage their menopausal symptoms. Despite the known benefits of hormone replacement therapy in prevention of heart disease and osteoporosis, only a third of menopausal women initiate it and 50 percent of those who do eventually stop the regimen because of headaches, return of menstrual bleeding, depression, and fear of cancer. They look for alternatives such as exercise, nutrition, massage, yoga, vitamins, herbs, homeopathy, acupuncture, and natural hormones. Our women's health educators and practitioners are offering some of these alternatives to women without sufficient documentation of their benefits or risks.

Another important area to study is the effect of phytoestrogens found in plants such as soy beans and yams. Researchers believe that the traditional soy diet in Japan may be responsible for the lack of menopausal symptoms in Japanese women. Blood levels of phytoestrogens are 10 to 40 times higher in Japanese women than in their Western counterparts (Wright, 1996). Researchers speculate that while these plant hormones act like estrogen, they may actually protect against breast cancer, since rates of breast cancer are dramatically lower in Japan than in the United States. Is it possible that these plant estrogens could pose the same risks as hormone replacement therapy? At this time, we do not know enough about any of these natural therapies to advise women on how or whether to use them.

In summary, there is a dearth of knowledge about complementary and alternative medicine in women's health. In spite of insufficient research results to guide women, these therapies are being widely used. Rigorous scientific evidence might help support the movement from a biomedical model of medicine into a more holistic biopsychosocial one. We believe women would benefit from an integrated model which combines traditional and conventional medical approaches. Once providers have science-based information on the effectiveness of alternative medicine, we can teach women about all of their choices.

Conclusion

Determining the effectiveness of women's health education in the primary care setting is a research priority. Armed with evidence that the majority of deaths among Americans below age 65 are preventable, the United States Preventive Services Task Force (1996) compiled a *Guide to Clinical Preventive Services* in the battle to prevent premature death and disability. This guide, resulting from the most comprehensive evaluation and synthesis of preventive interventions to date, offers an operational blueprint for clinicians. The authors note in their preface that the new morbidity of injuries, infections, and chronic diseases demands a new paradigm for prevention in primary care — one that includes counseling to change unhealthy behaviors related to diet, smoking, exercise, injuries, and sexually transmitted diseases, as well as giving immunizations and screening for cancer. While this compendium addresses several women's issues such as breast cancer, cervical cancer, and osteoporosis, it does not address other diseases that are common to men and women in a gender-specific way, nor does it suggest appropriate communication methods for prevention and compliance that will result in better health for women. This is most likely due to the lack of research in this area of women's health.

In conclusion, we encourage research studies which evaluate the outcomes of health promotion strategies and preventive interventions which incorporate psychosocial support and relational concepts, as well as their cost effectiveness. This research should consider several demographic variables, including ethnicity, race, age, and socioeconomic background. It should consider methods, content, timing, setting, teaching/learning strategies, and compliance issues with various groups of women. Some learning approaches may be better than others in reaching diverse, underserved populations (Clark and McLeroy, 1995).

Marin, et al., (1995) have conducted research with special population groups, groups of similar culture, gender, and age, and note that the cultures represented within these groups are quite diverse. They observed that interventions developed for general audiences of average Americans are probably much less effective than those that take into account the culture, social norms, and traditional practices of subgroups of the population. They make clear that we need more comparative research to demonstrate what we all suspect to be the case, that is, group-specific programs are more effective. We also need to understand why and how they are more effective.

Just as ORWH works to improve research into diseases affecting women and to ensure that women are appropriately represented in biomedical and biobehavioral research, the members of the National Association of Women's Health Professionals, at the local level, work to disseminate the results of scientific studies and to provide gender expertise in treatment and education to improve women's health and quality of life. In this era of cost containment, we need further research in the two areas suggested in this paper to scientifically verify the effectiveness of health education and alternative health care practices.

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Ladies and gentleman, it is indeed a pleasure to be able to briefly discuss with you my vision of the role of the pharmacy profession and its relationship to women's health issues. For centuries, the pharmacist has been a respected trustee of the public's health. The role of the pharmacist has changed from the earliest compounding of healing medicaments to the provision of more sophisticated care. Since 1990, the pharmacy profession has come to embrace the notion of pharmaceutical care. This paradigm shift espouses a new philosophy for the profession. The pharmacist has a shared and equal responsibility with the physician and other health care providers to guarantee suitable outcomes and quality-of-life indicators stemming from a person's drug therapy. Ongoing research efforts are underway to decide the clinical and economic benefits of pharmaceutical care to both patients and the overall health care system.

It must be appreciated that important gender differences exist which may affect the quality of health care received by women. Sex discrepancies are found between diagnostic and treatment decisions, drug prescribing patterns, susceptibility to poor health care, communication with health care providers, recruitment for clinical trials, and even drug action and metabolic fate.

I am happy to inform you that the pharmacy profession is beginning to recognize the unique health care needs of women. Both pharmaceutical care efforts and scientific inquiry are being directed toward solving gender-specific, drug-related problems. Curricula in colleges/schools of pharmacy reflect an increased awareness and sensitivity to women's health care issues. Professional associations and publications are devoting more educational programming and editorial space for women's health care topics. My own research has shown that many pharmacists are engaged in counseling women about their unique health care concerns and that women tend to be proactive in requesting advice from the pharmacist. Notably, women want the pharmacist to be an active participant in their health care education about prescription and non-prescription drugs (e.g., hormone replacement therapy, feminine hygiene products, contraceptives, vitamins).

Despite these positive efforts, I challenge the pharmacy profession to continually seek a better understanding of the role of gender and its overall influence on the provision of pharmaceutical care. At the national level, there still remains a need to more thoroughly understand the attitudes of pharmacists regarding women's health issues and to discover the kinds of pharmaceutical care services rendered to women. These and other "pharmacogender" research endeavors will better define the profession's future initiatives aimed at this largest segment of our population. Such initiatives could include focused, disease-state management strategies (e.g., diabetes mellitus), curricular revisions, outcomes development, and public policy framing. Collective involvement by pharmacists (the most accessible health care provider) in the women's health care arena could result in an improved health status for women and its attendant socioeconomic benefits.

Linda Ransom *Self*

My name is Linda Ransom, and my interest in women's health for the 21st century is making sure my 10-year-old daughter reaches the 21st century with a chance to develop into the woman she should become. She needs a shunt made of silicone to control hydrocephalus. The current litigious climate has threatened the availability of medical devices, including her shunt.

First, let me give you some background on Tara, my concerns, and what it means to women's health in general.

Background

Tara was born 9-weeks prematurely. She weighed 3 pounds, 9 ounces at birth, breathed on her own and had no apparent problems. Within hours she was upgraded to a "feed her/grow her" and moved to the annex in the NICU. On her fourth day, she began vomiting every feeding. A spinal tap the next day revealed an intraventricular hemorrhage. In spite of efforts to drain off the blood clots in her brain, a month later a medical device called a "shunt" was implanted to control the hydrocephalus which she acquired. She has had a total of five surgeries to date. Her last was 6 1/2 years ago, and it was predicted that she would need another one before the age of 10. She is 10 today, but fortunately the shunt is currently functioning normally and there is still some length for growth.

Hydrocephalus (sometimes called "water on the brain") is an abnormal accumulation of the cerebrospinal fluid within the brain. The current medical intervention for most forms of hydrocephalus, including for my daughter Tara, is the implantation of a shunt. Cerebrospinal fluid is produced constantly within the brain to cushion it and keep it pliable. Normally, the excess fluid drains down the spinal column and is reabsorbed by the body. In Tara's case, bleeding created scar tissue which blocked the flow of the fluid, much like a clogged drain. A shunt is a flexible silicone tube with a pressure regulating pump which bypasses the blockage and allows the fluid to drain. One end is implanted in the ventricles of her brain, the pump is just under her scalp, and the tube is threaded through the tissue of her neck and chest wall into an incision in her abdomen and the peritoneal cavity where the fluid is absorbed. The surgery requires two incisions. An infection caused meningitis when Tara was 11 weeks old and left her temporarily blinded. The shunt is totally contained within her body. The only way to make any correction or adjustment is with surgery. Some patient's shunts are outgrown, some disconnect, some have tissue invade the ends like tree roots growing into sewer pipes, and some need to be replaced to adjust the pressure. It can be just as damaging to the brain to have too much fluid drain off as too little.

There are some very specific forms of hydrocephalus which have been successfully controlled by a surgical procedure called Third Ventriculoscopy. In this procedure, passages within the brain are opened by placing a hole with a laser in the bottom of the third ventricle to allow the flow of fluid between the third and fourth ventricles of the brain. However, very few shunted individuals are candidates for this invasive procedure making the shunt the only option for most people with hydrocephalus, including Tara. A future without a shunt is a long way off for most people with hydrocephalus.

Today, Tara has just finished 4th grade in the Magnet Traditional School. She took the Stanford Achievement Test in March, 1997 and scored "Post High School" on the battery and subtests. She has always scored high on standardized tests and has won numerous school academic awards including Honor Roll every quarter that she has been in school. She sings in the Church choir, has been a Brownie, and finished the summer reading program at the library in about 10 days. She participated as the representative of Phoenix City Council District 7 at the Pee Wee Kids' Shoot-out when the Super Bowl was held in Phoenix 2 years ago. She was a first place winner in the National Geographic/Pizza Hut Kids' Hall of Fame. Tara has testified before a joint House subcommittee in Washington, D.C. and has spoken at two Congressional press conferences in Washington.

These achievements, by any child, are a source of pride for a parent. Coming from a child for whom the present is medically difficult, and whose future without a shunt will be retardation, blindness, and death, is pretty remarkable. She deserves the opportunity to grow up and become a contributing woman of the 21st century. If given that chance to grow up she may be the first woman president or whatever else she wants to do. And Tara is not the only child who deserves these opportunities. There are many shunted young girls just like her.

Concerns

Obviously my concern is to make sure that Tara gets the medical care she needs to grow. This involves both access to the latest treatments (in her case the latest shunt technology or some future intervention which is today not even a research idea) and the ability to pay for that care. The monetary issues are essentially the same as are probably being discussed elsewhere in the conferences; but, I just want to say that when you have a condition such as hydrocephalus, continuing medical care (especially since today's medical option is neurosurgery and expensive imaging techniques), can be financially devastating to families. Many are dropped from insurance and thereafter labeled "uninsurable." The financial responsibility for parenting a child with a disability or being handicapped yourself falls hardest on women.

I might add too, that our 12-year-old daughter Lindsey is healthy today, but I have the same concerns for her. I feel more vulnerable when faced with serious issues with one child, and I appreciate having resources to deal with unforeseen events. We all deserve that level of comfort. There are times when stress takes a big toll on me.

Effect on Women's Health

Unfortunately, even with today's technology and neurosurgical techniques, the very shunt which keeps Tara alive, and more specifically the silicone from which the shunt is made, may be lost to litigation and politics.

To date, 14 major suppliers of materials used in medical devices have terminated or severely limited the amount of raw materials available to the implant manufacturers. Suppliers have been repeatedly targeted for litigation. Even if they win all the cases against them, the companies lose millions to legal fees spent defending themselves.

In the case of the silicone needed for Tara's shunt, Dow Corning (forced into bankruptcy) is the producer of the specialized silastic. At this point in medical science, silicone is the best material, being the most biocompatible, and having the strength, flexibility, and elasticity necessary to meet the needs of an implanted shunt.

Tara's shunt is silicone. Established science indicates that silicone is one of the safest materials available for implants. I realize that the "perfect" material has not been produced yet, but I believe that silicone is the safest material available in 1997. If anecdotal accounts are credible, I can show you my daughter with silicone in her brain for 10 years and other women who have had hydrocephalus shunts for over 30 years. These women lead normal lives, have college educations, careers, marriages, and children.

Equally dangerous to Tara's future is the effect of the litigious atmosphere on research, especially into new biomaterials and devices. Time and research money are now being diverted to finding replacement materials rather than to expanding medical knowledge. We are reinventing the wheel. The market study, *Biomaterials Supply for Permanent Medical Implants* by Aronoff Associates predicts the following:

> **LONG-TERM SCENARIOS (3 TO 10 YEARS)**
>
> *"It appears almost certain that some well established, reliable products, which have been the products of choice for surgical procedures, will disappear entirely as stocks of them are depleted. This will be a consequence of the unavailability of the materials from which they are made."*
>
> **LONG-TERM IMPACT (3 TO 10 YEARS)**
>
> *"If the present situation continues, all companies will face an era of supply instability and discomfort with supply patterns. New suppliers may emerge for some commodity materials such as PET yarn, for which there are about 150 producers worldwide. However, there may be no new suppliers for other materials such as polyacetal, for which there are probably fewer than a dozen independent producers."*
>
> *"Under any circumstances, including indemnification agreements, new and old suppliers with United States interests will want to be in a position to back out if they consider the risk of liability, and the consequences thereof, too uncomfortable to live with. The results will be the perpetual seeking of replacement suppliers for essential materials and a continuing need to requalify new supplier materials for the FDA. Where old materials are no longer available, substitutes to fill their functions will have to be found and qualified."*
>
> *"With continuation of the present circumstances, offshore raw material suppliers, with insignificant United States assets and few United States employees, will be the best source of raw materials as judgments decreed against them by United States courts may be totally unenforceable in practice, and to sue them in their home countries may be equally impractical, hence, raw material supply, where possible, may move offshore."*

Phyllis Greenberger, Executive Director of the Society for the Advancement of Women's Health Research, made the following statement on January 31, 1995.

> *"The availability of biomaterials is extremely critical to the health of American women so that necessary medical devices continue to be available and new products are developed."*
>
> *"Women may be disproportionately impacted by a biomaterial shortage simply because they live longer than men, and as a result, suffer more from chronic disease, increasing their chances of needing a medical device. Secondly,*

> *the history of women's health products, coupled with the unpredictable character of liability, have made companies shy away from committing to researching and developing new products for women. If the raw materials for existing products continue to become unavailable, it becomes more and more likely that women will be left without crucial life-saving and life-enhancing medical devices."*
>
> *"Consider what biomaterials we have already lost: Polyethylene, the bearing surface of hip and joint replacements; teflon for heart components; silicone for contraceptives, breast implants, incontinence treatments, and orthopedics. The list goes on. And, unfortunately, many of these materials do not have suitable replacements. For those of us in good health, the loss of these substances seems inconsequential. Yet for those suffering from osteoporosis, heart disease, rheumatoid arthritis, and other diseases, access to a full range of medical devices is crucial."*

There is a paper presented by Anita Hotchkiss, Esq. (Porzio, Bromberg, and Newman) to the Corporate Advisory Council Meeting for the Society for the Advancement of Women's Health Research in 1995. She told about the futuristic life and times of Sally Smith, "a typical American woman." It is so relevant and told so well that I have included it here in its entirety as it was printed.

> *"Sally Smith was born in New Jersey in 1995, she had a comfortable childhood in a New Jersey suburb and, in the year 2007, she entered puberty and began to menstruate. From then until she was 18, Sally had to restrict her teenage activities somewhat because the tampons that her mother told her about, which used to make life easier for women, were no longer available. Tampons were taken off the market in 1998 because of a new wave of lawsuits claiming that they caused not only toxic shock syndrome but also chronic fatigue syndrome and multiple chemical sensitivities."*
>
> *"Like the majority of American teenagers, Sally became sexually active when she was about 16. She got pregnant in 2014 when she was only 18. Sally had been fitted for a diaphragm, but she forgot to wear it on one of her dates and her boyfriend forgot to use, or refused to use a condom. Her mother told her that there used to be pills, implants, injections, and other hormonal contraceptives which could reliably, safely, and easily prevent conception over periods of months and years, but U.S. companies stopped making them in 1999 as a result of dozens of class action lawsuits filed against them. Sally's mother told her that the implants (*Norplant*) — cartridges placed under the skin which released contraceptives for several years — had been one of the few new contraceptives released in the United States since 1960. In the lawsuits, people claimed that the cartridges caused connective tissue disease, autoimmune diseases, and a whole array of other side effects. Even though there was no scientific basis for the vast majority of the claims, it finally became just too expensive for the implant manufacturer to keep fighting, so it gave up and took the product off the market."*
>
> *"Sally knew that there were a lot of other hormonal contraceptives used in dozens of other countries, but they were only available in the United States on a contraceptive black market. Sally's mother also told her about a so-called "morning-after" pill — RU486 — which almost got released in the United States in the mid 1990s; but the pharmaceutical manufacturers did not want to risk either the bad publicity generated by anti-abortion groups, or the inevitable lawsuits which would accompany its release. Private groups which tried to underwrite testing of the drug simply didn't have the financial wherewithal to carry it all the way to market."*

"Injectable contraceptives, which could protect against pregnancy for several months, came onto the market briefly in the mid 1990s, but were driven off again by lawsuits claiming that they caused osteoporosis."

"Sally had big plans for her future — she had hoped to go to college and have a career as a dancer — and a baby didn't fit in with those plans. But, since abortion had been ruled illegal in the year 2000, she and her boyfriend decided to go ahead and have the baby."

"Unfortunately, Sally couldn't even finish the school year while she was pregnant because she had such severe morning sickness that she could barely get out of bed each day. Once again her mother told her that there used to be a drug (Bendectin) which women took for the problem, but the only company that made it had pulled it off the market in 1983, after over 2,000 lawsuits were filed claiming that it caused birth defects. Even though every valid scientific study which had been done showed that there was no evidence that the drug caused birth defects, and even though the company won almost every lawsuit filed on the basis of that scientific evidence, it simply couldn't afford to keep making the product and defending it in court."

"Sally was lucky. Her baby was born healthy. Unfortunately, the baby died in a whooping cough epidemic when he was barely a year old. Her best friend's baby died the same year of polio. Sally's mother told her that thousands and thousands of children had died in the early 1900s from whooping cough, and polio as well, but that for almost 50 years from the 1930s and 40s to the 1980s, routine vaccination virtually wiped out those diseases. Then, in the 1980s, hundreds of lawsuits were filed against the vaccine manufacturers, claiming, without any valid scientific evidence, that pertussis vaccine caused seizures and brain damage. Most of the vaccine makers gave up and took their pertussis and polio vaccines off the market."

