

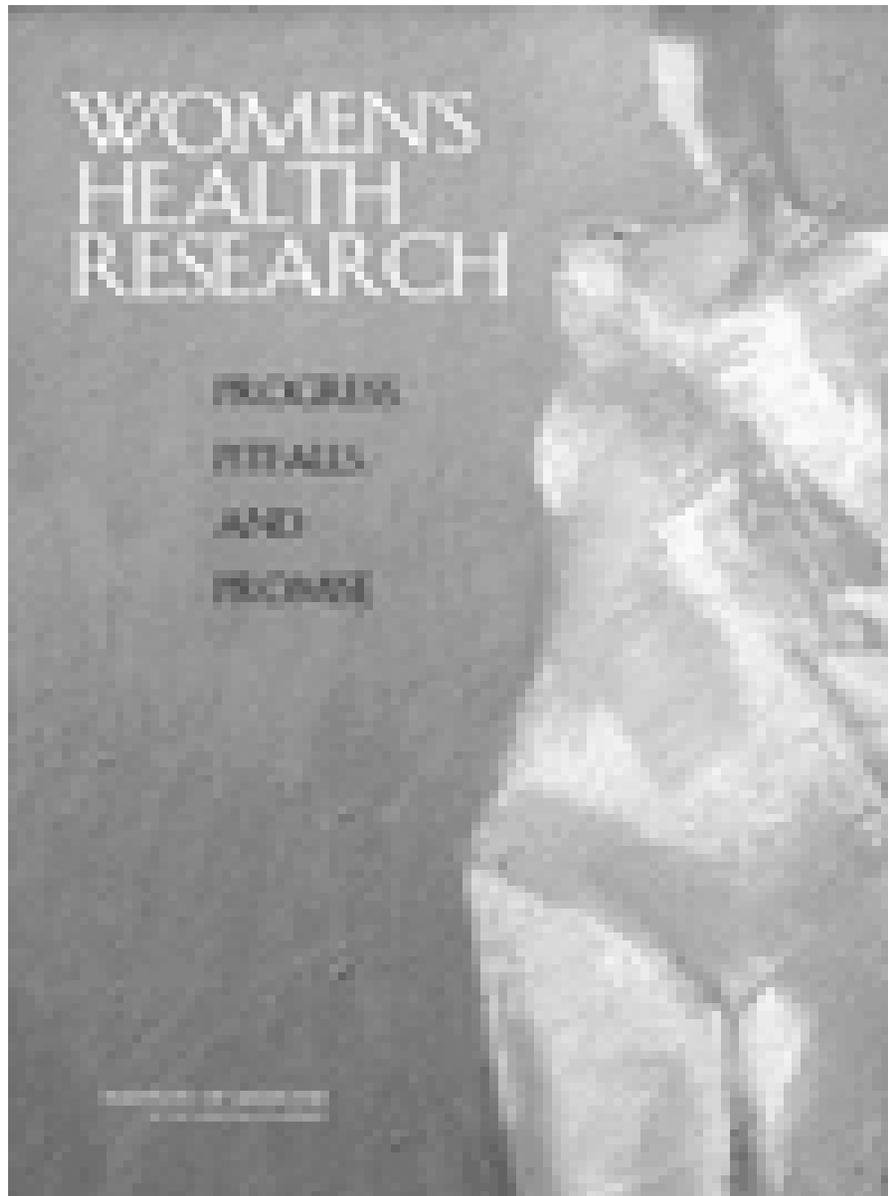
CONSORTIUM • PBRN

VA WOMEN'S HEALTH RESEARCH NETWORK

Supporting Practice and Research Collaboration

Spotlight on Women Cyberseminar Series

Funded by the VA HSR&D (Project# SDR 10-012)



Women's Health Research: Progress, Pitfalls and Promise

Committee on Women's
Health Research, Board on
Population Health and
Public Health Practice

Institute of Medicine *of the*
National Academies

National Academy Press,
Washington, DC, 2010

Reviewed by Robert B.
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University of Iowa

Agenda for Today

- Discuss the genesis of the report
- Outline the structure of the report
- Discuss some of the key findings
- Provide comment on the nature and success of the report in meeting its goals
- Suggest some additional directions for Women's Health Research

Source of the Study and Funding

- Consolidated Appropriations Act of 2008 (PL 110-161)
- Department of Health and Human Services
- Office of Women's Health

“To conduct a comprehensive review of the status of women's health research....

