The Importance of Women's Health

Phyllis Greenberger, M.S.W.

Securing the right to vote, controlling fertility, earning (almost) equal pay for equal work—to this list of milestones for women, add one more: being included in all federally financed health studies. In 1993 Congress passed the equivalent of the Equal Rights Amendment for medical research: a law mandating that women be part of all studies that receive funding from the National Institutes of Health and that women be included in the final stages of all clinical trials of new drugs, unless there is some compelling medical reason they shouldn't be.

For many years, women were not systematically included in biomedical research and clinical trials, in part because of concern that if women became pregnant during the course of the study, the fetus might be harmed. Unfortunately, though, the policy meant that researchers simply did not know certain facts about women's health.

The 1993 law was a crucial landmark in the effort to look more closely at women's health—a movement that has been under way at least since the publication of the book *Our Bodies, Ourselves* in 1969. And as researchers have been asking more questions about women's health, they've been uncovering some fascinating and compelling answers. In this special issue of SCIENTIFIC AMERICAN, we hope to share with you some of these answers—from the experts who have been working to uncover them.

We've divided the issue by age groups to reflect the growing awareness that women's health is not just about the reproductive system but rather about a lifelong approach to staying healthy. We start off in the teen years, because it's really only after puberty that health concerns for boys and girls begin to diverge.

To introduce the issue, we asked ***EVELYN STRAUSS,*** special correspondent for SCIENTIFIC AMERICAN, to discuss priorities in women's health research and public policy with three women who are experts in these fields: ***PHYLLIS GREENBERGER, M.S.W.,*** executive director of the Society for the Advancement of Women's Health Research in Washington, D.C., an organization that has played a key role in altering the status of women's health research in this country and that continues to push for public policies that improve women's health; ***WANDA K. JONES, Dr.P.H.,*** deputy assistant secretary for health (women's health) in the Department of Health and Human Services; and ***VIVIAN W. PINN, M.D.,*** director of the Office of Research on Women's Health at the National Institutes of Health. *—The Editors*

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Q *What are the most significant health concerns facing women today?*

A **PINN:** We can consider the most important health concerns from two different perspectives: the leading causes of death for women and the major conditions or disorders that affect the health of women and the quality of their lives. One crucial consideration is to face the reality of the facts, rather than just common perceptions.

For example, many women (and even some of their physicians) still think of breast cancer as their leading cause of death, but that's not correct. Although breast cancer is the most common cancer in women and the leading cancer cause of death for women between the ages of 35 and 54, lung cancer has been the leading cancer cause of death for all women since 1985. And when women's entire life spans are considered, heart disease is the overall leading cause of death, followed by cancer, then stroke.

Most of the questions we receive at the Office of Research on Women's Health are about hormone replacement therapy (HRT) and menopause and about breast cancer. Women also ask about other conditions that affect them, such as urinary incontinence, aging, immune system diseases like lupus, and mental health disorders.

Traditionally, women's health concerns have been thought of as just associated with the reproductive system during childbearing years. But women's health has come to be seen in the context of an entire life span.

Some conditions are unique to women; these mostly relate to the reproductive system. Other conditions affect both men and women but may have different symptoms in the two sexes. As the concept of women's health has been expanded to the total body and health of women, we now have the deserved scientific attention focused on issues such as prevention, behavior and treatments that are of particular concern to women.

What is the Women's Health Initiative? What has it accomplished so far?

PINN: The Women's Health Initiative, or WHI, is a 15-year national study sponsored by the NIH to define better ways to prevent some of the major causes of death and disability in postmenopausal women: heart disease, cancers and osteoporotic fractures. The WHI, which will involve more than 167,000 women between the ages of 50 and 79, is one of the most definitive clinical trials of women's health ever undertaken in the U.S. This initiative will provide practical information to women and their physicians about the role of hormone replacement therapy in the prevention of heart disease and osteoporotic fractures; about dietary patterns in the prevention of heart disease, breast and colon cancer; and about the effects of calcium and vitamin D supplements on osteoporosis and colon cancer. This study should help resolve some of the questions related to the risks and benefits of long-term hormone replacement therapy. Another arm of this study is the community prevention study, a collaborative effort with the Centers for Disease Control and Prevention, to develop community-based public health intervention models that can achieve healthy behaviors in women ages 40 and older.

The WHI is a really powerful study because of the large numbers and diversity of women involved and the excitement of the women who are volunteers. There are 40 centers across the U.S., so we can take into account geographic factors as well as diversity in race and economic status in interpreting the findings to benefit all women in this country.

The study has succeeded in meeting its recruitment goals, including enrolling the largest number of minority women ever involved in a study funded by the NIH. When this study first started, many doubted that we would be able to get so many women to volunteer. But the women we've recruited have been very enthusiastic about the project and excited about being a part of a study that could lead to many answers that women have been seeking. This is significant because we're

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getting away from attitudes that can make clinical research hard to do, when women do not understand the value of their participation. If we want more answers, women really have to volunteer for clinical trials such as the WHI. It's especially heartening that women are participating even though the results might not make a big difference for them but rather will benefit their daughters and granddaughters.