"The few remaining manufacturers told the government that they wouldn't run the risk of lawsuits either, so in the late 1980s, the government set up a fund to compensate any child who had a seizure within three days of receiving a vaccine, or who developed polio."

"Unfortunately, in the year 2000, the funding ran out for that program, and the court began allowing lawsuits directly against the vaccine manufacturers, in spite of the intent of the Vaccine Compensation Act. The new wave of lawsuits claimed that the vaccine caused AIDS and immune disorders. What the plaintiffs lawyers like to call "chemical AIDS." By that time, the percentage of children vaccinated was very low anyway because of the fact that the widespread press coverage about the lawsuits alleging death and brain damage had frightened many parents into not having their children vaccinated against these killer diseases. Finally, the vaccine makers gave up."

"Since the year 2000, no company had been willing to risk manufacturing either polio virus or pertussis vaccine. So Sally went on with her life. Unfortunately, she was never able to conceive another child. Once again, her mother told her that there used to be drugs which were available to help women conceive. One of them was called Clomid; but they too, were taken off the market in the year 2005. A wave of lawsuits in the late 1990s claimed that, although these drugs helped women have the babies they couldn't have otherwise, they caused birth defects, cancer, and chronic fatigue syndrome. Companies couldn't get insurance anymore to cover the risks, and the profit they made on that small market for these drugs simply didn't make it worth their while to continue manufacturing them. So they stopped."

> *"Sally Smith got breast cancer in 2045 when she was just 50. She had one breast removed and, although she didn't die from the disease, she never quite got over the change that it made in her appearance. People told her that had she lived in the early 1990s, she could have had a breast implant which would have restored her breast anatomy to normal size and feel, but manufacturers stopped making implants in the late 1990s after an onslaught of lawsuits. The lawsuits claimed that breast implants caused chronic fatigue, autoimmune disease, headaches, insomnia, rashes, cancer, flu-like symptoms, and a whole host of other vague illnesses. It really didn't make any difference that, during that same era, lawsuits were being filed claiming that these same diseases and symptoms were caused by carpeting, kitchen cabinets, insulation, magic markers, carbonless copy paper, pesticides, Xerox machines, and "sick" buildings. And it really didn't make any difference after the lawsuits were filed that several independent scientific studies were done which showed no association between breast implants and any of these problems. Press reports of the claims in the suits made people fearful, and so much political pressure was generated, that it was simply too expensive for manufacturers to fight; so breast implants went off the market entirely."*
>
> *"Sally Smith finally died at age 70 from complications resulting from a fractured hip. After menopause, she was one of the millions of postmenopausal women who suffer from osteoporosis, a condition in which the bones lose mass and strength. It was estimated in 1994 that over 19 million women had osteoporosis and that over a million and a half fractures result from it every year, causing over 25 percent of all nursing home admissions. Once again it seemed that Sally had been born too late. In the final years of the 20th century there had been hormonal replacement which helped prevent osteoporosis for postmenopausal women. Unfortunately for Sally, the manufacturers stopped after a rash of lawsuits claimed, without any scientific basis, that the drugs caused blood clots, strokes, and multiple sclerosis. Sally had a lovely funeral."*

Ms. Hotchkiss concluded, "You're probably listening to this with a grain of salt and thinking that it really can't get that bad. Every one of these products that I spoke about has been the target of dozens, if not thousands, of lawsuits."

What if the story were different?

> *Also born in 1995, but into a totally different world, Betty Brown was a generally healthy child. However, she did have persistent ear infections, so her doctor put tubes in her ears to help control the problem. As a teenager, Betty liked changing the color of her eyes with contact lenses to match her clothes. When she hurt her knee playing soccer in college, it was repaired surgically with the help of two screws.*
>
> *When she became sexually active, Betty tried the pill, but found she didn't like it. She changed to an implant after trying several options. Now she is married and her two children were planned to allow her to have both her career and family. Unfortunately, her daughter was born in 2025 with a hole in her heart, but it was quickly repaired with a patch. It had been diagnosed when Sarah was still in utero, so everything was ready as soon as she was delivered. In 2050, Sarah made Betty a grandmother. When her son Kevin burned his hands badly on a campout, the area was covered with Integra to allow healing without some of previous complications a severe burn caused. Today Kevin is a surgeon. Her husband Frank needed a pacemaker in 2055, and Betty needed cataract lenses in 2060.*
>
> *Betty and her family were able to make choices and have medical options which allowed them to live long happy lives.*

As Ms. Hotchkiss concluded, “In my view, reduced choices translate into reduced chances for women — the chance to be whatever you want to be, the chance to go to the school you want to, to get the job you want, to compete economically. When a woman can’t make fertility choices because there is a limited choice of contraceptives available, her other choices disappear as well. Without the freedom to make choices, women’s social and economic freedom is going to be limited. I don’t believe that that’s in the long-term interest of women.”

Even Betty Brown is affected by what has already happened. Betty can buy a DACRON dress, but not a DACRON heart valve, DACRON sutures, or artificial ligaments made of DACRON. She can buy a frying pan coated with TEFLON, but she cannot get heart valves and vascular grafts made from TEFLON. She can buy the DuPont products which make life more enjoyable, but the same materials are no longer available to save lives. Katherine F. Knox, Business Program Manager, DuPont Company, testified before the Senate Committee on Governmental Affairs on May 20, 1994. She said, “We at DuPont are saddened by the need to withhold our materials from use in permanent medical implants. It was not a decision we arrived at lightly….Unfortunately, the realities of the American litigation system no longer allow companies such as DuPont to supply small amounts of highly valued materials for use in implants without risking involvement in large-scale implant litigation.”

In a letter dated October 27, 1994, Ms. Knox said DuPont was aware of attempts to pass biomaterials legislation. She said, “If such legislation is passed, some companies may indeed be willing to again supply materials for use in implantable medical devices, and we hope that will be the case. However, for many reasons, it is not likely that DuPont will do so.”

Final Thoughts

Personally, I have to wonder why so many of the products targeted by the lawyers are women’s products. Are they inherently more dangerous, or are they just more convenient? After all, losing a product designed for women will not affect the men involved in taking the products to court. If, in fact, they are more dangerous, then why are they allowed by the FDA to reach the market in such large numbers in the first place? Are products intended for use primarily by women approved with lesser standards than those intended for men? These questions may be rhetorical, but they need to be addressed in any discussion of the research, development, and availability of medical products, especially devices, designed for women.

Unless the focus of women’s medicine becomes more active in protecting products designed for women, we will find ourselves with few options. We cannot allow choices to be taken away because they are not perfect for everyone. On that basis, we would not have penicillin or aspirin available today either. There is no medication or treatment which will work perfectly for everyone in every situation. Women need to be thoroughly educated and completely informed about possible side effects and complications. Many of the women filing lawsuits today claim they were never “informed.”

Women’s medicine cannot allow today’s products to be judged with tomorrow’s science. If continuing scientific study, at some future date, indicates some unforeseen problem, then information and options should be provided at that time; but this should not be taken as legal proof that something was known to be dangerous initially.

You will be making decisions about the direction medicine will take in the next few years. In the case of the breast implants, the FDA panel headed by Dr. Elizabeth Connell, Emory University, specifically recommended that breast implants not be removed from the market, but that they be further studied. However, Dr. David Kessler of the FDA issued a ban, and that started the domino chain reaction which endangers my daughter today. Had more voices spoken against the ban, it may never have happened. If more voices will speak up for the need for legislation to protect the availability of devices and products women use, the current crisis might be avoided.

Women's medicine must become more proactive rather than reactive.

The world of Sally Smith is not the future I want for my daughters, Tara and Lindsey, or for any of our daughters. It is not a step forward, but rather a fall backwards. And I really fear for Tara's life in such a world. What will happen to the hydrocephalus shunts which give her life and keep her from the increasing pressure within her brain and the painful death which she'll experience when she is no longer able to get a shunt? Thank you.

Joan Y. Reede, M.D., M.P.H., M.S. *Harvard Medical School*

Breaking Through the Glass Ceilings: Increasing the Representation of Minority Physicians and Scientists in Medicine, Research, and Policy

As assistant dean for Faculty Development and Diversity at Harvard Medical School, I wish to share with you the history of this department and how we have addressed the issue of minority underrepresentation in the biomedical sciences. The Office for Faculty Development and Diversity was established in 1995 to provide leadership, guidance, and support for academic and professional career development; and promote increased recruitment, retention, and advancement of underrepresented minorities and women.

Historically, African Americans, Mexican Americans, Puerto Ricans and Native Americans have been chronically underrepresented in the biomedical sciences. The rise in minority medical student enrollment in the late 1970s should have resulted in a concomitant increase in the representation of minority physicians, scientists, faculty, and leaders in the 1980s and 1990s. Between 1971 and 1994, there was an increase in the number of minority medical faculty from 1,001 to 2,813 — an increase from 3.4 to 3.9 percent when compared to total faculty. The Association of American Medical Colleges attributes part of this growth to the accreditation of three predominantly minority medical schools: Universidad Central del Caribe School of Medicine, Morehouse School of Medicine, and Ponce School of Medicine In fact, six of the 125 medical schools in the United States — Caribe, Howard University School of Medicine, Meharry Medical College School of Medicine, Morehouse, Ponce, and the University of Puerto Rico School of Medicine — account for approximately 27 percent of all underrepresented minority faculty. In essence, little progress has been made.

If underrepresented minority students are to become future leaders in our academic medical centers research institutions, industry, and government, they must be informed of educational, training, and employment opportunities and must be encouraged to pursue positions where they can become change agents.

Harvard Medical School (HMS) has created a system of programs designed to address minority faculty underrepresentation. In May 1990, the Minority Faculty Development Program (MFDP) was established. This program became part of the Office for Faculty Development and Diversity in 1995. The four goals of MFDP were to: (1) increase the number of medical school minority faculty; (2) increase the number of minority professionals who enter graduate medical education programs at HMS-affiliated hospitals; (3) establish program models for the development of minority faculty with an emphasis on mentoring; and (4) develop outreach programs at the pre-college and college levels.

Reviewing national, regional, and local efforts to increase minority participation and advancement in the sciences revealed three recurring obstacles to achieving these goals. First, there has been poor communication of information pertaining to prerequisites for entry and advancement; poor communication on available supports such as targeted programs, scholarships, research supplements, and fellowships; and insufficient understanding on how to get through the bureaucracy. The second obstacle has been the ongoing lack of continuity in advancing students, trainees, and professionals from one stage to another along the career pipeline. Succinctly stated, in the development and implementation of programs, “the right hand often does not know what the left hand is doing.” Third, there is an absence of evaluative data on the effectiveness of strategies and outcomes achieved.

Having determined these obstacles, programs were designed that furnished information about training opportunities and funding resources; provided students exposure to academic health centers, research experiences, and faculty role models; improved the preparedness of students, residents, and junior faculty to make informed career decisions; promoted the development of mentoring relationships; and supported the building of student and professional networks that cross disciplines, departments, and institutions. A brief description of several programs follows.

Precollege

At the precollege level, MFDP has implemented programs that include the development of science curricula used in middle and secondary classrooms — through the Teacher Institute and the training of science teachers in both laboratory techniques and the use of the case study method — and through *Project Success* — hands-on, mentored research experiences for high school students.

College

Students completing the precollege program can continue in *Project Success* while in college. They can also be linked to research programs at HMS-affiliated hospitals, in private industry, and at other academic and research institutions. In addition, MFDP sponsors a health policy summer research program for college students who attend Minority Access to Research (MARC)-funded historically black colleges and Hispanic serving institutions.

Medical Student

Through the Visiting Clerkship Program (VCP), another MFDP project, more than 250 underrepresented minority students from U.S. medical schools have participated in the HMS Exchange Clerkship Program. Along with financial support, this program informs students about residency and fellowship training opportunities and provides career guidance from senior faculty. VCP's success is measured not merely by the number of student participants who become HMS residents, but by whether students become better informed about existing academic training opportunities and the impact their current choices will have on future career options.

Biomedical Science Careers Project

In conjunction with the Massachusetts Medical Society and the New England Board of Higher Education, MFDP founded the Biomedical Science Careers Project (BSCP). BSCP is a not-for-profit organization that provides New England minority trainees, junior faculty, and students (from high school through graduate school) with mentors, career guidance, and comprehensive information on programs and opportunities. BSCP is supported by a collaborative of area professional societies, teaching hospitals, biotechnology companies, community and 4-year colleges, universities, high schools, and private industry.

Since its inception, this organization has initiated several activities including publication of the *New England Resource Directory of Science Programs*, and production of a newsletter, *In Touch with BSCP*, that is distributed to more than 2,500 students, teachers, guidance counselors, administrators, and community organizations. The organization also sponsors regional conferences that have brought together more than 1,500 minority students and professionals with senior advisors and mentors.

Fellowships

During the implementation of the above programs, major changes continue to occur within the areas of academic medicine, health care, public health, and health policy. These changes include: movement toward increased enrollment in managed care, increasing emphasis on quality and outcomes, persistent disparity in health status among various ethnic and racial populations, shifting support for graduate medical education, and increased competition for research dollars.

In this changing environment as policies are developed, priorities are set, and funding is allocated, it is imperative that minority physicians and scientists be included in the decisionmaking process. Failure to include minority individuals, as leaders with recognized expertise and the power to make decisions, will result in solutions that are exclusionary, shortsighted, and continue to be less than effective.

Recognizing the need to proactively prepare physicians to assume leadership roles in this era of change, MFDP, through a collaboration between Harvard Medical School, Harvard School of Public Health, and the Kennedy School of Government, has established the Commonwealth Fund/Harvard University Fellowship in Minority Health Policy. This is a 1-year, full-time, academic, degree-granting program designed to create physician leaders, particularly minority physician leaders, who will pursue careers in health policy, public health practice, and academia. A total of 25 fellowships will be awarded over a 5-year period.

The fellowship has five primary objectives:

1. to enhance the leadership skills of physicians, preparing them to identify, analyze, quantify, and develop solutions to public health problems; and offering them substantive knowledge in health policy, financial and organizational management, communication, politics, economics, and ethics; while creating a network of physician leaders capable of successfully advancing among the public, nonprofit, and academic sectors;
2. to provide rigorous academic training, including both academic work leading to a master's-level degree in public health and advanced leadership training beyond it;
3. to develop physician-leaders who will, over time, improve the capacity of the health care system to address the health needs of minority and disadvantaged populations;
4. to enhance the health leadership training offerings at Harvard institutions; and
5. to remedy the underrepresentation of minority physician-leaders who are well-trained academically and professionally in clinical medicine, public health, health policy, and health management and who are prepared to pursue careers that bridge the academic and public service arenas.

To accomplish these objectives, the fellowship's enhanced curriculum incorporates academic work leading to a master's in public health, leadership forums, a seminar series, site visits, attendance at national meetings, introductions to key leaders in both the public and private sectors, mentoring, career guidance, and networking with other minority professionals.

Over the past 7 years, the Harvard Medical School Office for Faculty Development and Diversity and the Minority Faculty Development Program have made substantial strides in trying to increase the numbers of minority students pursuing biomedical careers, residents in academic training programs, and physicians preparing for leadership roles. In addition, individual counseling and career development programs have been provided for fellows and junior faculty. Next steps include increasing the availability of mentors and addressing issues of promotion and retention.

While the results of these program efforts are not all in, it is clear that the issues of minority underrepresentation in the biomedical sciences are ones that require creativity and collaboration in program planning and implementation, better evaluation, and a long-term commitment.

Karen Renick

Board Member
DES Action USA

The Health Legacy for Women of the DES-exposed Population

Good afternoon. My name is Karen Renick and I represent DES Action USA, a national consumer advocacy organization for the approximately 10 million Americans exposed to the synthetic estrogen, diethylstilbestrol, better known as DES. I am very pleased to be here today on behalf of DES Action USA and I welcome the opportunity to present this testimony before a gathering of people who are deeply committed to the important common goal of improving the health of all women through better research.

Unlike many of you, I am not a clinician, an academic, or a research scientist. I am here because I have been profoundly affected by a pharmaceutical “magic bullet” that went terribly awry. And hence, because of this life-altering experience, I stand before you today as a women’s health advocate.

In writing this testimony, I realized that nearly 10 years have gone by since I first learned that I am DES exposed. And yet, I can still recall most vividly the feelings of disbelief, fear, sadness, and isolation that overcame me following my first enlightening conversation with the specialist to whom I had been referred. I was 36 years old at the time and I had *never* heard of the drug DES. For nearly 20 years prior to this experience, I had been going regularly to reputable gynecologists and not one of them had detected the telltale signs of my DES exposure, much less even discussed the *possibility* of my exposure to the drug. It was the wonderful midwife to whom I had turned for my health care in excited anticipation of becoming pregnant who detected my probable exposure on my first visit to her office. Mine is not the story of someone living in a small, rural town. I was living in New York City.

What I would gradually piece together over time was the forgotten happenstance that my mother had been prescribed the drug diethylstilbestrol (DES), while pregnant with me in 1951, because she had suffered a miscarriage in her previous pregnancy. Her doctor was simply doing what most of his peers had been doing for years and would continue to do for twenty more: prescribing an FDA-approved drug that was persuasively and aggressively advertised by the pharmaceutical industry for use with pregnant women to not only, as advertisements claimed, “prevent abortion, miscarriage, and premature labor,” but to also help them have “bigger and stronger babies.”

My mother, like pregnant women everywhere, wanted nothing more than to bring a healthy baby into the world. She trusted the assurances that the drug was safe and effective. DES was neither. My mother had no way of knowing that the drug she was taking was actually harming the same child she sought to protect.

Sadly, she had no way of knowing what researchers had already discovered in 1940 with laboratory animals: that DES, when given to pregnant rats, caused reproductive tract abnormalities in both the female and male offspring. She also had no way of knowing that by that same year there were over 40 published articles in the United States and European medical journals documenting carcinogenic effects in animals from natural estrogens and synthetic estrogens, including DES.