....summarize what has been learned about how diseases specifically affect women....

....report to the Congress on suggestions for the direction of future research.

Committee's Approach to the Issues

...focused on health conditions that:

- are specific to women
- are more common or more serious in women
- have distinct causes or manifestations in women, or
- have high morbidity or mortality in women

(Forms a definition of women's health research)

Not all conditions could be evaluated, so examples:

- specific to women
- differences in prevalence or severity, preferred treatment or understanding among women
- special research needs, whether or not there are sex differences

General Questions Posed by the Committee On Women's Health Research

1. The most appropriate and relevant determinants of health?
2. Focus on the most appropriate and relevant conditions and end points?
3. Are the most relevant groups of women being studied? (e.g., SES groups at highest risk of various diseases)
4. Are the most appropriate research methods being used to study women's health?
5. Are the research findings being translated in a way that affects practice?
6. Are the research findings being communicated effectively to women?

Substantive Chapters

- A. Administrative history of major agencies and programs related to women's health (Intro chapt.)
 - B. Research on Determinants of Women's Health
 - C. Research on Conditions with Particular Relevance to Women's Health
 - D. Methodologic Issues in Women's Health Research
 - E. Transforming Discovery to Impact: Translation and Communication of Findings of Women's Health Research
 - F. Recommendations
- Appendix C: Selected Studies of Women's Health

A. Administrative History of Women's Health: Issues

Useful US federal regulatory and agency history;
congressional actions; major studies

Begins with 1977 FDA regulation banning clinical research
on pregnant women, due to thalidomide and
diethylstilbestrol experience (*and the backlash*)

Some issues (*and scholarship needs*):

- Omits the history and role of the women's movement and effect
on policy and politics
- Over the centuries, were women's diseases less attended to by
medical research?
- If so, two major reasons: 1) military role in health science
2) the 20th Cent. coronary epidemic

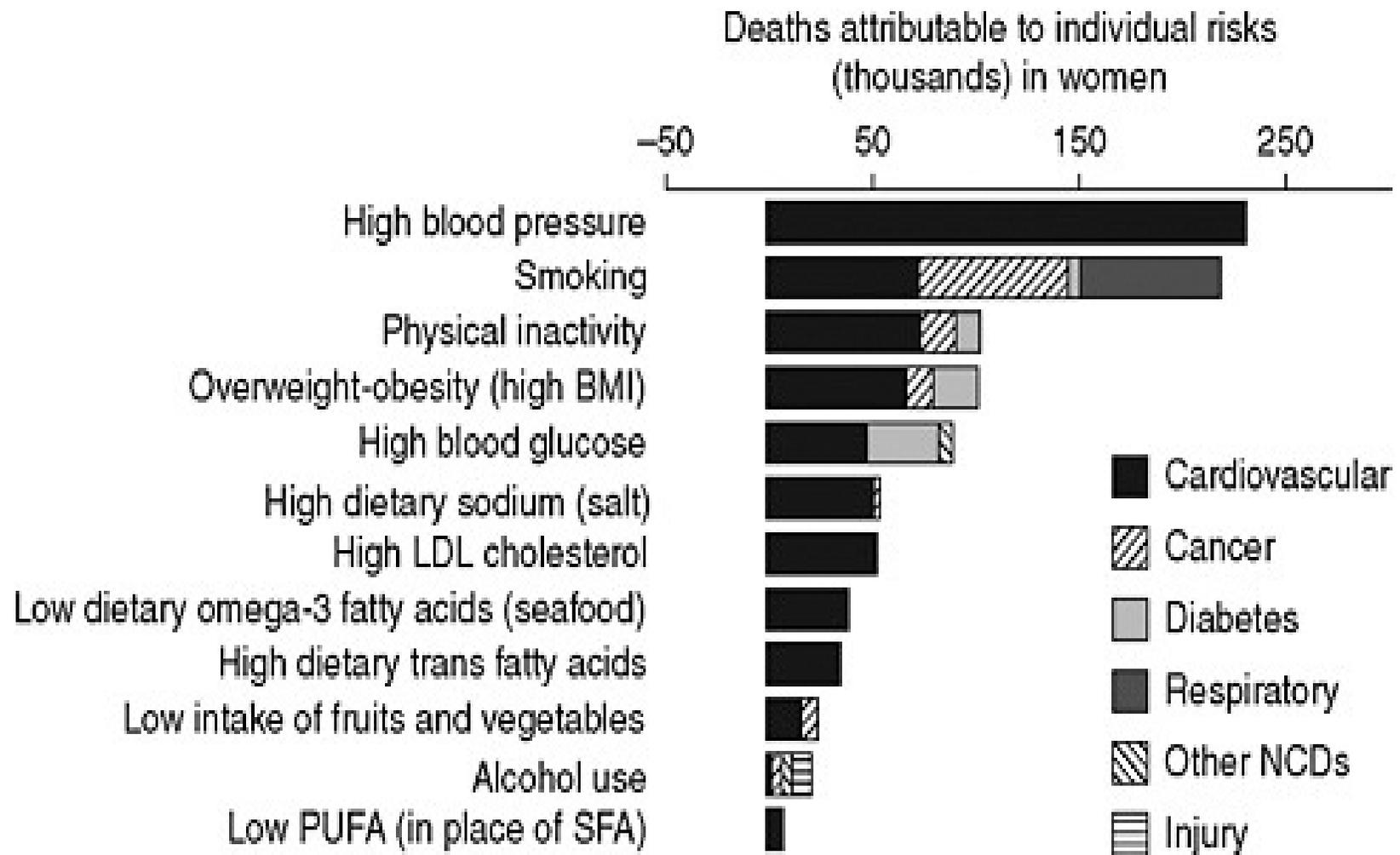
(How do you study gender bias in health research?)