Has the recent increased focus on women's health changed how women take care of themselves and how research involving women is conducted?

GREENBERGER: I would hope so. We would be colossal failures if it hadn't. A lot of the knowledge up until now has been based on men, but women are demanding answers to their questions, and they want to know how research findings affect them. There are many more women in clinical trials now, and this is the only way we're going to get answers.

Because of demographics, the baby boom generation is going to be front and center in the public eye during the next few years, so issues relevant to these women are becoming very prominent. It's only recently that women have been spending almost a third of their lives after menopause—they realize they've got a lot of life left to live, and they want to remain healthy.

JONES: Unfortunately, we don't have a good indication that women are actually taking better care of themselves today. There's certainly much more information about health than there's ever been, but some of it conflicts—so the potential for confusion is higher than before, too. Today you hear coffee's okay, and tomorrow it's not. The six o'clock news will cover a study conducted on only 40 people, even if the results don't necessarily translate or have any relevance to the larger population. People don't have the ability to sift through this overload of sometimes contradictory information. It's worrisome to me that the public and the media want to put so much emphasis on every little new medical finding.

> *"WOMEN WANT TO KNOW HOW RESEARCH FINDINGS AFFECT THEM."*

One of the interesting things that will come out of the Women's Health Initiative is whether women's health behaviors changed during their involvement in the trial and whether they changed for better or worse. That might help us figure out ways to communicate important health issues to women.

PINN: I definitely think the increased focus on women's health has changed how women see their bodies and their health and has helped them to appreciate their own responsibilities for their health through their behavior. Many more women realize the role of nutrition and physical fitness in protecting their health, for instance. And these days, a postmenopausal woman isn't sitting in a rocking chair watching life go by. She's the CEO of a company or the winner of a tennis match at the sports club. Women are realizing that if they want to be active as mature women, they need to modify their behavior earlier in life. We're seeing issues like menopause and depression come out of the closet. Women are realizing that it's acceptable to ask questions and to seek medical help for conditions such as urinary incontinence, arthritis, depression and domestic violence, conditions that can occur in all cultures, at any socioeconomic status.

Research is designed to answer scientific questions. Women are realizing they should ask if they don't know the answer to questions about their health. And as they raise more questions about their health, their physicians and health care providers better realize the conditions for which research has not yet provided definitive answers: How will pregnancy or oral contraceptives affect my lupus? What is the real story about hormone replacement therapy? What are the medical alternatives to surgical hysterectomy? Why is there a higher mortality rate for some cancers in minority women? Why does heart disease occur later in life in women than in men and often lead to a higher mortality rate in women after a heart attack? Will the same interventions for the prevention of heart disease in men also prevent heart disease in women?

These kinds of questions reveal gaps in our scientific knowledge, and the way to get answers is through research. Previously, studies were done primarily on men, even when the conditions affected both women and men. Now we have a strengthened policy at the NIH that requires the inclusion of women in clinical studies, so women are participating in studies of the conditions that affect them.

What are the most important findings in women's health research from the past several years?

GREENBERGER: We're beginning to develop so-called designer estrogens for use in hormone replacement therapy—compounds that differentially affect estrogen receptors in different parts of the body, for example. We've discovered compounds that can selectively turn on and off the estrogen receptors in bone but not in the breast. This information can be used to develop compounds that can potentially eliminate some of the side effects of hormone treatment, such as the possible increased risk of breast cancer.

We're also beginning to see gender differences in terms of addiction, depression and cardiovascular disease as well as reaction to pain and anesthesia. We're recognizing that the circuitry of the male and female brains is different, which leads to questions about how different brain activity leads to depression, dyslexia and schizophrenia. With regard to pain, drugs known as kappa opioids work very well to kill pain after wisdom tooth extraction in women but hardly at all in men, suggesting that the neurology underlying pain pathways is different in men and women. Women have a far more powerful response to the drugs than men do, and the analgesic effects last considerably longer for women than for men.

Women smoke fewer and lighter-tar cigarettes than men do, but they have more cases and different kinds of lung cancer. It used to be thought that because more women are smoking, they're catching up to men in the incidence of lung cancer. But it's not just that women are smoking more; it's that they're more sensitive to whatever gives them lung cancer.

JONES: We're beginning to reap the benefits of research that was done several years ago. For example, we're seeing a decline in the number of HIV-infected newborns; several years ago researchers showed that treating infected women reduces the incidence of viral transmission to the fetus.