But the pharmaceutical industry, applying to the FDA in 1941 for approval of DES, *did* know and chose to exclude the animal studies while only emphasizing positive anecdotal clinical reports in its application to the agency. As the legal scholar and author Lucinda Finley wrote in her treatise of 1996, *The Pharmaceutical Industry and Women's Health,*

> *The exclusive focus of the pharmaceutical industry on what DES might do* for *women, instead of also considering what it might do* to *women, demonstrates greater concern for controlling the female reproductive system for profit than for the ultimate health and safety of women.*

Because of my exposure in utero to DES, my reproductive system is so severely deformed that I am unable to bear a child of my own. Like the DES mothers before me who would give anything for a successful pregnancy, I underwent repeated rounds of fertility drugs desperately trying to prove the statistics were wrong. I do not know the effect these fertility drugs might have on me as a woman, much less the effect they may have on me as a DES daughter.

Because of my DES exposure, I nearly died from an undetected ectopic pregnancy. Silently, I face the fear of cancer. I am now entering my menopausal years which also causes me great concern because of my prenatal "bath" in high levels of estrogen. No one can alleviate these fears of mine because there is no research that I can turn to for the answers to my questions.

I am but one of a vast, highly dispersed and diverse population of 10 million Americans all closely connected by the common bond of having been exposed to the most destructive estrogen ever created, DES. We illustrate one of the first examples of grand-scale toxic exposure, the effects of which do not surface until decades later.

The National Cancer Institute estimates that 50 percent of our population — millions of Americans— are unaware of their exposure to DES. This lack of awareness is hardly benign. It translates into a public health crisis which is both serious and complex. The unaware portion of our population has no idea that their health, and ultimately their lives, may be in serious danger because at present, they are not receiving the critical information they need regarding screening and followup medical care. Reaching out to the general public *and* to health care providers to properly educate both groups has been a mandate of our organization since its inception in 1976.

What this population needs to know — and what we all need to remember — is that the history of DES is a story of enormous suffering and even death. They need to know that DES was identified in 1971 as the first known human transplacental carcinogen. And that one out of every 1,000 DES daughters will develop clear cell adenocarcinoma of the vagina or cervix. And while survival rates for clear cell cancer are over 80 percent when detected early, there is still no effective treatment for recurrences of this cancer.

Of an estimated 2.4 million DES daughters, many have been born with reproductive tract deformities which include cellular and/or structural malformations of the vagina, cervix, uterus, and Fallopian tubes. These abnormalities cause health problems ranging from infertility to serious difficulties with conception and childbearing.

DES daughters have five times the risk for ectopic pregnancy, twice the risk for miscarriage or stillbirth, and three times the risk for premature labor and delivery, which in turn increases the risk of serious birth injuries, such as cerebral palsy or even death among the third generation, the DES grandchildren. Many DES daughters will never bear a child of their own.

DES mothers also inherited a perilous medical legacy for themselves as studies point to an increased risk for breast cancer for these women. And we in the DES advocacy community cannot forget to include the 2.4 million DES sons who also face increased risks for reproductive tract abnormalities. Unfortunately, even less research has been done for the sons exposed to DES.

Why should we consider DES a “special health concern” for women? I hope I have made clear some of the very pressing health problems facing many DES daughters and mothers. But there are other reasons for a special focus on DES by all of us who care about women and their health.

Today, as we face the question of wider inclusions for women in clinical drug trials, we must also address the issue of the pregnant woman and her ability to participate in these trials. Much of today’s knowledge about the fragility of the human fetus, and the medical caution about the pregnant woman’s exposure to a variety of substances, can be traced to the tragic lessons learned from DES. The full history of DES can, and should, serve as a reminder of the need for vigilance so that a similar disconnect between basic science and it’s practical application is less likely to happen again. In other words, it is only by acknowledging the lessons which DES has to teach us that we can hope for more medical successes and less tragic failures in the future.

Research on the long-term effects resulting from DES exposure is far from conclusive, and must be pursued to do justice both to our population and to all women. Animal studies, as well as preliminary clinical studies, indicate that the effects of DES may be much broader than first thought. The endocrine, skeletal, cardiovascular, neurological, and autoimmune systems, all need to be examined thoroughly.

Although DES is better known because of its link to cancer, the effects of exposure go far beyond cancer to include both obvious and subtle changes to reproductive function. Because of this, DES is also a critical example of a hormone disruptor. We would do well to learn as much as possible from the DES experience as we seek to understand the full implication of long-term, worldwide exposure to endocrine-disrupting chemicals. It is not surprising that most of the leading scientists who are calling for an investigation of estrogenic chemicals pervasive in our environment are carefully studying the known effects of DES.

With today’s widening appreciation for the power of estrogen to affect our bodies, we need to follow through and learn as much as possible about the DES model. The timing for this research is especially critical now as DES daughters approach the age of menopause because researchers suspect even greater risks for DES-related problems occurring as a result of this major hormonal shift.

Among the questions DES Action USA repeatedly poses to researchers are the following which I would like to share with you today:

- Will there be a new peak of clear cell vaginal or cervical cancers as DES daughters reach menopause? How many cancer DES daughters will suffer recurrences triggered by a new hormonal milestone?
- Will DES daughters, as we age, develop an increased rate of breast cancer as animal studies seem to suggest?
- Should DES daughters be candidates for hormone replacement therapy during menopause?
- What are the long-term effects of fertility drugs on a population already exposed to synthetic estrogen in utero?
- What are the effects of DES on the endocrine, skeletal, cardiovascular, neurological, and immune systems?
- What are the risks for the third generation exposed to DES?

I, and my DES Action USA colleagues here today, look forward to working with you in the next few days and beyond to develop a women's health research agenda that will truly serve not only the women in our population of the DES exposed, but for all women, today and in the future.

Peggy Roberts, M.D. *Self*

My name is Peggy Roberts and I am a family physician from Albuquerque. As a practicing primary care physician for 20 years, I spend less time preventing injury, cancer, and chronic disease and more time helping people manage symptoms and dysfunction from these conditions and overcoming barriers to their care. I value opportunities to reinforce healthier lifestyles, safety, and stress reduction, and to encourage health maintenance and well-person exams for screening and further education. I feel that knowledge of one's state of health and of preventive measures, along with detection of possible disease and injury, can give individuals choice in further evaluation and treatment options. However, much early detection does *not* represent prevention, or even secondary prevention, as claimed by some well-known health campaigns.

True primary prevention means limiting the incidence and extent of disease and disability in the first place and supporting our body's own homeostatic mechanisms for maintaining health and healing. One way we can help prevent the increasing rates of many malignancies, reproductive disorders, and infertility, as well as some chronic diseases in women, is to understand and respond to the growing evidence of the deleterious effects of toxic chemicals and pollutants in the environment on our own health, as well as on that of wildlife around us.

I wish to focus on a review of environmental components of women's health and their effects during a woman's life span. I strongly recommend that the Office of Research on Women's Health study the full texts and include specific research recommendations from recent and upcoming reports on known, environmentally related women's health conditions. Suggested documents are: several publications for primary care physicians from Physicians for Social Responsibility, 1993-1997, including *Pesticides and Children, Environmental Pollutants and Reproductive Health,* and *Cancer and the Environment;* the congressionally mandated NIH/National Institute of Environmental Health Sciences March 1997, report on *Women's Health and the Environment;* the comprehensive upcoming report (due late 1997) from the Institute of Medicine on *Women's Health and the Environment – Gender Differences in Susceptibility to Environmental Factors;* and the annual report by the Public Health Service Office of Women's Health on *Women's Health and the Environment: Federal Inventory of Activities.*

In studies and by testing of mutagenicity and in animals, natural as well as man-made chemicals and radiation have been found to act directly, and possibly indirectly, as environmental triggers of cancer. Chlorinated hydrocarbons [such as the insecticide DDT and electrical-insulating polychlorinated biphenyls (PCB's)], herbicides (atrazine, 2,4-D and 2,4,5-T), and heavy metals (lead and mercury) can mimic estrogen in our bodies. These toxic chemicals can also have other endocrine-disrupting activity and genetic-damaging effects in susceptible individuals, are lipophilic, and accumulable in fat tissue throughout life. Low-level exposures to some endocrine-disrupting chemicals are associated with higher risk of disease, such as high levels of DDE from DDT linked to higher risk for breast cancer in Caucasian and African-American women, though not in Asian-American women. In utero exposures to these toxic chemicals can cause fetal loss, birth defects, and neurological development deficiency, or even delayed immunological effects such as DES use in pregnancy later causing male children's reproductive abnormalities and also clear-cell carcinoma of the vagina and cervix in women children in their late teens or 20s. Skeletal and nervous systems can be affected during times of growth, including in utero development. Asthma and autoimmune diseases, such as rheumatoid arthritis, diabetes, lupus, and thyroid disorders, are often more active during pregnancy and may be susceptible to adverse effects of hormonally active environmental toxicants. Exposure to dioxins and other toxic chemicals have been linked to endometriosis, and infertility in animals and may affect humans as well, contributing to delays in getting pregnant along with such lifestyle factors as smoking, drinking caffeine, and douching.

For women, occupational exposure to chemicals and chemical processes can adversely affect fertility, cause pregnancy abnormalities, and increase risk of cancers (e.g., the link with breast cancer in nursing aides and orderlies, thyroid cancers among dentists and dental assistants, and invasive cervical cancers in maids and cleaners). Obtaining more demographic information through ongoing studies, such as the Women's Health Initiative and the Nurses' Study, may help show whether occupational or recreational exposures to environmental toxicants play a role with other risk factors such as nulliparity in possibly increasing ovarian and breast cancer risks for lesbians or neurodegenerative diseases in older women or women with disabilities. Whether one lives in the inner city or in rural areas and possibly near family, and whether one can afford more organic foods and be around fewer chlorinated compounds at home and at work, will effect exposures to environmental toxicants and thus risk for disease. Dietary deficiencies or excesses, smoking, alcohol consumption, and recreational activities can interact adversely with exposure to environmental toxicants and increase risk of disease or birth defects. The metabolic ability to dispose of or distribute toxins in our bodies may be impacted throughout women's lives by hormonally active toxicants such as heavy metals (lead and cadmium) on bone metabolisms during growth, pregnancy, and development of osteoporosis. Also unknown are the potential interactions of environmental estrogenic and endocrine-disrupting toxicants with commonly prescribed contraceptive and estrogen replacement pharmacologic agents, as well as the overall lifetime benefits versus risks of such therapies.

Thus, there is certainly abundant evidence of adverse effects and risks for women from exposure to environmental toxicants throughout their life spans, along with a need for more education and for continued research on ways to diminish the impact from these exposures. As a public-health-minded primary care physician, I feel it is prudent and precautionary to advise a reduction of much environmental exposure to these toxicants for women, as well as for all individuals in families and communities and nations, in order to prevent known disease and disability.

We can insist on our right to cleaner air and water and on our right to know what kinds and levels of toxins are produced and released into the environment in our home, work, and communities.

- We can require that chemicals be tested for endocrine-disrupting activities and possible indirect carcinogenicity; and that containers be so labeled and the public informed.
- We can advocate for zero chlorine and dioxin discharge from all industry, including medical work incineration, and also for removal of chlorine from paper production.
- We cannot support the use or production of known toxic chemicals and drugs, including cigarettes, nor their exportation to other countries.
- We can avoid using pesticides and practice integrated pest management at home and in our communities.
- We can eat organic, pesticide-free foods, with more vegetables, grains, beans, and fruit and less fatty-animal and fish products, thus minimizing body fat and potential toxic chemical burden.
- We can support education and outreach for affordable and safe home, work, and community environments for all persons in our country and abroad.
- We can ensure access to good health care for all.
- We can reduce waste and encourage recycling, relying less on petrochemicals, and supporting development and use of alternative, biodegradable and nontoxic chemicals and materials.
- We can continue further study, education, and outreach on the effects of the environment on our health, as well as on global health, and move towards less deleterious and more harmonious ways of living on and with this earth.

Such personal, professional, and political commitment, and actions based on sound scientific evidence, can truly prevent disease and disability for ourselves and future generations.

Gail Robin Seydel *Action for Women's Health*

The links between women's health and industrially produced environmental contaminants is an extremely serious concern that must be addressed in future research and in outreach and educational efforts in large and small, urban and rural communities. Understanding the links between health and environment has been popularized by the women's cancer movement in light of the fact that approximately 70 percent of women with breast cancer do not have the established medical risks; and the breast cancer gene only accounts for about 5 percent of women. Looking for answers to what can be called a plague on our nation's women, that grassroots movement spotlighted the research and work of scientists and doctors, including Ana Soto, Mary Wolfe, Devra Lee Davis, Theo Coburn, and many others, as it searched for answers.

More work must be done in this area if we are to prevent breast cancer as well as address a host of other women's health problems. With over 70,000 chemicals in our air, water, soil, food, household products, feminine hygiene products, cosmetics, etc., that have yet to be tested for endocrine-disrupting effects, both individually and in combination, every woman is at risk from the toxic soup in which we live. The fact that organochlorines, as well as other chemicals, heavy metals, and radioactive materials can cross placenta barriers and affect the first environment all humanity experiences, our mother's womb, makes this research of immediate importance to the well being of future generations.

Exposure to environmental contaminants has been shown to cause health problems, including all kinds of cancers, infertility, other reproductive disorders, endometriosis, birth defects, behavioral and learning disabilities, diabetes, and other health problems in test animals with exposure levels within those which we women currently experience. Most affected are poor women and women and communities of color. Here in New Mexico, this is of great importance with Native American and Hispanic peoples being a large proportion of our population.

A variety of research, regulatory education, and outreach opportunities and suggestions to respond to, and combat, the above ills will be presented as part of my testimony on July 21st. I look forward to meeting with you in Santa Fe.

Cynthia M. Shewan, Ph.D. *The American Physical Therapy Association*

The American Physical Therapy Association (APTA) is pleased to have this opportunity to provide written testimony to the Office of Research on Women's Health on recommendations for future research. We appreciate the invitation to participate in the development of a research agenda for women's health research in the coming decade. The Association believes that research is especially needed in the following areas:

Environmental

The workplace should be studied to identify and correct health hazards for women as well as men. Emphasis should focus on reducing identified hazards rather than prohibiting the employment of women in these environments. In particular, research is needed to identify practical, effective ways to protect workers from job-related musculoskeletal risks, including repetitive stress syndrome. Women employed in jobs where they are seated at computer monitors and type on keyboards are particularly susceptible to musculoskeletal disorders of the wrist, arm, and back. This research area is particularly important because musculoskeletal disorders are the country's most costly category of workplace injury and illness. In addition to spending $20 billion annually in the United States on workers' compensation due to repetitive stress injuries, it costs the United States another $100 billion in lost productivity, employee turnover, and other indirect expenses.

Additionally, research is needed on the topics of prevention of musculoskeletal disorders of the lower back, intervention effectiveness research, and the consequences of workplace injury.

Recreational and Sports-related Injuries

As more women participate in recreational and organized sports activities, investigations into the prevention, causes, and treatment of musculoskeletal injuries, especially knee injuries, are needed.

Prevention of Chronic Conditions

Research is needed to identify strategies that can be employed during childhood, adolescence, and adulthood to encourage women to develop good health habits, including appropriate exercise regimes so that chronic health problems can be prevented. Strategies to encourage good health habits in older women should be included since it is never too late to start an appropriate health and exercise program.

- There needs to be continuing research emphasis on the prevention of osteoporosis and hip fractures, including a focus on designing effective strategies to instill good exercise habits, including weight bearing and weight training, in women. Osteoporosis is a major cause of the estimated 850,000 fractures occurring annually in the United States among persons older than 65 years of age. Because bones diminish in size and strength with disuse, weight-bearing exercises, like walking and running, help increase bone mass by stimulating the cells responsible for generating new bone. Regular programs of exercise have been shown to improve older women's strength and muscle tone and keep joints, tendons, and ligaments more flexible. Mild weight-bearing activities may reduce the loss of bone due to osteoporosis. Additional research is needed to show the effectiveness of programs developed by health care professionals, such as physical therapists, to assist individuals to choose the type of exercise program best for them. Since it is especially important that women who have osteoporosis of the spine not perform exercise that jolts or puts weight on the back because of the possibility of causing fractures, research is needed to provide data on alternate exercise programs.

- The influence of exercise and physical activity on balance activities, including the prevention of falls, would be studied more extensively. Also, research is needed to facilitate the development of programs to prevent falls and their resulting fractures. Changes in vision, hearing, muscle strength, coordination, and reflexes may make older women more likely to fall. Preventing falls is especially important for individuals with severe osteoporosis because even a minor fall can result in broken bones.

- Additional research is needed on the benefits of exercise for the prevention of disease and disability. Physical inactivity contributes to coronary heart disease, obesity, and high blood pressure. Sedentary women may also suffer from chronic back pain, stiffness, weak muscles, and shortness of breath. Women who perform aerobic activity can circumvent some of these problems. Although studies have shown that aerobic activity or muscle strength training can reduce mortality from cardiovascular disease and cancer, additional research is needed.

Chronic Conditions

- Increased research is needed on chronic conditions and diseases, such as cancer, stroke, diabetes, and chronic pulmonary disease, that impact the quality of life of older women in the United States. Since the current life expectancy for U.S. women is 82 years, it is important that women be able to spend their older years in good health and with a good quality of life.

- Urinary incontinence is experienced by an estimated 11 million American women, three million of whom developed incontinence before the age of 35. Additional research is needed to improve urinary incontinence treatments, including behavioral techniques, muscle exercises, and biofeedback, all of which have been shown to be effective in reducing episodes of incontinence.

- Cardiovascular disease, especially in women over age 50, continues to have a major impact on women's health. Research on the etiology, prevention, and treatment of cardiovascular disease and cardiac rehabilitation for women is needed. The area of cardiac rehabilitation includes exercise, education, and learning how to live a healthier life. Exercise programs help individuals learn how to exercise safely, strengthen muscles, and improve stamina.

- Osteoarthritis has disabling effects on the musculoskeletal system. Arthritis alters the musculoskeletal system and influences a person's ability to perform functional activities and tasks. Research is needed to identify the most effective way to reduce musculoskeletal impairment and improve function.