B. Research on Determinants of Women's Health (Risk Factors)

- Most (or all) of the risk factors are related to conditions affecting both men and women
- Takes a behavioral as well as physiological approach
 - Vulnerable populations
 - Diet, exercise, blood pressure
 - Sexual risk behaviors
- Evaluates interventions on risk factors
- Social connectedness; exposure to violence, substances
- Access to health care as a “risk factor”

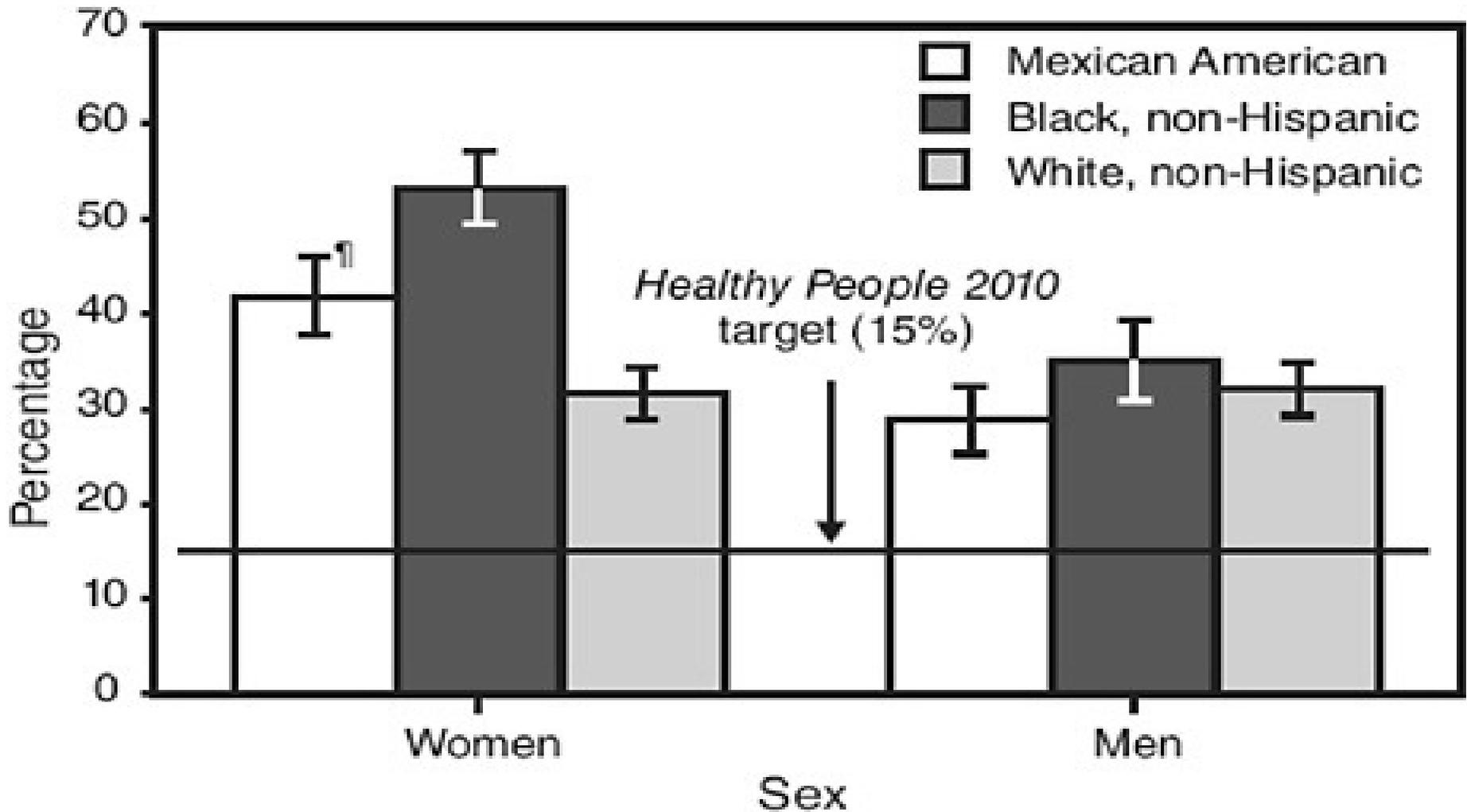
Risk Factors Responsible for Attributable Deaths In Women