PINN: Many of the things we've learned confirm what we thought before. For example, sexual activity increases the risk of infection with human papillomavirus, and there's now a proven connection between the virus and cervical cancer. We've also learned that taking hormone replacement therapy

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reduces risk factors for heart disease in women. The Women's Health Initiative will provide information about actual reduction in mortality. We're getting results suggesting that estrogen may play a role in preventing Alzheimer's disease in elderly women. We're gaining a lot more information about osteoporosis and how to prevent it through diet, calcium, physical activity and new medications.

Some of the most exciting new findings, however, are related to breast cancer. During the past several years, there have been breakthroughs in the recognition of the genetic mutations that may be responsible for breast cancer, and we are learning more about the detection of these mutations and how to manage them medically. The very recent and extremely important findings that tamoxifen, a drug that has been used to treat breast cancer, is also effective in reducing the chances of developing breast cancer offer new hope to women who fear breast cancer. Even as we learn more about the risks and benefits of tamoxifen, these results are a major step forward for women and their physicians in learning how to prevent this common cancer.

"WE NEED TO MAKE THE RESEARCH WE'VE ALREADY PAID FOR WORK FOR WOMEN. AND WE NEED TO FACILITATE WOMEN'S ACCESS TO HEALTH CARE."

What are the top questions concerning women's health that remain to be answered?

GREENBERGER: We need to understand why some diseases affect men and women differently and figure out what to do about it. For example, 80 percent of people with autoimmune disease are women. Why does depression affect women two to three times more than men? It's startling that we've gotten this far and not asked why—and what do we do about it.

JONES: A serious question that needs to be answered is, What are the unique features of disease in women that might require different or modified treatment strategies relative to men? In some instances, drugs are administered based on weight, but even so, a woman's metabolism might be different. Her hormones might have some modulating effect. I hear from women who are on medications for epilepsy or anxiety disorders that they notice a difference at various times of their menstrual cycles.

In terms of public health, it's important to know how men and women understand health messages—how they're likely to take information and figure out if it's relevant to them and then act on it. We also need more research to better understand how women use health care systems. Most women want to simplify their health care. It would be ideal if women could see their endocrinologist and their orthopedist in the same place on the same day. And for mothers, it would be good if the kids could go to their appointments at the same time as Mom—or if there were day care on the premises. We need to investigate these integrative approaches to providing health care.

The other big question is how research findings get translated into clinical practice. Why does it take 10 years for something to become standard practice? Right now in arthritis, too many people are being told that they should take a couple of anti-inflammatories and rest, and their arthritis will improve. But immobility lets the joints solidify. And this isn't just a women's research issue: arthritis affects more than 40 million people in the U.S., with about 60 percent of them women.

PINN: We need to understand not only the genetic and molecular basis of disease but also whether—and why—some of these conditions affect women and men differently. We need to know more about when and why there may be gender differences in the effects of drugs or other therapies. We need to understand the role of female sex hormones and their effects on health and disease.

In addition to comparing women with men, we need to look at other factors that result in differences in health status and outcome among various populations of women. Educational level, genetic inheritance, biological mechanisms, the environment, ethnicity, cultural practices and occupation are such factors that must be considered in addition to women's access to health care. And as we learn more about risk factors for disease, we must learn how to modify unhealthy behavior in women, such as smoking and poor dietary habits. Then, I hope, we can decrease the incidence of many health problems as well as learn how to detect them earlier with better interventions to prevent or cure diseases.

Women's health groups have become more politically active over the past few years. Has that paid off? If so, how?

GREENBERGER: The efforts of our group, the breast cancer groups and many others are definitely paying off in both the private and public sectors. We've gotten more funding for women's health research. Pharmaceutical companies are churning out many more products—particularly for women or for diseases that women suffer from disproportionately as compared with men. Plus we've been instrumental in setting up offices of women's health in several federal agencies. There's been a lot of recent legislation for funding research into diagnosis and treatment programs directed at women.

JONES: Advocacy by the National Breast Cancer Coalition and other groups—such as the Susan G. Komen Breast Cancer Foundation, the Y-ME National Breast Cancer Organization and the National Alliance of Breast Cancer Organizations—to increase breast cancer research has had a big impact. It's increased the budgetary commitment to breast cancer over the past five years and heightened women's awareness of the disease. That's great, but we also need to make the research we've already paid for work for women. The communication issues are critical. We also need to facilitate women's access to health care.

PINN: This attention from women's health advocacy groups and women's health professionals has raised women's health issues to a level where the scientific, medical, legislative and public-policy communities have gained an increased consciousness of our gaps in knowledge and have increasingly responded in effective and positive ways. We also have much more responsible and extensive media coverage of women's health issues, which assists in getting the messages out to individual women and their families. They're putting forward not just sensational sound bites but also the real controversies that exist within the health research community. That's important because we must get this information back to women and their health care providers, so that our expanded knowledge about women's health can make a difference in the quality of women's lives. SA

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