- Osteoporosis, a major health problem affecting an estimated 20 million Americans, is most common in the elderly and in postmenopausal women. Osteoporosis is estimated to be up to eight times more common in women than in men. In early adult life, women develop less bone mass than men. Even more critical is that for years after menopause, women lose bone mass much more rapidly because of a reduction in their production of estrogen. Additional research on the prevention and treatment of osteoporosis, including studies on the effectiveness of weight-bearing and weight-training exercise, is indicated.

- Diabetes, widely recognized as one of the leading causes of death and disability in the United States, is associated with long-term complications that affect almost every major part of the body. Uncontrolled diabetes can complicate pregnancy, with birth defects more common in babies born to women with diabetes. In 1992, the medical costs for diabetes totaled $45 billion, with another $47 billion in indirect costs, including disability payment and time lost from work. Noninsulin-dependent diabetes is most common in older people, especially older women who are overweight, and occurs most often among African Americans, Hispanics, and Native Americans. Although recent advances in diabetes research have led to better ways to manage diabetes and treat its complications, additional research is needed, including the prevention and treatment of foot ulcers, due to both neurologic and vascular complications.

Additional Topics

- Biomedical research should be expanded to ensure emphasis on conditions and diseases unique to, or more prevalent in, women of all age groups. Much is needed to investigate the effect of interventions, including surgery, on female anatomy, as well as the impact of these interventions on women's health. For example, during gynecological surgery, support structures for the uterus, bladder, and vagina may be damaged, leading to instabilities of the pelvic floor that require additional interventions.
- There is a need for studies to expand the knowledge of hormones and hormone replacement as it relates to and influences diseases and conditions that affect women.
- Research is needed to study the etiology and treatment of the high incidence of musculoskeletal problems in menopausal and postmenopausal women.
- Separate studies on men and women to investigate the different effects of drugs are needed. Because recent research indicates that women react differently to some drugs than men, future drug research should include separate studies on women and men.
- Research is needed that would identify which aspects of mental and physical decline associated with aging can be reversed.
- Studies are needed that investigate how exercise can promote healthy aging in women.
- Investigations targeting the identification of domestic violence by health care professionals, as well as the effect of domestic violence on women, are also necessary.

Recommendations to Promote Research on Women's Health

- Promote efforts to include women in clinical trials, including choosing study site locations and hours that are conducive to participation by women.
- Promote funding for programs that foster women's health research.
- Expand the mission of the Office of Research on Women's Health to monitor funding for women researchers and career opportunities to ensure equality and the elimination of career barriers for women.

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API WOMEN GET BREAST CANCER TOO: MYTH OF THE MODEL HEALTH MINORITY

Introduction

If you are a woman, you are at risk for breast cancer. Breast cancer is the most commonly diagnosed cancer in women living in the United States, and it is the leading cause of cancer death for American women between the ages of 20 and 54.

Over the last 30 years, the incidence of breast cancer has steadily increased in the United States. This may be due to increased attention to earlier detection. Yet, despite over 20 years of research, the death rate from breast cancer has remained constant over the past 50 years.

In the United States, every 3 minutes a woman is diagnosed with breast cancer; every 11 minutes one woman dies of breast cancer.

I was just 34 years old when I was diagnosed with infiltrating ductal carcinoma of the breast. Presenting with a prominent breast lump that did *not* show up on a mammogram, I was told by every doctor, every nurse — every health care provider I saw — that I was simply too young to have breast cancer. It provided me no comfort when the doctors kept saying that I had “nothing to worry about.” That year, faced with the cold, hard fact that my doctors did not take something that I knew was happening in my body seriously, was when I first became an activist.

The truth is, for the vast majority of cases, we still don’t know what causes breast cancer. Treatment, whether it be surgery, chemotherapy, radiation therapy, or a combination, is still drastic and barbaric for many women. I’ve undergone all of these. It can be brutal. We call it “slash, poison, and burn.”

We can’t prevent breast cancer. We *can* change our behavior, such as eating a healthy diet, which may be able to reduce our cancer risk, and the goal of screening is early detection. But we really don’t know how to prevent breast cancer at this time. And we survivors all live with the knowledge that recurrence could come at any time. The nightmare of recurrence became a reality for me earlier this year. Five years ago, I was told that I was cured of an early Stage I breast cancer. Right now I am being treated for a rare recurrence in my cerebrospinal fluid, called carcinomatosis meningitis (or leptomeningeal carcinomatosis). While my prognosis is not a good one, I never give up hope — never!

API Women Get Breast Cancer, Too

There was one other thing the doctors told me when they said I had nothing to worry about. They said that “Asian women don’t get breast cancer.” I bought into it — thought I was a statistical anomaly. But I was soon to learn that statement to be an absolute fallacy perpetuated by inadequate and aggregate national statistics, which also perpetuate the myth of Asian Pacific Islanders (APIs) as the "model health minority."

Breast cancer incidence and mortality rates in API women are consistently reported to be among the lowest for all women in the United States. While the probability of any woman in the United States developing breast cancer throughout her lifetime is 1 in 8 (12.5 percent), the lifetime risk for API women is reported to be 7.6 percent, and the available literature reports their risk to be anywhere from 1 in 13 to 1 in 20 — the lowest lifetime risk for all women nationwide.

These low rates for women compared to all other ethnic groups have led to the belief among health care providers, public health policy makers, governmental agencies, and the general population that API women are not at risk for breast cancer. But these statistics are skewed. They have perpetuated a dangerous myth and provided justification for an outcome all too familiar to API communities — once again, when health dollars are allocated, we are left out of the equation.

A review and evaluation of breast cancer and reported research statistics is important to the understanding of how these beliefs negatively impact the health of API women living in the United States.

Breast Cancer 101

A woman's breasts are the organs that produce milk which provide nourishment to our infant children. In our American society, they are also symbols of blossoming womanhood, sensuality, power, fertility, and exploitation. They come in all shapes, sizes, and colors. But one thing is certain. If you are a woman, you are at risk for breast cancer.

The Human Breast

A woman's breast is a fatty organ designed to produce milk. Each breast has 15 to 20 sections, called *lobes*. Each lobe has many smaller *lobules* ending in numerous tiny *bulbs* capable of producing milk. These lobes and lobules are linked to the milk-producing bulbs by tiny tubes known as *ducts*, which also lead to the nipple supplying milk to the suckling infant. These breast components are held in place by fatty tissue. For some women, these normal features may make the breasts feel lumpy. For other women, this lumpiness may occur cyclicly in association with her menarche.

There are no muscles in the breast, although muscle lies between the breast tissue and the rib cage. Small breasted women may be able to feel their rib cage through the breast, which may add to the feeling of lumpiness.

Nearly all women, at one time or another during their life, will experience breast tenderness, lumps, pain, or breast discharge other than during lactation. There are many causes for these symptoms, but the vast majority of them are benign conditions.

What is Cancer?

Cancer is a name of a group of diseases in which abnormal cells grow out of control and destroy normal body tissues. There are over 100 types of cancer, of which breast cancer is the most common type found in women. *Tumors* are formed when cells lose their ability to control their own growth and form excess tissue. Tumors may be *benign*, which are ***not*** cancerous, or *malignant*, which are cancerous. Malignant tumors can invade and destroy adjacent health tissues and organs. Sometimes cancer cells break away from the tumor and *infiltrate* into other parts of the body through circulating blood or in the *lymphatic system* by invading the lymph nodes. When cancer spreads and invades other parts of the body away from the primary tumor site, we say that the cancer has become *metastatic*. It is possible for *metastases* to occur even when the primary tumor has been removed if cancerous cells had already spread to other parts of the body.

API Breast Cancer Statistics: Skewing Our Perception?

The low breast cancer incidence and mortality rates of Asian-American women, compared to all other ethnic groups, have led to the belief among health care providers, policymakers, and the general population that Asian American women are not at risk for breast cancer. But are these statistics skewing our perceptions of the risk of breast cancer for Asian-American women? Have they perpetuated the “healthy minority” myth and provided justification to leave Asian-American communities out of the equation when health dollars are allocated? Do these statistics:

- Promote a false sense of security among API women?
- Create the illusion among providers and policymakers that there is a lack of need for breast cancer education among API populations?; and,
- Validate the argument that governmental agencies and service providers do not need to expend funds for breast cancer education and early detection in API populations?

Let’s Examine These Statistics

Approximately 182,000 cases of female breast cancer were newly diagnosed in the United States in 1995, with an overall incidence rate of 110 new cases per 100,000 woman. While the incident rate has steadily increased over the past several decades (about 2 percent per year since 1980), mortality rates in the United States have remained relatively stable, with approximately 46,000 deaths due to female breast cancer in 1995. Nationwide, the incidence rates per 100,000 population, by race, have been reported by the American Cancer Society for the period 1977-1983 and NIH/NCI for the period 1988-1992, as shown in Table 1.

This year in California, the American Cancer Society estimates that there will be 19,990 new cases of female breast cancer and 4,345 deaths due to female breast cancer. Overall, for all women in California, the incidence of female breast cancer is 107 cases per 100,000 women, with a mortality rate per 100,000 of 25.8. Selected California incidence and mortality rates are shown in Table 2.

TABLE 1. Age-adjusted (United States, 1970) Female Breast Cancer Incidence and Mortality Rates per 100,000

	American Cancer Society (1977-1983)		National Cancer Institute (1988-1992)	
	Incidence	Mortality	Incidence	Mortality
Non-Hispanic White	88.8	26.8	115.7	27.7
African American	75.2	26.9	95.4	31.4
Hispanic/Latina	52.1	19.4	69.8	15.0
American Indian	21.3	9.0	31.6	—
Native Hawaiian	106.1	37.2	105.6	25.0
Chinese	57.8	12.0	55.0	11.2
Filipina	41.3	7.8	73.1	11.9
Japanese	55.0	10.2	82.3	12.5
Korean	—	—	28.5	—
Vietnamese	—	—	37.5	—

The probability of a woman in the United States developing breast cancer throughout her lifetime is 1 in 8 (12.5 percent). In California, the lifetime risk for all races and ethnicities is comparable (12.6 percent). For Asian Pacific-American women, the reported risk decreases to 7.6 percent, and the available literature reports lifetime risk to be anywhere from 1 in 13, to a low of 1 in 20 — the lowest lifetime risk for all women nationwide.

TABLE 2. California Selected Annual Age-adjusted (United States, 1970) Female Breast Cancer Incidence and Mortality Rates per 100,000 by Race/Ethnicity

	American Cancer Society (1988-1992)		California Cancer Registry (1988-1993)	
	Incidence	Mortality	Incidence	Mortality
Non-Hispanic White	119.0	25.8	117.4	27.4
African American	98.5	28.0	96.5	32.4
Hispanic/Latina	69.0	17.8	68.5	17.9
Asian/Other	60.4	12.6	60.7	12.6
Asian Indian	59.8	—		
Chinese	52.1	12.1		
Filipina	73.8	14.2		
Japanese	74.0	14.3		
Korean	23.3	6.7		
Selected SE Asians	31.8	7.3		

APIs: Who Are We?

Several recent studies and reviews on API women and immigration status have shed new light on the myth that API women have a low breast cancer incidence. A look at changing demographics in the United States reveals why policies based on reported aggregate API breast cancer statistics are shortsighted.

API Population Growth

APIs are the fastest growing minority population in the United States, increasing at a rate of 4.5 percent annually. In 1994, the total API population in the United States was 8.8 million, comprising 3 percent of the total U.S. population. The U.S. Bureau of the Census estimates that by the year 2000, 12.1 million APIs will be 4.3 percent of the population. By 2050, the API population will increase to comprise 10 percent of the total U.S. census.

Between 1960 and 1990, the largest increase in API populations occurred in the south and northeast, with the greatest API population increases seen in the states of Rhode Island (246 percent), New Hampshire (219 percent), Georgia (209 percent), Wisconsin (195 percent), and Minnesota (194 percent) — states which were largely unprepared for this phenomenal growth of diverse and divergent populations.

Thirty-nine percent of all API populations currently live in the state of California, comprising 9.6 percent of the total state population. Since 1980, the API population in California has increased at a rate of 116.7 percent. By the year 2010, it is projected that 45 percent of the total U.S. API population will be living in California. The top ten counties/metropolitan areas nationwide with the largest API populations are Los Angeles, New York, Santa Clara, Orange, San Francisco, San Diego, Chicago, Alameda, Washington, D.C., and Houston. Of these, six counties are located in California and are home to 90 percent of the total API population in the state.

California is the stated, intended ultimate state of residency (secondary immigration) for 70 percent of all APIs living in the United States.

By 1990, 68.2 percent of the total API population was foreign-born, 11 times greater than the general U.S. population. Over 90 percent of the U.S. Laotian, Cambodian, and Vietnamese populations were foreign born. U.S. Thai and Korean populations are approximately 82 percent foreign born. U.S. Tongan and Asian-Indian populations are 75 and 70 percent foreign born, respectively. Sixty-four percent (65 percent) of Filipinos and 63.3 percent of Chinese are foreign born. U.S. Samoans and Japanese populations are 36 and 28 percent, respectively, foreign born.

API Demographics

The median age of APIs is the lowest of all identified ethnic/racial populations at 30.4 years. Women comprise 51.3 percent of the total API population, with a median age of 31.1 years. The median age for U.S.-born API women is 15.8 years; for foreign-born women the median age is 32.5 years. U.S.-born Cambodian females have the lowest median age at only 4.7 years.

From 1990 to 1994, the percentage of APIs living in poverty increased from 11.9 percent to 15.3 percent. Of women over the age of 65 years, 14.8 percent live in poverty and 26 percent use public assistance.

In 1990, 665,605 households in California spoke API languages; of these, 32.8 percent were considered "linguistically isolated," in which no members over the age of 13 spoke English "well" or "very well." The most common APA languages spoken in California households are, in order of prominence, Chinese, Tagalog, Korean, Vietnamese, Japanese, Indic, and Mon-Khmer.

Asian and Pacific Americans have the highest naturalization rate of all U.S. immigrant populations. With voter registration rates comparable to the U.S. average of registered voters, APIs have the highest voting rates of all ethnic/racial groups nationwide.

Impact of Immigration on API Breast Cancer Statistics

Among all API populations, breast cancer rates were significantly (60 percent) higher than those found in the women's native countries. Immigrant API women living in the United States for as little as 10 years have an 80 percent higher risk of breast cancer than their new immigrant counterparts. It may be that for these women immigration to the United States is their greatest risk factor for breast cancer. And for API women born in the United States who have at least one grandparent born in the West, breast cancer rates are higher than for white women living in the some communities. This means that the actual breast cancer risk for third and fourth generation Chinese- and Japanese-American women equals, or may exceed, that of the general population.

In Native Hawaiian women, the incidence of breast cancer remains significantly higher in comparative national ethnicity studies. Research conducted at the Cancer Research Center in Hawaii confirms that while Native Hawaiian women have a breast cancer incidence second to that of white women living in Hawaii, mortality due to breast cancer in Native Hawaiian women far exceeds that of any other ethnic group including white females. Further, a retrospective epidemiologic study of age differences of newly diagnosed breast cancer cases in Hawaii revealed that 28 to 35 percent of Native Hawaiian women diagnosed with breast cancer annually are premenopausal, compared to NIH/SEER data showing a 10 to 20 percent premenopausal breast cancer rate for all women. This suggests that a significant percentage of Native Hawaiian women at risk for breast cancer are not being screened, and possibly that the disease may be more aggressive in this subpopulation of women, contributing to the higher mortality rates for breast cancer in Native Hawaiian females.

Therefore, currently reported statistics for API women are skewed because API populations have (1) the highest U.S. immigration rates at nearly 70 percent, (2) immigrated from their native countries with the overall lowest breast cancer incidence in the world, and (3) have the lowest median age of all U.S. populations. As the current U.S. API population ages, acculturates, and increases due to fertility, the reported incidence and mortality rates will begin to show a steady increase. Yet, the rapid growth of API populations, fueled by immigration over the next 10 to 15 years, will prevent the statistics from depicting an accurate picture of breast cancer risk in API women. For California, which has by far the largest API population, this disparity will be even greater. And the trend to study cancer in API populations, as an aggregate group, only obscures the reality of breast cancer risk, incidence, and mortality in our many diverse and divergent subpopulations.

In fact, while the ACS last year reported that U.S. cancer deaths are declining, cancer deaths have increased at a faster rate among APIs than any other racial/ethnic population. Between 1980 and 1993, cancer death rates for APIs more than doubled (290 percent for males and 240 percent for females), representing the highest percentage increase in the United States. And while cancer is the second leading cause of death for most Americans, cancer has already become the number one cause of death for API females. Why? Well, we know that breast cancer is the leading cancer for Chinese, Filipina, Hawaiian, Japanese, and Korean women in the United States. And we know that cervical cancer rates among Vietnamese women living in the United States are nearly five times higher than those among white American women. And we know that for women living in the Marshall Islands, a U.S.-associated Pacific Jurisdiction, breast cancer mortality is fivefold and cervical cancer mortality is sixtyfold that of U.S. rates. In the Republic of Belau, another U.S.-associated Pacific Jurisdiction, breast and cervical cancer mortality rates are also markedly above U.S. mortality rates. In addition to breast cancer, Native-Hawaiian women have among the highest mortality rates from uterine and ovarian cancers in the United States. Unfortunately, because of inadequate research and aggregate API cancer data, the true cause of this great disparity in cancer deaths for API females over every other U.S. racial and ethnic group remains obscured.

These inaccuracies are now reflected, and will continue to be reflected, in the lack of knowledge about actual female cancer risks among API women, and the paucity of health care funding and programs targeted to breast cancer outreach and education in API communities, which will continue to result in late stage diagnoses with and a disproportionately high mortality rate. In addition, the myth among health care providers and public health policymakers of APIs as the "model minority" only serves to exacerbate this situation.

The Myth about Breast Cancer in API Women — What's at Risk?

The myth that API women are not at risk for breast cancer (1) promotes a false sense of health security among API women; (2) creates the illusion among health care providers and policymakers that there is a lack of need for breast cancer education, screening, treatment, and support among API populations; and (3) validates the arguments that justify policies precluding the utilization of resources to provide for the overall spectrum of breast cancer in API populations.