(Figure 2-2 in Report)



Prevalence of Obesity in the US

(Figure 2-3 in the Report)



Some Important Areas Not Well Covered for Disease Risk Factors

- Physio-chemical environment in general
- Genetic/ biological mediation of general environments
- Public health programs and policies
- Effects of workplace on health

C. Research on Conditions with Particular Relevance to Women's Health

The Report's Approach:

- Occurrence/ mortality
- Disparities in groups
- Advances in prevention
- Advances in diagnosis
- Advances in treatment
- Knowledge gaps

Progress in Surmounting Medical Conditions

Research has contributed to major progress

- Breast cancer
- Cardiovascular disease
- Cervical cancer

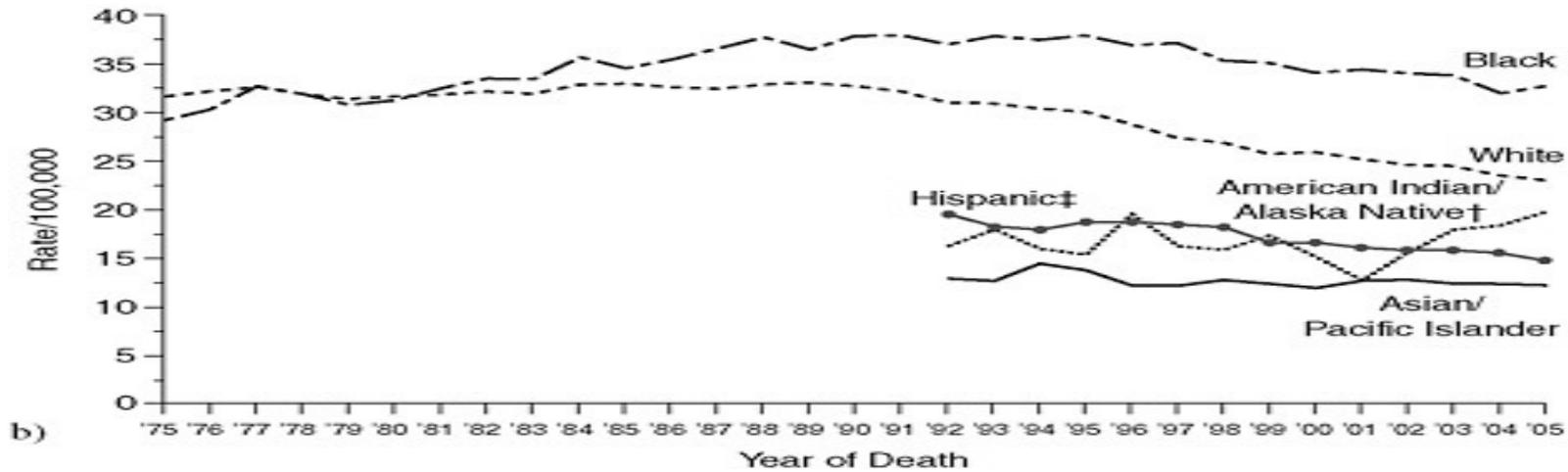
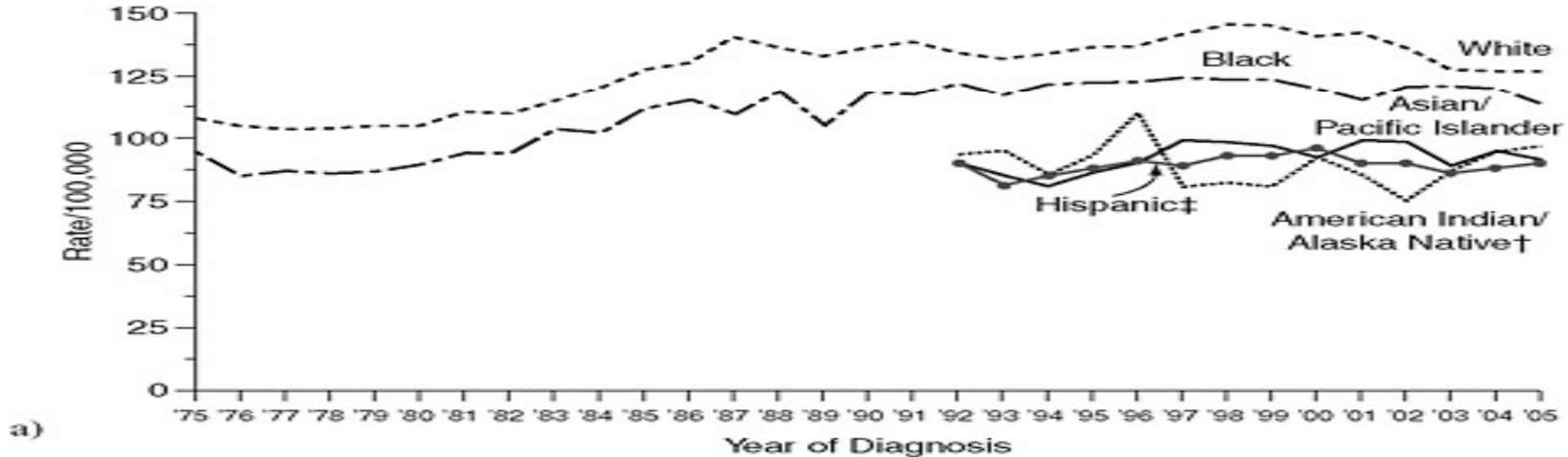
Research has lead to some progress

- Depression
- HIV/ AIDS
- Osteoporosis

Conditions with little progress

- Unintended pregnancy
- Maternal morbidity and mortality
- Autoimmune disease
- Alcohol & drug addiction
- Lung cancer
- Other gynecological cancers
- Non-malignant gynecol. cond.
- Alzheimer's disease

Occurrence of Breast Cancer-United States



Comments on this Approach

1. Information on disease control is widely available and understood among clinicians
2. Applaud some representation of mental illness, but probably not enough
3. Some conflating of social with medical issues (e.g. unintended pregnancy)
4. The largest group of medical conditions in women (and men) is “Other,” e.g.:
 - Skin conditions
 - Other mental illnesses
 - Degenerative arthritis
 - Neurological cond.
 - Gastrointestinal cond.
 - Endocrine cond.
5. No particular attention to public health or aging

D. Methodologic Issues in Women's Health Research

- Short chapter; technical study designs not revisited:
- Some general issues usefully characterized:
 - Inclusion of women in studies of men and women; or women-only studies
 - Sampling
 - Statistical power for subgroup analysis
 - Routine sex-specific analysis of data
 - Revisiting the fetal harm issue
 - Female-appropriate endpoints (e.g., unstable angina)
 - Quality-of-life endpoints that are women-oriented
 - Composite outcomes (e.g., WHI's Global Health Index)