This myth perpetuates another myth well established in the American medical and political environment — that APIs are the model, healthy minority, who take care of themselves and do not require preventive health services.

Combined, these factors result in a lack of concern, knowledge, and resources for breast cancer education in API populations. A devastating outcome is that this lack of concern and knowledge is also found within API communities. API women have been told that their risk of breast cancer is low (virtually nonexistent), and they believe what they have been told. This false sense of security has brought about a complacency that API women do not need to know about, talk about, or learn about their risks for breast cancer, and how to detect breast cancer early. The illusion has been created for clinical service providers, at all levels, that there is a lack of need for breast cancer education, screening, and diagnostic services in API populations. *Suc Khoe La Vang!* (Health is Gold!) Vietnamese Community Health Promotion Project found that few Vietnamese immigrants are familiar with prevention practices and the American health care system. Similar findings are evident in many API communities.

The result of these misconceptions results in a failure at the national, statewide, and regional levels to implement breast cancer outreach and education programs in Asian-American communities. While breast cancer receives a great deal of media and public attention, to date little effort has been expended to implement outreach and education activities necessary to ensure that API women are aware of, and use, early detection practices and the many available (and financially accessible) breast cancer screening, diagnostic, and advocacy services.

Outreach and inreach are admittedly challenging for API communities due to language and cultural barriers. Nonetheless, if outreach education and services are not provided and resources at every level continue to be denied, the nation as a whole, and California specifically, will find themselves facing a new health care crisis in the 21st century.

As the API population ages, acculturates, and increases its own numbers through fertility and secondary migration, the reported incidence and mortality rates for API women will begin to increase steadily. Still, growth of the overall API population, fueled by continuing immigration over the next 10 to 20 years, will prevent the breast cancer statistics from depicting an accurate picture of the breast cancer risk in API women. While the national perception of the statistical landscape is skewed, breast cancer incidence, especially for API women born in the United States, will rise dramatically.

Demographically based projections are critical in developing sound public policies for California's API communities. Including demographic projections for the next 20 years in the breast cancer equation for API communities will provide the necessary justification to allow for implementation of public health policies and targeted outreach and education programs focusing on prevention (lifestyle interventions) and early detection *now*, rather than treatment 10 and 20 years from now.

Myth of APIs as the "Model Health Minority"

The myth of APIs as the "model minority" has given rise to public welfare and health policies that exclude Asian Americans from minority programs, and perpetuates the myth that APIs are not at high risk for health problems.

The prevailing picture of Asian Pacific Islander health in the United States is that of diversity. Reporting of API statistics in the aggregate conceals the diverse and divergent socioeconomic, educational, linguistic, and health level of this heterogenic population.

Socioeconomic Status

While the prevailing image of APIs is of economic success, in reality API's socioeconomic success lies on opposite ends of a wide spectrum, which hides the poverty in which many of these populations live. For APIs, high educational attainment does not necessarily culminated in high paying jobs, as might be expected.

- While the overall average unemployment rate for APIs is lower than the national average (5 percent), Hmong, Laotians, Cambodians, and Samoans had unemployment rates in double digits 100 to 200 percent greater than the national average.

  - 94 percent of those not seeking employment cited health reasons; 54 percent cited limited or lack of English language capabilities.

- 14 of 17 Asian-American groups have the highest percentage of families living below the federal poverty line. Greater than 60 percent of Laotian and Hmongs live in poverty. More than 35 percent of Vietnamese, 28 percent of Samoans, and more than 13 percent of Koreans and Thais live below the federal poverty line compared to less than 10 percent of the total U.S. population.
  - However, local surveys found even greater percentages (76 percent) of Hmong, Khmer, Laotians, Chinese/Vietnamese, and Vietnamese lived below the federal poverty line. In San Diego, California, nearly 95 percent of Hmong live in poverty, compared to 9 percent of whites, 20 percent of African Americans, and 21 percent of Latinos living in the same area.
- API families, with incomes below the federal poverty lines, are poorer than any other group.

Education/Literacy/Language Barrier

- The stereotype of the highly educated API population is untrue. Again, aggregate statistics mask the reality. Ten percent of APIs have had no education at all.
- Limited education and literacy, in both English and native languages, are barriers to health care so that for many API populations, bilingual written materials are of little value in overcoming language barriers.
- Facilities utilizing bilingual staff are often not trained in medical terminology and/or rely on family members to translate. Because of the familial hierarchical nature of many API cultures, this can lead to additional problems when children, often young, are relied upon to relay health information to their non-English-speaking parents.

Lack of Cultural Competence

- The API health paradigm of holistic health and somatization (view that the mind and body are one) is markedly different from that of Western medicine (treating specific diseases as specialties).
- API concepts of illness and death, traditional healing practices, and unfamiliarity with and distrust of the Western health care system, combined with language and other institutional, medical/provider, and cultural barriers, has resulted in a prevalence of "unexpressed health needs" among APIs.
  - lack of concept of preventative medicine (vs. somatization),
  - illness and death are considered to be one's karma — nothing can or should be done to prevent the inevitable,
  - The concepts of "face" and "harmony," in which group harmony is valued over individuality, are commonly found among API groups. Respect for social rank is pervasive; therefore, not wanting

  to question the physician's authority which might cause him/her to lose face and creates disharmony, APIs will often deny specific complaints, and say "yes" to whatever the doctor recommends, regardless of their true desires or intentions,
  - lack of understanding of cancer risk factors and cancer screening practices,
  - lack of concept of appointments scheduled in advance, and
  - lack of concept of informed consent.

- Lack of culturally competent health care providers and staff, and a lack of formal cultural awareness and cultural competence training for health care professionals in dealing with diverse cultures.

Health Care Utilization Rates

- Low reported API health care utilization rates give the image that APIs have few health problems. However, additional unreported barriers add to the lack of health care visits by API groups.
- Lack of health insurance is a major problem.
  - The national statistics for uninsured APIs is 21 percent,
  - In Boston, more than 60 percent of APIs are employed in low-paying jobs and are uninsured, and
  - In California, APIs were among the groups least likely to have access to employer-paid health insurance (20 percent of employed men and women did not have health insurance).
- APIs, as with other low-income and uninsured populations, tend to use the hospital emergency room for front line medical access. For Laotian and Vietnamese families, 41 percent and 69 percent, respectively, utilize the emergency room as their primary health care venue.
- Fear of deportation or jeopardizing immigration status are barriers to APIs seeking health care.
- Immigration reform will have a great and adverse affect on APIs, whose populations are more than 70 percent immigrant born.

Barriers to API Outreach, Education, and Screening

The culture within which we operate makes a profound impression on our lives — greatly influencing how we observe our world, receive and assimilate information, and how we react to the stimulus. Dr. Marjorie Kagawa-Singer states that culture *"profoundly affects the illness experience through beliefs about the meaning of cancer, use of screening and early detection programs, emotional and physical responses to the treatments, side effects of the treatments, patterns of decisionmaking, and the family dynamics that infuse each step along the continuum of care."*

Because of the voluminous Asian Pacific Islander ethnicities, cultures, and languages, it is foolish to fall into the trap of lumping all APIs together. However, common themes and belief systems seem to be present in most API populations.

Table 3. Collective API Philosophical Values and Beliefs

- Appropriate behavior and conduct
    - "Face"
- Group harmony valued over individuality and intimacy
    - "Enro"
    - Self-sufficiency valued
- Hierarchical familial/social relationships
    - Asking questions of physicians considered disrespectful
    - Close interpersonal relationships communicated by action vs. talking
- Reciprocity
    - Endure uncomfortable situation alone rather than take on burden of obligation
- Body Image
    - Greater value and emphasis on role fulfillment than physical attributes

In health care, many divergent cultures converge creating a hodge-podge of perceptions, attitudes, and beliefs, and an even greater concoction of reactions to information about health and illness. The health care provider, community health educator, and lay person all perceive "health" and "medicine" differently. Add in a variety of ethnicities, national cultures, languages, ages, gender, sexual orientation, generation, socioeconomic levels, and educational levels, and the perceptions become even more diverse. Then say the words "breast cancer" and imagine the vast array of reactions you would receive. You are beginning to get an idea of how immense the barriers might be.

There are three main levels of barriers to breast cancer outreach, education, and screening practices — institutional (societal), community (collective and personal), and medical/provider (collective and individual). Listed below are some of the identified barriers in each of the three levels. See if you can add any of your own.

Institutional Barriers

- Socioeconomic factors,
- Poverty, exposure to crowding, inadequate education, substandard housing, chronic malnutrition, higher smoking rates, psychosocial stress, noxious environmental agents,
- Medical costs,
- Unemployment or underemployment,
- Lack of accessibility to screening services,
- Lack of transportation (availability, costs),
- Lack of available, affordable child care,

- Lack of outreach to immigrant and/or non-English-speaking communities,
- Lack of culturally competent and language-appropriate education practices,
- Lack of language-appropriate interpreters/staff,
- Use of children as interpreters,
- Data regarding the health status of APIs are inadequate,
- Myth that APIs are a healthy population/model minority, and
- Literature does not address the underlying cultural and historical events that have profoundly shaped the lives of refugees.

Medical and Provider Barriers

- Lack of screening referrals by ethnic providers,
- Focus only on medical problems with which patients present themselves or acute medical problems,
- Lack of availability of health care providers,
- Paucity of female providers,
- Scheduling time and logistics,
- Singularity of services provided at each visit/site,
- Unfamiliarity of traditional beliefs about physician/patient relationship,
- Cultural norms prevent providers from intruding Western medical values on families,
- Lack of cultural training in medical education,
- Provider unaware that patients may not be accustomed to detailed history taking or chronological sequencing of health events, and
- Misinterpretation of side effects of traditional folk medicines,
    - evidence of pinching, scratching skin, moxibustion, cupping, or coining may erroneously appear to provider as spousal or child abuse.

Community Barriers

- Lack of preventive health care orientation,
- Traditional beliefs about health and illness,
  - YIN and YANG
    - female and male,
    - dark, cold, wet, passive, weak; bright, hot, active, strong,
    - yielding nature of earth; firm nature of heaven,
    - evil, negative, weak; good, positive, strong,
    - night and day, and
    - moon and sun.
  - CHI
    - life energy, destruction of,
    - failure to be in harmony with nature,
    - curse by offended spirit, and
    - punishment for immoral behavior.
  - ENRO
    - endure suffering, pain,
    - don't complain, and
    - don't be a burden to others.
  - SHIGATA GA NAI
    - don't worry about something you have no control over, and
    - you can't change the future.
- Lack of knowledge about preventive practices,
- Lack of knowledge about early detection practices,

- Lack of familiarity and/or trust of Western health care system,
- Lack of or limited English-language proficiency,
- Traditional health beliefs and practices,
- Traditional family health practices and role of women,
- Modesty,
  - unmarried women not to talk, think about breasts, and
  - only husband to touch sexual organs.
- Focus on sexual organs only during childbearing years,
  - female organs cease to function if not used for procreation.
- Diversity between API populations,
- Overall "cost" to family of screening and early detection,
- Definition of "cancer," and
- Heavy mortality of elderly refugees has depleted populations of their cultural gatekeepers.

Effective Strategies to Overcome Barrier in API Communities

Effective strategies to overcoming barriers to health care information, access, and utilization in Asian-American communities have been successfully utilized addressing breast cancer and (albeit primarily) other health care issues. Incorporating the appropriate in-language and culturally competent strategies to your breast cancer outreach and education programs should greatly enhance utilization of early detection behaviors and screening services in the communities you service.

Some effective strategies used in addressing health care issues in various Asian-American communities are listed below:

- In-language health education materials,
  - appropriate literacy level.
- Coordinated in-language media campaign (newspaper, radio, television),
- Coordinated in-language advertising campaign (newspaper, radio, television, billboards),
- Community promotional raffles and contests,

- Promotional giveaways,
  - Potholders, key chains, bottle gripper, note pads, pens/pencils, mirrors, desk clocks, magnets.
- Health fairs and ethnic community events,
- Affordable services,
- Transportation and child care assistance,
- Same ethnicity and in-language health care “navigators,”
- Reduce need for multiple return visits, at several sites (multiservice centers),
- Emphasis on women’s role in the family,
- Stress that relief of suffering may better enable patients to fulfill their familial obligations,
- Use of cultural imagery,
  - Khmer: Apsara, and
  - Hmong: tiger, kinship solidarity, equilibrium.
- Use of culturally bound syndromes (Khmer, koucharang — thinking too much),
- Use current life experiences in relaying information,
- Use of Southeast Asian folklore, story telling techniques, and
- Provider intervention,
  - reminders notices and software programs,
  - CME programs,
  - provision of in-language educational materials,
  - PDQ access,
  - same ethnicity, language,
  - bicultural and bilingual staff,
  - culturally competent, language-appropriate communication styles, and
  - familiarity, sensitivity to cultural beliefs and practices.

The table below delineates the differences between American and Asian cultural belief, perceptions, and responses to various situations.

Ego Ideal

American	Asian
Individual ego ideal	Socially contextual ego ideal
Personal autonomy, freedom	Role appropriation, duties
Assertiveness, self-determination	Harmony, consideration, tolerance
Self confidence	Modesty
Perfection	Moderation
Youth, physical vigor	Seniority, virtue, wisdom

Communication Style and Expression of Emotion

American	Asian
Verbal	Nonverbal
Open, direct	Subtle, indirect
Expressiveness	Serenity, stoicism, suppression of negative emotion
Direct verbal and physical expression of love and affection	Indirect expression of love and affection by fulfilling mutual obligations and tending to physical and sociocultural needs

Physician-Patient Relationship

	American	Asian
Power structure	Egalitarian	Hierarchical
Expectations in relationship	Contractual agreements, participation in decisionmaking	Reciprocity, mutual obligations according to order in the relationship
Physician's role	Having professionalism and competence	Having great virtue, being concerned, giving, and responsible for the patient's welfare
Patient's role	Taking care of one's own welfare and rights, participating in decisionmaking	Showing respect and deference for the physician's authority and suggestions, being grateful

Meaning of Life, Illness, and Death

	American	Asian
Life	= happiness, health, opportunity	= suffering
	One has control over one's own life	One's life is determined by various factors out of one's control
	Your life is yours	Your life is not yours
Death and illness	Disruption of normal life	Part of normal life cycle
	Personal failure	Bad luck, result of former deeds, etc.
	Something to be beaten	Something to be accepted and dealt with calmly
Response to illness		
Ideal	Seeking control, fighting (beating) illness, heroic self-healing	Serenity, stoicism
Possible problems	Burden of having to be positive	Helplessness
	Sense of personal failure	Denial
	Anger and depression	Depression
	Difficulty letting go	
Sick role	Little permission for regression and dependency	More permission for regression and dependency
	Participation	Cooperation
	Conflicts over losing independence and control	Conflicts over unmet expectations and dependency needs

Role of Family

	American	Asian
Definition of family	Present generations	Past, present, future generations
Financial obligation	Fiscally independent	Economic obligation to kin
Core relationship	Husband-wife	Parent-child
Emphasis	Happiness of individual	Welfare of family
Orientation	Feeling oriented	Task oriented

[Nilchaikovit, T., Hill, J.M., and Holland, J.C. The effect of culture on illness behavior and medical care: Asian and American differences. *General Hospital Psychiatry* 15 (1993): 41–50.]

Summary

Breast cancer incidence and mortality rates in API women are consistently reported to be among the lowest for all women in the United States.

These statistics have long been used to justify policies precluding the utilization of resources to provide for breast cancer education and outreach to API communities. Recently, however, several studies on API women and immigration status have shed new light on the myth that API women have a low breast cancer incidence. A look at California's changing demographics reveals why such policies are shortsighted:

- APIs are the fastest growing minority population in the United States — increasing at a rate of 4.5 percent annually.
- Nearly 40 percent of the total U.S. API population resides in California — comprising 9.6 percent of the state's population. By the year 2010, 45 percent of all APIs will be living in California. California is the intended ultimate state of residency (secondary immigration) for 70 percent of all APIs living in the United States.
- The largest API population growth has occurred in the southern and northeastern United States where health care systems were not prepared to take on the rapid growth of these diverse and divergent population groups.
- 68.2 percent of the total API population is foreign born — 11 times greater than the general U.S. population. APIs are the only group in which more than 50 percent of its population is attributable to immigration.
- Women comprise 51.3 percent of the total API population, with the lowest median age for all U.S. populations: 32.5 and 15.8 years, respectively, for foreign-born and U.S.-born API women.

Breast cancer rates in the United States were significantly higher (60 percent) in all API populations than those found in the women's native countries. Immigrant API women living in the United States, for as little as 10 years, have an 80 percent higher risk of breast cancer than new immigrants. And for API women born in the United States who have at least one grandparent born in the West, breast cancer rates are higher than for white women living in the same communities.

Currently reported statistics for API women are skewed because API populations have (1) the highest immigration rate at nearly 70 percent, (2) immigrated from their native countries with the overall lowest breast cancer incidence in the world, and (3) the lowest median age of all U.S. populations. As the current California API population ages, acculturates, and increases due to fertility and secondary immigration, the reported incidence and mortality rates will begin to show a steady increase. Yet, the rapid growth of API populations, fueled by immigration over the next 10 to 15 years, will prevent the statistics from depicting an accurate picture of breast cancer risk in API women. For California, which has by far the largest API population, this disparity will be even greater.

These inaccuracies are reflected in the lack of knowledge about actual breast cancer risk in Asian-American women, the paucity funding and programs targeted to breast cancer outreach and education in Asian-American communities, late stage diagnoses, and high mortality.

In addition, the myth of APIs as a “model minority” and “model health minority” is false, resulting in a lack of culturally competent outreach and intervention for these diverse populations.

Demographically based projections are a critical and necessary tool in developing public health policies for U.S. API communities. Without them, statistics will continue to skew the landscape while *actual* breast cancer incidence and mortality rates for API women, especially those born in the United States, will rise dramatically. Failure to educate API women on healthy lifestyle interventions and early detection methods *now* will result in a virtual breast cancer epidemic in API communities over the coming decades. Immediate development and implementation of intervention programs, which will bring APIs in greater numbers into a culturally competent, community relevant, and language appropriate U.S. health care system, must take place. The time to act is NOW!

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Susan Silverton, M.D., Ph.D. *American Association of Dental Schools*

I am Dr. Susan Silverton, a member of the faculty of the School of Medicine and School of Dental Medicine at the University of Pennsylvania. I am an endocrinologist, caring for patients with metabolic bone diseases, including osteoporosis. I also have a Ph.D. and my research concerns osteoclast-related bone destruction. At the School of Dental Medicine, I instruct predoctoral dental students in required medicine and medical practice topic areas. It is my pleasure to present testimony on behalf of the American Association of Dental Schools (AADS). The AADS represents 55 U.S. and ten Canadian dental schools, the postgraduate programs in dentistry, and the allied oral health professional schools. The AADS works closely with the research community on matters related to education and training. The AADS is the one national organization that speaks on behalf of dental education.

As a physician teaching in an oral health care setting, I have been exposed to a unique set of circumstances which I would like to share with you. I would like to start by asking you to recognize that everything I wish to convey in this testimony can be condensed into two messages. First, oral health is an integral part of general health and should be considered whenever health needs are discussed. Second, postmenopausal women, elderly women, and frail elderly women need oral health care. In addition, they need a proper integration of oral health and health care to decrease morbidity and mortality and to secure a better quality of life.

My goal is to place you comfortably into the perspective contained in these two messages. To do so, I will discuss several issues which have led me to these conclusions, illustrate the issues with a case presentation, comment on initiatives in progress to implement change, and conclude with short list of recommendations for improving the oral health and general health landscape.

Oral Health Care Economics and Impact

First, I would like to acquaint you with data showing that dental and oral diseases affect most older Americans. 99.5 percent of Americans 65 years and older have had cavities and 40 percent of these elderly Americans have lost all of their teeth. Of those who are poor, a disproportionate number (50 percent), are also edentulous. In general, in the edentulous elderly population, only 10 percent had a yearly dental visit. In addition, those in poorer health or limited by disability show a 28 percent decrease in regular oral health followup visits. By the year 2000, it is estimated that 62.3 billion dollars will be spent yearly on dental services. Yet, only 15 percent of those 65 and older have dental insurance. The Public Health Report concludes that “oral diseases remain an unnecessary obstacle to better health.”

Gender-specific data on women shows that increasing age is accompanied by an increase in the edentulous population. While women aged 45 to 54 have only a 12 percent prevalence of complete loss of teeth, 46 percent of women over 75 years of age have lost all their teeth. The loss of teeth does not signal an end to the need for oral health care. In fact, the health problems of edentulous patients demand continued care. The vast majority of nursing home residents are women. New nursing home regulations on oral health care have been in place for 2 years, but oral health screening is not standardized and no provision is made for coverage of oral health care costs unless the service required is an emergency or is covered by Medicare.

Oral Health Diseases of Postmenopausal and Elderly Women

In addition, a litany of conditions present orally, undermining an elderly person’s quality of life. Several of the most common oral health diseases occur more frequently in elderly women.

Temporomandibular Disease. Headache is a very common presenting complaint. The symptoms of headache range from stress and hypoglycemia to brain tumor and meningitis. Oral health practitioners are often consulted for chronic headaches. One of the causes of chronic headache is temporomandibular joint syndrome. Women have a higher rate of headache from temporomandibular joint syndrome than men. It has been reported that women present for treatment for temporomandibular symptoms five times as frequently as men. Since chronic headache is a debilitating condition, solving and treating headache symptoms appropriately may require input from an oral health practitioner.

Trigeminal Neuralgia. An excruciating burst of pain across the face, triggered by gentle touch or by a change in the position of the neck, may be a sign of this painful chronic condition. The pain may be caused by a variety of conditions, some benign and others which are life threatening. Trigeminal neuralgia is more common in women, and its onset is highest in the fifth decade. Oral health practitioners diagnose the origin of these symptoms and treat this chronic condition.

Atypical Facial Pain. Atypical facial pain is a chronic pain disorder which occurs most frequently in women (female:male ratio is 19:1). Often these patients have been treated by multiple health care providers and have had extensive work-ups for tumor and multiple root canals for possible tooth involvement. More effective integration of care between oral health practitioners and physicians would be helpful in decreasing the number of interventions these patients suffer before the syndrome is recognized.

Pemphigus. Women are more likely to be affected by autoimmune disease than men. Pemphigus is a blistering deforming disease which may present with mainly oral lesions or may involve a large enough area of the skin to be life threatening. Treatment of the oral and skin lesions should be coordinated by the integration of oral health services with the dermatology treatments. Many of the medications used to treat pemphigus have serious side effects: aplastic anemia can be caused by methotrexate, osteoporosis, and fractures result from corticosteroid treatment. Since the total accumulated dose of these agents determines the severity of some of these complications, both the oral health practitioner and the physician need to coordinate care to effectively treat the disease and minimize the complications.

Burning Mouth is an oral and taste disorder of postmenopausal women. This condition presents after menopause and is presumed to be another of the postmenopausal effects of estrogen withdrawal. Estrogen replacement therapy is a possible treatment of this disorder, but studies need to be coordinated between oral health care practitioners and gynecologists to explore this health problem.

Discoid Lupus Erythematosus and Systemic Lupus Erythematosus have oral presentations and occur more frequently in women. Connective tissue disease can be limited and benign, or severe and systemic. Oral lesions can be the presenting feature of these disease. The oral lesions can by painful and may cause malnutrition in the seriously ill patient.

Although the loss of teeth in women has been attributed to alveolar osteoporosis, another cause of tooth loss in women is *periodontal disease*. Periodontal disease occurs frequently in elderly women. Severe periodontal inflammation is a precursor of tooth loss. Non-institutionalized women visit dentists more frequently, suggesting that this periodontal disease is not a product of neglect, but is another disease which affects elderly women.

Fibrous Dysplasia, a disease of bone, occurs more frequently in women and may be exacerbated by pregnancy or estrogen therapy. Fibrous dysplasia of the jaw is seen and diagnosed by oral health care practitioners.

Dental implants are more common in women, and more women are denied dental implants than men. In a study by Andersson, et al., more women than men received single tooth implants. In addition, a larger proportion of women than men were rejected for dental implant placement in this study. The reasons for rejection in this study were not defined, however, most dental implant devices have been tested in jaw locations which are defined by bone geometry. Women have smaller, thinner alveolar ridges which may not be suitable for the devices being tested.

Oral cancer is more common than cancer of the cervix or ovary. Oral cancer is associated with smoking or tobacco use. New patterns of smoking suggest that younger cohorts of women will be at increased risk of contracting oral cancer as they become elderly women. Oral cancers have a poor prognosis, with a survival rate at 5 years of less than 50 percent. Oral cancers are disfiguring and can result in severe disabilities and malnutrition in survivors.

Oral Manifestations of Systemic Disease

Sometimes, oral symptoms are the prodrome of systemic disease. Below are some examples of systemic diseases which oral health care practitioners recognize and treat or refer.

Anemias can be caused by vitamin B deficiency and by iron deficiency. These vitamin deficiencies are associated with painful oral symptoms.

Multiple myeloma is a devastating plasma cell malignancy which may present as facial pain.

Paget's disease of bone predominately affects the elderly. This progressive disease is characterized by bony deformities which may induce neuropathies by compressing nerves. Paget's disease may present with jaw pain or numbness.

Diabetes mellitus may present with oral mucosal infections, altered taste sensation, or complaints of dry or burning mouth. In a study of patients with these symptoms, the frequency of non-insulin dependent diabetes was twice that expected in the general population.

Connective tissue diseases affecting women in greater proportion include *Sjögren's syndrome, systemic lupus erythematosus,* and *temporal arteritis*. These disease have oral and orofacial symptoms and may present to either an oral health care practitioner or to a general health care practitioner.

The Traditions of the Oral Health Practitioner Include Prevention and Screening

Oral health practitioners and their allied health professionals have a tradition of providing effective preventive health care. A visit to the dentist usually encompasses a mixture of education, prevention, and treatment. Eighty percent of general practitioners are trained to take a comprehensive medical and oral history, blood pressure, and any other diagnostic tests which are required for risk assessment prior to the surgical treatments of health care. Preventive counseling highlights caries and periodontal care. However, dental care practitioners also include information on smoking and tobacco cessation (oral cancer risk) and nutrition counseling (caries, alveolar bone loss, anorexia-bulimia-related tooth erosion). In older or more medically compromised populations, dentists are competent to take blood pressures and recommend a physician followup for hypertension control. With the AIDS epidemic, oral manifestations of AIDS in severely immunocompromised, medically complex patients are being treated by oral health care practitioners. In hospitals, dentists are an integral part of the transplant team for heart, lung, liver, and kidney transplant patients. The oral health care practitioner sees patients when they are well, before the subclinical illness becomes clinically evident and forces the patient to present to a physician. Thus, oral health care practitioners recognize systemic disease manifestations and encourage the patient to consult a physician, realizing an important benefit for the patient.

Oral Health in the Medical Curriculum

While there is considerable overlap in the knowledge base of physicians and oral health practitioners, there are also barriers in the education and training of health care practitioners and oral health care practitioners which limit the integration of oral health care and general health care. A recent survey and report of the medical school curriculum sponsored by PHS, HRSA, and ORWH, documented a requirement for instruction in oral health and in women's oral health concerns in only 35 percent of medical schools surveyed. A complimentary study of the dental school curriculum is in progress, and results will be forthcoming this fall, 1997. The gap in knowledge in oral health means that physicians without special training are not informed about oral disease and are not knowledgeable about the role of oral health practitioners in caring for their shared patients. As a physician working at this interface of general health and oral health, I am often a practical link between these two worlds. As an example, I would like to share a case with you which illustrates the advantage of integrating oral health care and general health care.

A Case Illustrating Integration of Health Care and Oral Health Care

The patient, Mrs. G., presented to a third-year dental student in the Clinic of the School of Dental Medicine. The patient was a 60-year-old female with extensive periodontal disease which had led to loss of several teeth. The patient had also been diagnosed with Paget's disease of bone, a localized, benign bone condition which causes bone deformity in the affected bones. Mrs. G. told the dental student that she had been to several dental practitioners asking if she could have dental implants placed. Once her diagnosis of Paget's disease was known, each dental practitioner had told her that dental implants were not possible and that dentures would also be a problem because she had a bone disease. Finally, Mrs. G. ended up at the University Dental Clinic hoping that someone could provide some solution for her tooth loss. The third year student had just finished a research rotation in my laboratory and he knew that my area of clinical expertise was in metabolic bone disease. He refereed the patient to me, asking if there were any contraindications to dental implants or to dentures.

The patient had a previous bone scan which did not show any Paget's disease in her maxilla, which was the area where her teeth had been lost. X-rays of the same area did not show any Paget's lesions in her maxilla. I was able to recommend that either dentures or dental implants could be provided for this patient. A week later, the Oral Surgeon who was inserting the implants called and asked if a bone graft from the pelvis could be used to build up the maxilla to house the dental implants. To this, I definitely replied "no," because the pelvic bones from which the graft would be harvested showed evidence of Paget's disease. In theory, use of the pelvic graft material might result in seeding of Paget's disease into the previously unaffected maxillary bone. A heterologous bone graft was used to build up the maxilla for Mrs. G. While this case did not involve a life and death decision for Mrs. G., her quality of life was seriously impaired before there was an effective integration of her oral health care and general health care.

The integration in this case was only possible because I was in the oral health care setting, interacting with oral health practitioners. Often, the patient is not able to benefit from this kind of integration. For example, in the university-based clinical setting, where I see patients with osteoporosis and metabolic bone disease, I have seen postmenopausal women with oral symptoms of estrogen deficiency, dry mouth, and burning mouth, who have not thought of consulting an oral health care practitioner about their problem, and have been told repeatedly by physicians that they have never heard of such symptoms associated with menopause. I cannot fault the physicians, because I was in the same position as they before I started teaching in the oral health environment.

Implementing Change

The barriers which divide oral health care and general health care for women are being challenged by two approaches. The survey and report of the medical curriculum and the ongoing survey of the dental curriculum should lead to reevaluation of the gaps between the training of health care and oral health care practitioners. One goal should include structuring the respective curricula to provide linkages between the disciplines of medicine and dentistry. Curricula can be designed to decrease the knowledge gaps and to lower barriers to the practice of integrated care. As far as practice integration is concerned, integrated medical and dental services are now beginning to be offered in some managed care settings. Working together on the same patients should help oral health and health care practitioners achieve better integration of oral health and health care for women.

Recommendations for Oral Health and General Health Care for Postmenopausal and Elderly Women

I will close by recommending specific changes aimed at improving oral health care and the integration of oral health care with general health care. First, I am currently involved as an investigator in an AADS nationwide survey of the dental curriculum. The object of the survey is to document the inclusion of women's health and oral health issues in dental school curricula. This survey should provide findings complimentary to the Women's Health in the Medical Curriculum: Report of a Survey and Recommendations (4) which was recently completed by ORWH, PHS, and HRSA. With the completion of our survey, the gaps in women's health and oral health care education can be systematically addressed. As a general frame for closing these gaps and implementing specific changes, I suggest the following three recommendations.

Improve Science Transfer and Education of the Public

The research community is continually improving the depth and applicability of scientific and medical knowledge, but only a very little of this substance is effectively transmitted to the patient and the public. It is imperative that we impact on the education of practitioners. We should also transmit and translate our findings into the area of continuing medical and dental education, and to the public.

Strengthen the Linkages Between Oral Health and General Health

My second recommendation would be a plea for research into the feasibility of integrating oral health clinical problem solving into general medical care and involving oral health care practitioners in the general health care setting. This recommendation is similar to Recommendation 5 from the recent Institute of Medicine Report on Dental Education at the Crossroads. Outcome analysis of the impact on clinical care should be followed for both kinds of practitioners to further the effectiveness of this initiative. This translates into more clinical research to support these studies of integrated care. I would recommend the series of short topics on Oral and Dental Problems in the Elderly edited by Bruce Baum in *Clinics in Geriatric Medicine* as a prototype of this approach. Crosstalk between oral health care practitioners and general health care practitioners should also be fostered in a continuing education environment, or in symposia.

Enhance Research Training Opportunities for Women as Future Educators and Researchers

The NIDR Strategic Initiative II includes a specific goal to enhance training and career development programs to attract and retain exceptional individuals in craniofacial, oral, and dental research. A subgoal is to facilitate the participation of women, ethic and racial minorities, and individuals with disabilities in research. The NSF POWRE program is another program aimed at involving women as future educators and researchers. These goals of inclusion of women as leaders in research and education are key to the future of women's health.

Thank you for this opportunity to give testimony. I will close by quoting C. Everett Koop, "You're not healthy without oral health."

Linda C. Skidmore, M.S.

Committee on Women in Science and Engineering
National Research Council

Committee on Women in Science and Engineering (CWSE) is the one unit of the National Research Council (NRC) that focuses on the retention of female scientists, engineers, and technicians (SETs) in science-based education and employment. This committee has the broad mandate to increase the participation of women in the scientific and engineering (S and E) labor force. Despite women's increasing participation in the S and E workforce during the past decade, the rate of increase of the participation by women of color (minority women) in both postsecondary S and E education and science-related careers remains fairly constant.

- At the undergraduate level, according to the National Science Foundation (NSF) (1996), "underrepresented minorities — blacks, Hispanics, and American Indians — are as likely to earn bachelor's degrees in science and engineering as they are to earn bachelor's degrees in other fields." In 1993, the rates ranged from 7 percent for blacks, 5 percent for Hispanics, but only 0.5 percent for America Indians. However, the rates were even lower for undergraduate women of color: of all S and E baccalaureate awardees, only 3.9 percent were black women, 2.5 percent were Hispanic women, and 0.3 percent were American-Indian women.

- 1996 data available from NSF reveal that "minorities earned 17 percent of master's degrees in science and engineering in 1993, compared with 13 percent in 1985;" however, no change was found for American Indians and the increase for both blacks and Hispanics was only 1 percentage point. At the same time, women were 35.8 percent of all S and E master's degree holders in 1993. Women of color were almost lost among the

"17 percent" figure, for they comprised a smaller group of S and E master's degree holders that year: 2.3 percent were black women, 1.5 percent were Hispanic women, and 0.2 percent were American-Indian women.

- While the basic biomedical sciences, behavioral sciences, and nursing remain attractive to women, oral health research and health services research have recruitment rates less that half of that for basic behavioral sciences. At the same time, women comprise about one-third of the participants in NIH's Medical Scientist Training Program (MSTP), which produces physician scientists.

- Among S and E doctorates, the committee found significant underrepresentation of minorities (particularly minority women) in all other research areas, noting an "alarming shortage of researchers" of all racial ethnic groups in oral health; in that field, participation by black women and men actually declined about 1 percentage point, to 2.6 percent, between 1986 and 1993. In fact, blacks and Hispanics were underrepresented in all five areas as well as among physician scientists. Native Americans were particularly underrepresented among the behavioral science research personnel. Representation by Asians typically reflected their percentage in the total U.S. population; however, the study found that they were underrepresented in the behavioral sciences but overrepresented in oral health research.

- Little difference is found in S and E employment: women are most likely to hold part-time research positions and to be concentrated at the rank of assistant professor. For instance, in 1993, women comprised only 13 percent of physician scientists and less than 19 percent of oral health researchers. Among research faculty, women were most likely to be found in the lower ranks in the basic biomedical sciences and the behavioral sciences, although they comprised about 40 and 55 percent, respectively, of researchers in those two areas.

As a result of the drastic underparticipation of women of color in the technological workforce of the United States, the National Research Council's Committee on Women in Science and Engineering examined, during its third national conference, both the quantitative information about their underparticipation and qualitative data that reflected the experiences common to many minority women interested in pursuing science-based careers. Information presented here is drawn from the transcripts of that conference, "Diversity in Science: Perspectives on the Retention of Minority Women in Science, Engineering, and Health Care Professions."