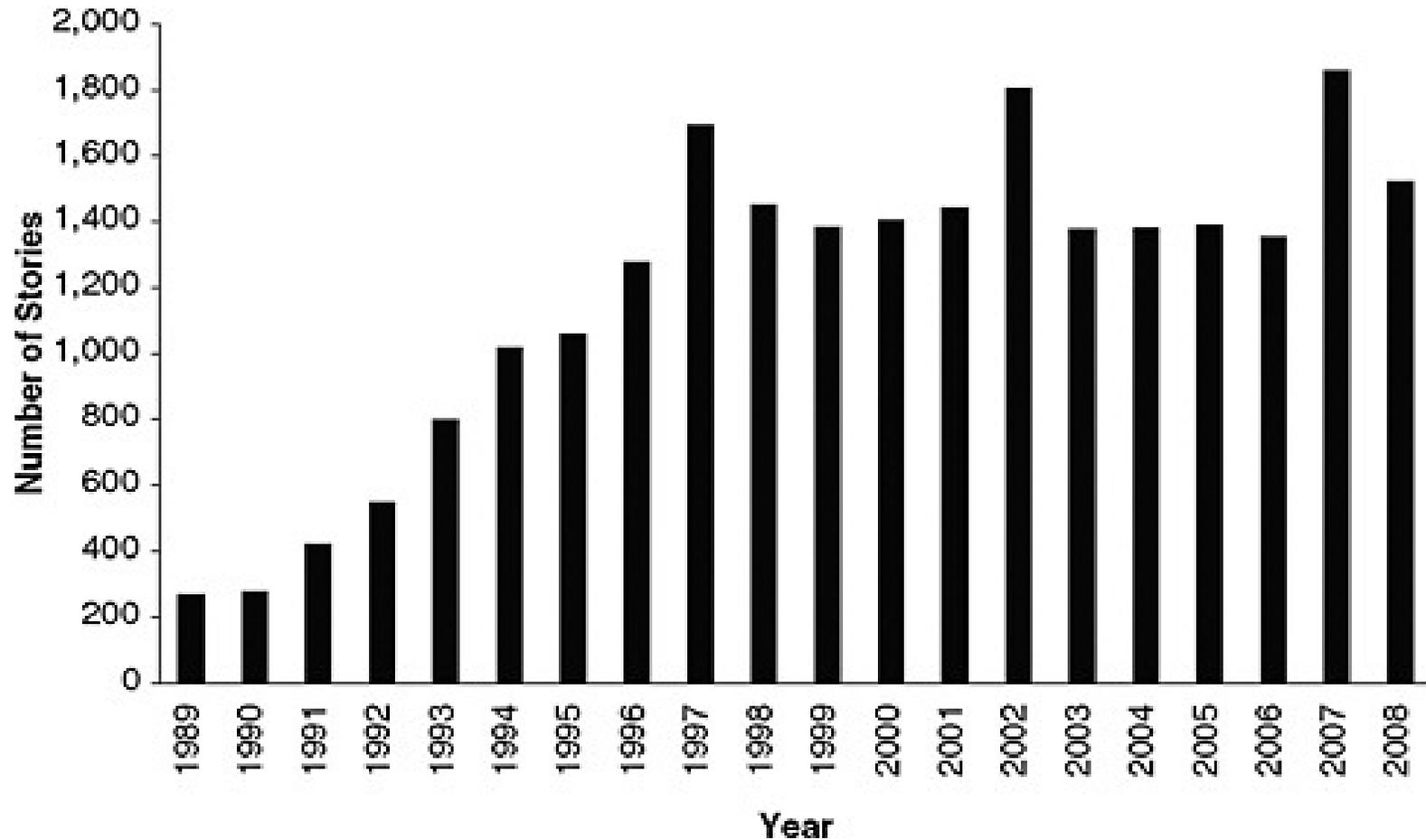
E. Translating and Communicating Women's Health Research

- *VA given credit for maintaining women's health research centers!*
- Who should translate? Gov't; investigators; media; industry? Not solely a women's issue
- Social and cultural issues in translation
- Special issues in communication
- Barriers in patient decision-making (Building in decision aids into the system)
- Barriers associated with health care providers – health plans and providers

A Case History of Prevention in Women: Mammography

Number of News Items on Mammography, by Year

Lexus-Nexus Database (Figure 5-2 in the Report)



New York Times Article--2002

WEEK IN REVIEW DESK | February 10, 2002, Sunday

The Nation: Second Opinion; The Painful Fact of Medical Uncertainty

By GINA KOLATA (NYT) 1088 words

Late Edition - Final, Section 4, Page 5, Column 1

ABSTRACT - Debate over role of mammography in early detection of breast cancer discussed; photo (M)

New Mammogram Studies Divided on Benefits

By GINA KOLATA

Two papers published today on the benefits and risks of mammography come to different conclusions about the breast cancer screening, continuing a debate that has erupted over the past year.

One paper, by the United States Preventive Services Task Force, makes recommendations that are generally followed by the nation's primary care doctors and concludes that the pooled data from randomized trials support mammography every one to two years for women ages 40 to 74.

The group announced its conclusions at a news conference last winter, but its paper, being published today in *The Annals of Internal Medicine*, is the first formal publication of its methods, results and conclusions.



Marty Katz for The New York Times

Dr. Steven Freedman has written an editorial questioning the public

wrote that his interpretation of an analysis of several large randomized clinical trials in Sweden was that they also failed to find a benefit from mammography in women under 50.

"The big picture message is that the effect of screening in any age group is limited at best," Dr. Sox said in a telephone interview. He said there appeared to be a small benefit in women starting at 50, and so he agreed with the task force for that age group. But, he said, for women in their 40's, "it is not clear that there is any benefit at all." With such questions, he added, "I think we should be worried about harms."

In interviews, medical experts with different views on the test's value maintained opinions that they had previously expressed.

Dr. Harmon Eyre, chief medical officer of the American Cancer Society, applauded the task force's re-

A Missed Opportunity for Scholarship (and Prevention Research)

- Why doesn't this uproar occur among men for prostate cancer?
- Why doesn't this happen among women concerning lung or colon cancer?
- What drives the culture of prevention?
- How do women, and the public in general, deal with ambiguous, controversial science?

Gender Concordance and Physicians' Perceptions of Their Patients

[Women & Health 48(2):2008]

Physician's Perceptions of Their Patients – Odds Ratios

	<u><i>Disease uncertainty</i></u>	<u><i>Hidden Agenda</i></u>	<u><i>Rapport</i></u>
Fem. Pt/ Male MD	1.3*	2.2**	0.9 (NS)
Fem. Pt/ Fem. MD	0.6*	2.1	1.6*

Appendix C: Information/ Findings on Some Major Studies of Women's Health

- Women's Health Initiative (WHI)
- Women's Health Study (WHS)
- Study of Women Across the Nation (SWAN)
- Black Women's Health Study (BWHS)
- Nurses' Health Study (NHS)

F. Recommendations to the Office of Women's Health (edited)

1. US government should sustain and increase focus on women's health
2. Target research initiatives that increase research on women's populations with highest disease burden
3. Research should include prevention and attention to the quality of life
4. Adequate participation of women in all relevant research
5. Better research translation of women's health research issues
6. Develop evidence-based strategies for communication research findings to women

A Proposal For Moving Forward on Women's Health Research: *Some Suggested Approaches*

1. Assess the biology of the condition in terms of unique gender or sex genetics or molecular biology.
2. Use research precedent to estimate how much of today's knowledge on a women's condition was created by "genderless" research and/ or research on males.
3. For translational therapeutic research on conditions that occur in both women and men, identify those situations where clear differential approaches are needed, where clinicians really need prompting.
4. Research the clinical environments that uniquely enhance the clinical outcomes of women, and adjust accordingly.

A Proposal For Moving Forward on Women's Health Research: *Some Suggested Approaches*

5. Use personalized medicine to surmount some gender differences in prevention and treatment
6. Above all else, don't confuse advocacy or uncorrectable disparities with the imperatives and responsibilities of high quality science

Gender and the Diagnostic, Management, and Surveillance of Chronic Obstructive Pulmonary Disease

[Proc Am Thor Soc 4:686]

Symptom

Gender Differences

Dyspnea

Women have greater severity

Chronic cough

Women more likely to be awakened by cough

Sputum production

Men have more

Depression

High in men and women; women have more

Anxiety/ fatigue

Ditto