Anne Stansell *United Silicone Survivors of the World*

Twenty-first century health care must work to bridge the gap between legitimate illnesses suffered by women with silicone breast implants (SBIs) and the manufacturers, who say nothing is wrong.

SBIs have caused serious illnesses in women for over 30 years. Why is it that this issue has received so little attention from the medical community, yet so much attention from the media? The answer is: economics!

SBIs are a major money tree for the manufacturers who, it appears, have convinced the media that their products are safe for the consumer. News reports and advertisements help grow this “money tree” based on misinformation.

They use this money to line their pockets and to buy research that fosters their own purposes. They use this money to give large grants to medical schools, where they tell young doctors and nurses that SBIs are safe and thus continue the money-making cycle!

Many women around the world, who are recipients of SBIs, tell us the truth. They experience many illnesses and symptoms. A recent data gathering of SBI survivors (and I say survivors because some have not survived), reveals the following disease categories and findings (by the way, the FDA now attributes 97 deaths directly to silicone):

- Peripheral neuropathy, 68 percent
- Demyelinating neuropathy, 36 percent
- Organic brain syndrome or cognitive dysfunction, 42 percent
- Lupus or lupus-like, 52 percent
- Fibromyalgia, 87 percent
- Atypical connective-tissue disease, 78 percent
- Mixed connective-tissue disease, 39 percent
- Scleroderma, 12 percent
- Esophageal reflux, 55 percent
- Gastrointestinal dis-mobility, 63 percent
- Chronic fatigue, 95 percent
- Sjögen’s syndrome, 47 percent
- Cancer, 9 percent

While there are a few health care providers around the United States who are treating SBI patients, there is a need for many more. We need providers who will support each other and communicate while treating patients, and share information through a network free from the fear of taunting by fellow physicians. We need providers who are free of pressure from their teaching hospitals which are supported by large grants from SBI manufacturers. We need providers who are *not* biased by previous research paid for and manipulated by SBI manufacturers such as the much-publicized Harvard and Mayo studies.

Most recently, we saw the media blitz by Linda S. Cook of Seattle's Fred Hutchinson Cancer Research Center suggesting that women with SBIs live a more socially irresponsible lifestyle. They have more abortions, drink more alcohol, and use more hair dye. Thus, she purports, there is a chance these "vices" will cause a higher incidence of arthritis and immune system disorders such as lupus and schleroderma. A total of 80 women were interviewed by telephone for that ludicrous "research." Come on now, are we to put much stock in this kind of survey? It borders on insult!

We are anxious to share with the medical community the more than 1,300 peer-reviewed, legitimate medical research articles published in many prestigious medical journals. The most recent appearing in the February 1997 issue of *Lancet*. Fenton Communications has commented on that article in a February 13, 1997, news release. Their commentary describes the research of Dr. Robert Garry of Tulane University. I'd like to share excerpts from that publication:

> A team of prominent researchers has established that women with silicone-gel breast implants, who have elevated levels of anti-polymer antibodies in their systems, also are likely to be afflicted with "severe manifestations" of immune-related health problems. This finding is from a study conducted at Tulane, Louisiana State University, and the Arizona Rheumatology Center.
>
> The study, based on blinded samples in clinical trials, adds to mounting scientific evidence that links silicone-gel breast implants to atypical (as opposed to classical) autoimmune diseases. Many doctors who are treating women with implants have reported these women may be suffering from a previously uncategorized disease.
>
> The lead researcher of the new study, Dr. Robert Garry, says his team developed a test that is able to identify women who specifically fit into this syndrome. "There is a disease out there," Dr. Garry says. "It's still being defined, but now a certain set of symptoms can be objectively measured with a diagnostic test. This assay can help researchers better understand the disease, help women get better treatment, and help manufacturers develop safer biomedical devices."
>
> Dr. Garry, an immunologist and microbiologist with Tulane University, is best known for his work on HIV, including identification of the non-HIV AIDS virus, HIAP. He is the author of more than 200 peer-reviewed articles on autoimmune disease.
>
> The new Garry-led study used clinical diagnostic evaluations of women to differentiate between healthy controls, women with silicone implants with mild symptoms, women with implants with "serious functional impairment," and women with classical immune diseases. The researchers found that only women with implants who are most debilitated by non-classical immune-related problems tested positive for elevated levels of antipolymer antibodies, the result of a reaction by their immune system. "These findings suggest that atypical symptoms represent a phenomenon different from specific, known, autoimmune diseases like rheumatoid arthritis, lupus, scleroderma, and others," said Garry.
>
> A University of Michigan study, presented at the College of Rheumatology's annual conference in October, found that women with silicone medical implants (including breast implants) have a threefold higher risk

> for a broad range of immune-related symptoms. The University of Michigan researchers were the first to conduct a large epidemiological survey of this disease syndrome, which they termed Undifferentiated Connective Tissue Disease (UCTD). Among the symptoms are chronic joint pains, compression of nerves, breathing difficulties, and blood abnormalities.
>
> A UCLA study, "A Case-Control Study of Prosthetic Implants and Selected Chronic Diseases," published in the *Annals of Epidemiology* in November, connected silicone medical implants to neurologic and arthritic conditions.
>
> Recent animal studies, including two by Wayne State University teams also presented at the October conference, have demonstrated that silicone can act as a potent adjuvant, overstimulating the immune system and causing it to break down.
>
> In addition, more than 30 recent studies have contradicted claims by the chemical industry that silicone is an inert, benign substance. "Silicones are neither biologically nor chemically inert, and there is classical and theoretical reason for concern," the *Western Journal of Medicine* has reported, based on a review of the available literature.

What we need to do is to identify and develop a nomenclature for symptoms that mimic classic diseases currently referred to as lupus-like syndrome and arthritis-like syndrome.

The manufacturers are spending $1 million every month on their public relations campaign through Burston-Marsalis in New York. We need to be brave enough to take the attention from the manufacturers and focus on the truth.

Someone once said, "There's lies, there's damn lies, and then there are statistics." Meaning, of course, if one skews the facts enough, you can develop statistics to support anything.

The truth is silicone is *not* an inert substance; it moves through the body and damages vital organs. From the moment of implantation, there is 100 percent incidence of gel-bleed through porous shells, which allows silicone migration.

We now see silicosis in the second generation: children born to mothers after SBI. Silicone has been found in breast milk, and it has also been discovered that silicone crosses the placental barrier. We now have newborns with rheumatoid arthritis, lupus, and esophageal reflux.

Since 1992, the FDA has banned SBIs for general use. SBIs are now only available to survivors of breast cancer for reconstructive purposes. Why is it that so-called medical devices are being implanted in these women whose health has already been harmed; whose immune systems have been compromised? Is it because we are a write-off anyway?

I asked Dr. Kimber Richter, Director of the Center for Devices and Radiological Health, that question at a recent FDA meeting. She and Dr. Marietta Anthony, of the FDA's Office of Women's Health, answered me with another question: "How do we decide which silicone medical devices should be available to the public? Silicone product manufacturers tell us if we continue the ban on SBIs, we should also ban pacemakers and brain shunts."

The answer is ridiculously simple: SBIs are *not* life-saving devices; they are, in fact, life-shortening devices.

To threaten the FDA and the medical community with the loss of good life-saving devices is equal to medical blackmail! These powerful, greedy manufacturers will stop at nothing! Women who are battling breast cancer are extremely vulnerable and cannot — indeed should not — be used as economic and political pawns.

I did not need SBI to survive breast cancer 10 years ago. Now I hope I survive the aftermath of SBI. In my search to regain my health, I have met many courageous women who have dealt with the impact of this life-threatening disease. Their strength of character and resolve to survive has inspired and helped me. My humble tribute to them is “Silicone, the Sequel.” I am pleased to share with you this photographic expression. The project grew out of an idea to put faces with the statistics. We want to let the world know that we are more than the number 440,000 implant survivors.

We are real women, strong women, with real lives and real families. We have dignity, and we are survivors! I thank them, and I thank you for hearing me.

Our Purpose

- To assist men, women, and children injured by silicone and saline implants.
- To educate all people on the facts concerning these implantable medical devices.
- To help all people become informed.
- To give survivors and their families support, and to help women empower themselves in their own healing process.

We have chapters in every state and in many foreign countries.

Leah Stiemel, M.D. *PreNatal Care Network*

Prenatal care is one of the best examples of preventive care and represents the best investment of the health care dollar. Prenatal care offers the best hope for improved pregnancy outcomes and thus represents one of the most important components of obstetrical care. Women who do not receive early and continuous prenatal care have three times the rate of low-birthweight babies. Several preventable factors increase the risk of delivering a low-birthweight baby including lack of prenatal care, maternal smoking, use of alcohol and drugs, pregnancy before the age of 18, and lower socioeconomic and educational levels. Low birthweight is a primary predictor of costs: as birthweight falls, costs increase. It is estimated that more than $6 in neonatal intensive care costs could be saved for every $1 spent on prenatal care.

New Mexico continues to rank next to last in the nation for the percentage of women who receive the recommended level of prenatal care. In 1995, only 52.6 percent of pregnant women in our state received adequate prenatal care. New Mexico still must make considerable improvements to reach the *Healthy People 2000* goal of 90 percent of pregnant women receiving prenatal case in the first trimester of pregnancy.

There were 26,914 births in New Mexico in 1995. Of these births, 11.6 percent were born to women who received late (third trimester) or no prenatal care compared to a national rate of 6 percent. Ethnic and racial differences exist when it comes to receiving adequate prenatal care in our state. In 1995, 61 percent of Anglo women who gave birth received adequate prenatal care, while only 48 percent of Hispanic women received adequate prenatal care, and 40 percent of Native American women received adequate prenatal care.

In addition, the number of babies born to teen mothers in New Mexico in 1995 was 18 percent; New Mexico ranks 49 in the United States for teen birth rate (ages 15 to 17). Of these teen mothers, only 35 percent received adequate prenatal care.

Why such dismal figures for New Mexico? Barriers to accessing adequate prenatal care are similar to access to health care for anyone in New Mexico. In a largely rural state, there simply are not enough health care providers; 30 of the 33 counties are designated health care provider shortage areas. Rural women struggle with traveling long distances for health care, and many lack public transportation to get to their appointments. New Mexico is culturally diverse, so language and cultural barriers affect access to health care. A high level of poverty and lack of health care insurance also influence access to health care.

New Mexico has established two programs to improve health care access for women: the County Maternal Child Health Program and the Community Health Worker Model. The Maternal Child Health Plan Act was passed by the New Mexico Legislature in 1991 to encourage the assessment and prioritization of maternal child health needs and the formation of a maternal child health council at the county level. The Community Health Worker Model is appropriate for New Mexico because it utilizes local resources to take basic education and health services to the client in their home.

New Mexico sits in a vulnerable position with regard to health care for pregnant women, putting its women and future children at a real disadvantage for a healthy birth, and potentially costing New Mexico millions of dollars. Efforts must be increased at all levels — state, county, and local — to change our states' poor ranking in this area. Prenatal care provided in a timely, continuous and regular manner, assists the woman in monitoring the progress of her pregnancy, provides her with essential health information to make sound decisions for herself and her baby, and reduces her risk of having a low-birthweight baby. Improved prenatal care is important for New Mexico's future.

Cecilia Tellez *Self*

Not only are lesbians subject to the same barriers to health care as other women, but they are also subject to barriers that are unique to their sexual orientation. Anti-gay bias within the medical community hinders the ability of lesbians to obtain comprehensive, quality health care. Examples of negative experiences include heterosexual assumptions and bias during the medical interview; perceived health care provider discomfort in treating lesbian patients; homophobic comments; repulsion; ignorance; and inferior care such as rudeness, intimidation, a rough physical exam, and hostility toward the lesbian patient, her partner, and/or her children. Many lesbians conceal their sexual orientation out of fear of disapproval, hostility, suboptimal treatment, or breach of confidentiality resulting in loss of employment, home, educational opportunities, insurance, or custody of children.

Our study is the first large study done on physician attitudes toward homosexuality since 1982. We found substantially less homophobia among physicians than previously reported. We found that the most homophobic specialties were, in ranked order, general practice, orthopedics, surgery, and pathology and radiology as a group. The four most homophilic specialties were psychiatry, pediatrics, emergency medicine, and family practice. We found that gender; specialty; urban versus rural practice; and association with lesbian and gay relatives, friends, colleagues, and patients were all associated with physician attitudes. Ethnicity was not associated with attitudes toward homosexuality. Physician homophobia was separate from issues of fear of AIDS. Although anti-gay bias among physicians is decreasing, it persists as a threat to the quality of patient care to the lesbian population.

Health Concerns. Lesbians have the same gynecological and non-gynecological health concerns as other women; however, lesbians also have unique health concerns. Although the risk for sexually transmitted diseases is lower for lesbians, those who have or have had sexual encounters with men are at risk for herpes viruses and human papillomavirus, and can transmit these infections to their female sexual partners. Most lesbians with HIV infection acquired it from injection drug use or from having sexual relations with men. It is assumed that transmission of HIV between lesbians is rare; however, few or no studies document the rate of female-to-female transmission.

Lesbians are less likely to have an annual gynecological exam than other women. They are probably at higher risk for breast cancer, ovarian cancer, and endometrial cancer than other women because they are more likely to be nulliparous. Lesbians who have never had vaginal intercourse with a man have a lower risk for cervical cancer than women who have or have had male sexual partners.

Sexually active lesbians are just as likely as other sexually active women to have traumatic penetration from digital, manual, sex toy, or penile penetration of the vagina or anus or from sadomasochistic activity. They also can have the same sexual dysfunctional problems that other women have.

Lesbian Families. A lesbian's family may consist of her partner, members of her family of origin, children, friends, or any number of diverse combinations. The partners of lesbians may be left out of family events or health care decisions made by the lesbian's family of origin.

Having children from a known donor, either through insemination or heterosexual intercourse, can potentially set up a lesbian mother for custody battles. In addition, many clinics continue to refuse insemination services to lesbians. Having children from any donors not screened for HIV puts the lesbian mother and her offspring at risk for HIV infection. Many states and adoption agencies do not permit known lesbians to adopt children, making adoption a limited alternative for having children.

Pregnant lesbians may not have support from their families of origin. Role models and support systems are lacking for nonbiological lesbian parents. If the nonbiological lesbian parent is even allowed in the delivery room, she and the biological mother may not be allowed to have the same level of intimacy as heterosexual partners in labor.

Mental Health and Psychosocial Issues. Lesbians do not have any more mental illness than other women, although they do have unique concerns related to their sexual orientation. They risk being rejected by their families of origin, friends, co-workers, and society at large. They risk losing their jobs, their homes, and their custody rights of their children because of their sexual orientation. They are at risk for hate crimes, verbal abuse, physical assault, sexual assault, and murder. Coming out can be stressful enough to lead to depression, self-harming activities, and/or suicide. No research supports the suggestion that psychosocial development of children with lesbian parents is compromised compared to those who are not raised by lesbian parents.

My recommendations may be considered quite ambitious, but I hope that some, if not all, of them will be put into effect.

- Develop curricula, in conjunction with lesbian health experts and activists, on appropriate and sensitive bedside manner with lesbians, lesbian sexuality, and on health, family, and psychosocial concerns unique to lesbians for medical, nursing, and other health care schools to incorporate into their programs.
- Develop continuing education and re-certification curricula, in conjunction with lesbian health experts and activists, on appropriate and sensitive bedside manner with lesbians, lesbian sexuality, and on updates in lesbian health for physicians, nurses, and other health care providers.
- Develop a quarterly newsletter to notify all health care providers of changes and updates in lesbian health.
- Develop a widespread campaign (to include patient literature; newspaper, magazine, radio, and television announcements; and health fairs and lesbian events), in conjunction with lesbian health experts and activists, for lesbians of all ethnicities and languages, ages, and educational and economic backgrounds, on what they should expect from health care providers and on their rights as patients.
- Develop a widespread campaign (to include patient literature; newspaper, magazine, radio, and television announcements; and health fairs and lesbian events), in conjunction with lesbian-health experts and activists,

for lesbians of all ethnicities and languages, ages, and educational and economic backgrounds, on the importance of routine and preventive gynecological and non-gynecological health care, and to dispel myths that lesbians have about their health risks and lack of health risks.

- Develop outreach strategies on how to inform and update all lesbians on health, family, and psychosocial concerns unique to lesbians.
- Develop patient education materials to inform lesbians of all ethnicities and languages, ages, and educational and economic backgrounds on lesbian sexuality, and on health, family, and psychosocial concerns unique to lesbians and not unique to lesbians.
- Develop workshops on how health care providers can encourage lesbians of all ethnicities and languages, ages, and educational and economic backgrounds to access health care.
- Develop Lamaze, childbearing, and childraising classes for lesbians of all ethnicities and languages, ages, and educational and economic backgrounds.
- Develop workshops for domestic violence and sexual assault workers to better serve their lesbian clients.

Patricia King-Urbanski, R.N., M.S.N., C.C.E., L.C.S.

Association of Women's Health, Obstetric and Neonatal Nurses

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) was established in 1969 within the American College of Obstetricians and Gynecologists as the Nurses Association of the American College of Obstetricians and Gynecologists (NAACOG). In 1993, the organization became an independent, nonprofit association now known as AWHONN. AWHONN continues the commitment of ensuring that women and newborns receive quality health care.

AWHONN's mission, to promote excellence in nursing practice to improve the health of women and newborns, is carried out by 22,000 members throughout the United States, Canada, and abroad. Representing a diversity of talents and experience, the members give the organization its strength and demonstrate why AWHONN is considered to be *the voice* for women's health, obstetric, and neonatal nursing care.

Sandra Welner, M.D.

Primary Care Gynecology for Women with Disabilities and Chronic Illnesses

Esteemed colleagues and friends, it is my honor and privilege to speak to you today regarding a special population of women in whom gaps in knowledge are great. I am referring to the over 27 million women with disabilities and chronic conditions in this country. These women are of all ages, races, and ethnic backgrounds. Disability does not discriminate. As America ages, all of us may confront a time in our lives where we may experience a decline in our independent functioning. Thus, as we chart new courses for improvements in health care delivery for women with disabilities and chronic conditions, these improvements may affect many of us personally at some point in our lives.

What are these gaps that I am speaking of? Certainly you might say there are a lot of advances in health care research and health care policy, and all of these changes and improvements most certainly, by extension, should be improving health care for women with disabilities and chronic conditions. Unfortunately, this does not happen automatically. Although all women have the same chromosomal compliments, their health care needs may be vastly different from each other and from women in the "mainstream society." I would like to turn your attention to key areas which I feel deserve our attention as we chart new courses for improving health care for all women.

We may take it for granted that medical care, if available, can be obtained. Unfortunately, for women with disabilities and chronic conditions, accessibility issues may prevent such medical care from being received. Structural barriers may limit access to facilities where medical care is administered although architectural barriers are improving — not all private doctor's offices and some older facilities will have made the appropriate structural modifications to allow easy entry for a woman with a disability or chronic condition. These women may be wheelchair users, ambulatory with canes or crutches, or suffer from a debilitating disorder which causes excessive fatigue — making stairs and high curbs a daunting obstacle. Other aspects of physical accessibility should not be overlooked. Some medical offices are not large enough to accommodate a woman in a wheelchair. Examination rooms may not be large enough to accommodate a patient in a wheelchair, an exam table, and other exam room equipment permitting the patient and any assistant to have adequate space to get the medical care she requires. In order to be truly accessible, bathrooms must consist of more than a small, closet-sized room with a toilet and hand rail. Guidelines for true accessibility in structural design are available but may not always be followed.

Frequently, suitable equipment is also not available. It is somewhat humiliating to have a woman have to go to a loading dock to be weighed if she is in a wheelchair. Platform scales for wheelchairs are available, however, very few centers caring for women have these on site. Examination tables, which lower to wheelchair height, are available for purchase with special design tailored to the diversified needs of women with chronic conditions and disabilities. However, these tables are often not found in many centers providing health care to women, thereby necessitating extra personnel to lift the patient on and off the examination table. This transfer has resulted in patients being dropped and suffering further injuries. It is also somewhat humiliating for extra people to hold a woman's legs apart while the health care professional is performing a pelvic examination. Unfortunately, equipment which would eliminate these dangerous and unpleasant experiences is frequently not purchased.

It is not surprising that if a woman cannot find accessible transportation to go to her medical appointments, she will not receive medical care. This seems to be such an obvious barrier but in many locations reasonably priced accessible transportation is unavailable. Some forms of insurance cover transportation to medical appointments, and some do not. There are models in isolated areas across the country for low-cost accessible transportation. However, these programs have not been universally implemented in all locations.

Insurance coverage for necessary medical care may be quite limited for many women with disabilities and chronic conditions, many of whom are not in the workforce or are single parents, or may have low-paying jobs. There is a real disincentive for a woman with a chronic condition to be employed at a job which does not have health benefits but has an earning level that would make her ineligible to receive publicly funded medical support. Even when insurance coverage is available, the specialized types of care required by women with complex medical conditions may not always be covered by the woman's health plan. The specialists and facilities that are expert in her unique condition are often not among the participating facilities at which she is allowed to receive her care. The false economy of having insurance cover suboptimal care, leading to serious secondary and avoidable complications, is obvious to women with disabilities and chronic conditions, but seems to be unrecognized by most health plans.

In order to provide appropriate medical care, we first need to determine the guidelines for what is considered to be appropriate medical care. Because there has been so little attention focused on research into medical care for women with disabilities and chronic conditions, such guidelines and standards are very poorly developed. The gaps are many: from basic medical needs to reproductive health care, to issues surrounding the aging process. To complicate these issues, different disabilities affect a woman's health in different ways, so generalizations on what would be applicable to all women cannot possibly apply. Each major disability group requires specific research questions to be asked and answered. In order to map out guidelines for appropriate medical treatment and standards of care, this research must be done. Otherwise it would be clearly impossible for necessary treatment to be ascertained as necessary, or alternatives explored. Some basic concepts, pertaining to health of women with disabilities and chronic conditions, are known but are not being taught to health professionals in any comprehensive fashion, neither during their training nor in medical conferences and publications.

Twenty-seven million women is a large number of women. These women are becoming more empowered because of the backing of federal legislation through the American's with Disabilities Act, Human Rights Acts, and other legislation. These are positive steps. However, these advances do not eliminate the gaps in medical care and medical knowledge that restrict women from receiving appropriate and adequate comprehensive care. In these women, more than in other populations, psychosocial factors may have a significant influence on compounding existing limitations. These limitations could also be improved or eliminated with the acknowledgment of the importance of assistive services to maximize independent functioning and productivity. This goal is a fairly universal one and most women would prefer to be contributing members of society but may need some assistance in doing so. If there is no medical coverage for such assistance, lack of knowledge on appropriate medical treatment, lack of awareness among medical professionals, and economic barriers for self determination, women with chronic medical conditions, although desiring to continue to be healthy and productive, may be prevented from doing so.

Joanne M. Williams, R.N.C., C.N.P. *OB/GYN Certified Nurse Practitioner*

Lack of Knowledge Regarding Hormone Levels and Effects on Aging and Disease

It is a known fact that as we age our hormone levels drop, the aging process accelerates, and degenerative diseases becomes more prevalent (i.e., decrease in mental function, decrease in muscle mass, coronary vascular disease, cancer [breast], osteoporosis, diabetes, etc.). There is a lack of long-term studies regarding the relationship between these processes and all natural hormones, specifically the "super hormones" (i.e., DHEA, Natural Estrogens [Estradiol, Estrone, Estriol], Human Growth Hormone, Melatonin, Natural Progesterone, Pregnenolone, Testosterone, and Thyroid Hormone). Because most studies are funded by pharmaceutical companies, they are conducted using synthetic hormones. This is an opportunity for NIH to support research that includes natural hormones.

More and more women are wanting natural solutions that produce improved quality of life as they age. Additionally, they are interested in the whole body (holistic) approach, which for many includes natural hormones. It is imperative that we develop a better understanding of these natural hormones and how they impact women's health over their life span.

Caroline J. Yu, M.P.A. *National Asian Women's Health Organization*

I wish to inform you about the most recent efforts of the National Asian Women's Health Organization (NAWHO) to expand the public knowledge about the reproductive and sexual health of Asian-American women. NAWHO is the only national agency of its kind that is solely dedicated to improving the health status of Asian women and girls. NAWHO's mission is to empower Asian women and girls, through a framework that reflects commonalties and differences within Asian-American communities, and ensure equal and adequate access to health care and life advancement opportunities.

In the area of research, NAWHO's goal is to close the major gaps in baseline health information, including gender- and ethnic-specific documentation, and address the need for reliable and timely data for policies and programs on Asian-American women's health. In particular, NAWHO has focused on reproductive and sexual health needs and concerns. NAWHO has found that, overall, Asian women's sense of risk regarding reproductive and sexual health is downplayed. Many Asian women only seek medical attention when the pain or symptoms of infection became unbearable or interfer with daily functioning.

To further examine these issues, NAWHO conducted a survey of 674 Asian-American women in California, a study that has been documented in NAWHO's 1997 publication, *Expanding Options*. The survey sought to analyze the knowledge of, attitudes towards, and use of reproductive health technologies by Asian-American women between the ages of 18 and 35 in six California counties with significant Asian populations.

The survey indicates clearly that Asian-American women are sexually active and thus face a number of decisions regarding their sexual and reproductive behavior. In brief, the survey found that nearly half of the women surveyed (49.8 percent) had not visited a health care provider within the last year for reproductive or sexual health needs, compared to 3 percent of women in a nationwide Kaiser Family Foundation study. In addition, one fourth of these women have never received reproductive health care in their entire lives. Also, Asian-American women are not adequately protecting themselves against pregnancy and sexually transmitted diseases, with 61 percent stating that they did not always use contraceptive methods.

Based on the survey results, NAWHO makes several recommendations to health educators and providers, women's health advocates and activists, and policymakers in the areas of information, services, research, and policy, including the need to make no assumptions about Asian-American woman's knowledge and understanding of contraceptive methods or reproductive health in general. These recommendations are detailed in *Expanding Options*, which may be obtained by calling the NAWHO office at (415) 989-9747.

Diana Zuckerman, Ph.D.

National Women's Health Network
Institute for Women's Policy Research

The National Women's Health Network focuses on the need for women to make informed decisions about their health care. We are concerned about a wide array of health issues, but, reflecting the interests of women across the country, breast cancer has been a particular concern. We believe that NIH would do a great public service by focusing greater attention on the unnecessary use of mastectomies in situations where the woman has no evidence of breast cancer, has no evidence of invasive breast cancer, or has a breast cancer that most experts believe does not require a mastectomy.

The history of breast cancer treatment in this country is a history with surgery as its central focus. Thousands of women were subjected to radical mastectomies before it was determined that less-radical breast removal was as effective in saving women's lives, and even then, the practice of medicine changed slowly. Mastectomies were also recommended for thousands of women with "fibrocystic breast disease" before research indicated that this was unnecessary. Similarly, when NlH-funded research and an NIH consensus conference indicated that lumpectomies were as effective with Stage I and Stage II breast cancers as mastectomies in saving women's lives, there was still a lag before medical practice reflected those findings. In some parts of the country, it appears that women are still being encouraged to undergo mastectomies in situations where virtually all experts would argue that they are unnecessary. NIH has played an important role in informing doctors and the public about appropriate medical treatment for cancer, and we believe that it is time for NIH to become more actively involved in some of the newer controversies regarding mastectomies.

Breast-conserving Surgeries

Several studies have shown that in certain parts of the country, and at more sophisticated medical facilities, women with Stage I or Stage II breast cancer are more likely to undergo breast-conserving surgeries rather than mastectomies. These regional variations were first noted in research published in the early 1990s. Although the rates of mastectomy as a percentage of breast surgeries has decreased in all regions of the country since then, the regional differences have been maintained. There are several possible explanations for these differences: the advice given by physicians, the attitudes of patients, and such practical factors as the difficulty of traveling long distances for repeated radiation treatment in some parts of the country. Despite the NIH consensus conference in 1990, there is clear evidence that many patients are not receiving the information they need to make the choices that are best for them.

Breast Cancer Genes and Preventive Mastectomy

Perhaps the most controversial issue is the use of mastectomy to prevent breast cancer in women whose family history of breast cancer has convinced them that mastectomy is the best strategy to save their lives. Certainly, women have the right to make this choice, but we are concerned that the choice is being made on the basis of very preliminary estimates of the likelihood of breast cancer associated with the breast cancer genes (BRCA1 and BRCA2); these estimates could prove to be quite inaccurate. We turn to NIH to do more to inform physicians and potential patients about these issues, such as holding a consensus conference and supporting desperately needed research and public education efforts.

Ductal Carcinoma in Situ of the Breast

The diagnosis of ductal carcinoma in situ (DCIS) has been increasing in recent years, but the diagnosis remains poorly understood. Many women report that their doctors advised them to have a mastectomy “to be safe” even though there was no sign that the cancer would spread. Other physicians tell their patients that DCIS is a precancerous condition or a very early form of cancer which can best be treated with a lumpectomy, with or without radiation treatment. Differences in suggested treatment choices may be based on differences in diagnostic findings, but it appears that differences in physicians’ attitudes and knowledge also greatly influence the advice a patient is given. We believe that NIH can do more to study the extent to which mastectomies may be unnecessarily performed for DCIS, and to inform the public and the medical community about the options that are most appropriate under various circumstances.

Lobular Carcinoma in Situ of the Breast

The diagnosis of lobular carcinoma in situ (LCIS) of the breast is less common, but the suggested treatment also varies from “watchful waiting” to double mastectomies. Since LCIS is not a strong predictor of invasive breast cancer, we strongly believe that women should be fully informed before making a irreversible decision to have a mastectomy. Again, we turn to NIH to do more to support research and inform the medical community and the public through a consensus conference or other means.

In conclusion, we are concerned that women patients who are at risk for breast cancer, and have been diagnosed with DCIS or LCIS, or Stage I or Stage II breast cancer, may not always receive the most accurate, up-to-date information about their treatment options. Although NIH's major focus is on basic research, NIH has played an important role in improving medical treatment through a wide range of research projects, and through various public education strategies. These efforts are essential in helping to make more accurate, understandable information available to patients and consumers.

WORKSHOP AGENDA AND PARTICIPANT ROSTER

BEYOND HUNT VALLEY:
RESEARCH ON WOMEN'S HEALTH FOR THE 21st CENTURY

Santa Fe Hilton Hotel
Santa Fe, New Mexico

July 21-23, 1997

AGENDA

Sponsored by:	***Office of Research on Women's Health*** ***National Institutes of Health***
Hosted by:	***University of New Mexico*** ***School of Medicine***
	University of Iowa ***College of Pharmacy***

MONDAY, JULY 21, 1997

PUBLIC HEARING DAY 1

9:00-11:00 a.m. ***Meeting***

- Task Force
- Working Group Cochairs
- Rapporteurs

1:00-2:40 p.m. ***Public Testimony: Women's Health Research for the 21st Century***

- ***I. Continuing or Emerging Gaps in Knowledge About Women's Health Across the Life Span***
- ***II. Population Differences: Race, Culture, and Ethnicity and Their Impact on Women's Health***
- ***III. Women with Special Health Concerns: Recommendations for Future Research***
- ***IV. Career Issues for Women Scientists***

2:40-3:00 p.m. ***Break***

3:00-5:00 p.m. ***Public Testimony continues***

TUESDAY, JULY 22, 1997

SCIENTIFIC WORKSHOP DAY 2

Special Populations of Women: Factors Impacting Health and the Scientific Research Agenda

7:00 a.m.-6:30 p.m. ***Conference Registration***

7:00-8:00 a.m. ***Continental Breakfast***

8:00 a.m.-12:00 p.m. ***Opening Plenary Session***

8:00-8:20 a.m. ***Opening Remarks***
Dr. Vivian W. Pinn

Welcoming Remarks
Dr. Gloria E. Sarto
Dr. Mary J. Berg

8:20-8:50 a.m. ***Overview: Beyond Hunt Valley: Research on Women's Health for the 21st Century***
Dr. Vivian W. Pinn

8:50-9:10 a.m. ***The Health of Special Populations of Women: Implications for Research***
Dr. Gloria E. Sarto

9:10-10:15 a.m. ***Panel Discussion: Definitions of Race, Culture, and Ethnicity***
Moderator
Dr. Vanessa Gamble

OMB: Current Activities
Ms. Katherine Wallman

Anthropological Perspectives
Dr. Louise Lamphere

Comments: Implications for NIH-Funded Research
Dr. Belinda Seto
Dr. Otis Brawley

Discussion

10:15-10:30 a.m. ***Break***

10:30-11:30 a.m. ***Panel Discussion: Impact of Traditional and Cultural Health Practices***
Introduction
Dr. Gloria Sarto

Co-Moderators
Dr. Linda Burhansstipanov
Dr. Amelie Ramirez

Asian
Dr. Barbara Yee

Hispanic
Dr. Helen Rodriguez-Trias

Hawaiian
Dr. Carol Korenbrot

African American
Dr. Marcia Bayne-Smith

Doctor-Patient Relationships
Dr. Marianne Legato

11:30-11:55 a.m. ***Discussion***

11:55 a.m.-12:00 p.m. ***Charge to Working Groups***
Dr. Marianne Legato
Dr. Donna Dean

12:00-1:15 p.m. ***Lunch***
Introduction of Speaker
Dr. Amelie Ramirez

Traditional Mexican Folk Medicine and Folk Beliefs: Their Influence in the Southwest
Dr. Eliseo "Cheo" Torres

1:30-4:15 p.m. ***Convening of Working Groups by Life Span***
Prenatal Years
Infancy and Childhood Years
Adolescent Years
Reproductive and Middle Years
Perimenopausal Years
Postmenopausal Years
Elderly and Frail Elderly Years
Career Issues for Special Populations of Women Scientists

4:15-4:30 p.m. ***Break***

4:30-6:15 p.m. ***Plenary Session***

4:30-6:15 p.m. ***Panel Discussion: Cancer Genetics and Its Implications for Different Populations of Women***

Moderator
Dr. Karen Antman

Breast Cancer Genetics
Dr. Barbara Weber

Breast Cancer Epidemiology
Dr. Elizabeth Schubert

Decision Analysis
Dr. Deborah Shrag

Ethics
Dr. Joan Gibson

Genetic Counseling
Ms. Stephanie Smith

Discussion

6:15 p.m. ***Adjourn***

6:30 p.m. ***Networking Reception — Native American Dance Program***

WEDNESDAY, JULY 23, 1997

SCIENTIFIC WORKSHOP DAY 3

7:00-8:00 a.m. ***Continental Breakfast***

8:15-9:30 a.m. ***Plenary Session***

8:00-8:15 a.m. ***Opening Comments***
Dr. Vivian W. Pinn

8:15-8:45 a.m. ***Introduction of Speaker***
Dr. Mary J. Berg

Psychosocial, Behavioral, and Educational Factors that Affect Population Differences in Health Among Women
Dr. Norman Anderson

8:45-9:00 a.m. ***Discussion***

9:00-9:15 a.m. ***Introduction of Speaker***
Dr. George Bryan

Health Issues for Women with Disabilities
Ms. Carol Howland

9:15-9:30 a.m. ***Discussion***

9:30-9:45 a.m.	***Break***
9:45 a.m.-12:00 p.m.	***Concurrent Working Groups (continue)***
12:15-1:15 p.m.	***Lunch*** ***Introduction of Native American Cultural Program*** Dr. Linda Burhansstipanov ***Where Tradition Meets Science: Traditional Practices in Conflict with Western Medicine*** Dr. Tieraona Low Dog
1:15-2:30 p.m.	***Closing Plenary Session***
1:15-2:25 p.m.	***Plenary: Working Group Reports*** Working Group Cochairs ***Discussion***
2:25-2:30 p.m.	***Closing Remarks/Adjourn*** Dr. Vivian W. Pinn

BEYOND HUNT VALLEY:
RESEARCH ON WOMEN'S HEALTH FOR THE 21ST CENTURY

SANTA FE, NEW MEXICO
JULY 21-23, 1997

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