





Women's Health — Respect at Last

BY SUSAN C. THOMSON, M.A., M.B.A.

It's Julie Schnieders' professional experience that, when it comes to their health, women want to know about much more than just pregnancy and childbirth. They also have questions about sleep, fitness, stroke, fatigue, hot flashes, weight, sexually transmitted diseases, heart disease, cancer, nutrition, depression, thyroid disease, migraines — the gamut of health issues affecting them, she said.

Schnieders is a women's health nurse practitioner and the public face and voice of St. Vincent Women's Hospital in Indianapolis. Her image has appeared on a highway billboard promoting the hospital's services. She records television and radio spots on women's health topics for the hospital. She answers questions women pose to her via its website. She tweets and blogs. And she sees patients by appointment.

The wide range of topics she talks and writes about in doing her job reflects today's evolved — and evolving — understanding of women's health among leading practitioners and thinkers in the field. They recognize that women are distinguished by not only their special capacity to conceive, bear and nurture children. They acknowledge that women are susceptible to uniquely female health risks unrelated to childbearing, even in their reproductive years.

Perhaps most importantly, they take into account that although those particular years end, women can live on for just as many more, years during which they may encounter health challenges specific to their gender.

This lifespan perspective has been a fairly recent development, according to Carol S. Weisman, Ph.D., distinguished professor of public health sciences and obstetrics and gynecology at the Penn State College of Medicine, Hershey, Pa.

She has written that from the late 1880s until the mid-20th century, the medical profession's thinking was that “the female reproductive organs were not only central to women's reproductive capacity but also controlled women's overall physical and mental condition. At the same time, prevailing gender ideology defined maternity as women's primary social function and moral purpose, thus giving legitimacy to the medical focus on reproduction.”¹

That restrictive view of women's health didn't come into serious public question until the 1960s and 1970s, when groups of activist women spoke up against what they perceived as the dismissive, inadequate and sometimes even dangerous treatment they were getting from their physicians, most of them male.

Research on women's health issues was scant,

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and women were poorly represented in or totally omitted from federally funded clinical trials. Medical researchers assumed — wrongly — that clinical trial results applied to men and women alike.

The 1990s saw the emergence of what Weisman referred to as the next major “wave of women’s health activism.”² A new generation of women leaders in government, academia and medicine joined their voices to those of women’s health advocates to press for policy change at the federal level. First, in 1990, the National Institutes of Health (NIH) opened its Office of Research on Women’s Health to ensure that women were adequately included in NIH-funded clinical research.

GROWING AWARENESS

A year later, NIH launched its landmark Women’s Health Initiative, the first large-scale study of cardiovascular disease, cancer and osteoporosis in postmenopausal women. Over the next 15 years, 161,000 mid- and later-life women across the country took part in clinical trials and obser-

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vational studies designed to discover the effect of diet, dietary supplements and two kinds of hormone replacement therapy on heart disease, fractures and breast and colorectal cancers — conditions data showed were the most common causes of death and disability in this previously understudied group.

The research concluded that a low-fat diet neither protected against colorectal cancer nor significantly reduced the incidence of breast cancer, heart disease or stroke in healthy postmenopausal women. It also determined that while marginally helpful for maintaining bone density and preventing hip fractures, a regimen of calcium supplemented with vitamin D didn’t prevent other fractures and could cause kidney stones.

But data collected during the hormone replacement studies literally stopped the researchers short. As Susan Wood, Ph.D., executive director of the Jacobs Institute of Women’s Health, a unit of

George Washington University’s School of Public Health Services in Washington, D.C., recalls, hormone replacement therapy (HRT) was being heavily promoted and widely prescribed at the time for relief of hot flashes and other menopausal symptoms and also for supposed benefits to older women’s overall health.

In 2002, the Women’s Health Initiative ended its investigation of combination estrogen-progestin HRT three years early upon finding that, while protecting women against hip fractures and colorectal cancer, it also heightened their risk of heart disease, stroke, pulmonary embolism and invasive breast cancer.

This was huge news — “a shock to the medical system,” as one front-page headline put it — for both the millions of postmenopausal women who were taking combinations of replacement hormones and for the physicians who prescribed the therapy.³

They got another jolt two years later, when the Women’s Health Initiative called off its study of women taking estrogen alone, having found that it made them more vulnerable to stroke. “The NIH believes that an increased risk of stroke is not acceptable in healthy women in a research study. This is especially true if estrogen alone does not affect (either increase or decrease) heart disease, as appears to be the case in the current study,” said Barbara Alving, MD, director of the Women’s Health Initiative, in the March 2, 2004, announcement.⁴

With its startling, headline-making announcements, the Women’s Health Initiative helped raise public consciousness of women’s health to a whole new level, sustained now with help from what Wood described as a women’s health “infrastructure” that has developed rapidly over the past 20 years. In this, she includes women’s health units in the federal Department of Health and Human Services, the Food and Drug Administration and the Centers for Disease Control and Prevention (CDC) as well as women’s health offices in many state governments — all with informative websites.

Gone are the days when information about women’s health was scant and hard to come by. Now there is a surfeit of it, offered up by media old and new, accessible at a keystroke, often mixed with opinion and misinformation, to the confusion of consumers. To break through the verbal and visual clutter, providers of information about



women and disease have turned, with varying success, to sophisticated, multimedia campaigns.

For example, the CDC's "Inside Knowledge" campaign, launched in 2010, uses traditional media such as free public service announcements and paid television, print and radio advertising to highlight gynecological cancers — cervical, ovarian, uterine, vulvar and vaginal. For extra visibility, the campaign also has invested in "search engine marketing," which drives traffic to www.cdc.gov/cancer/knowledge/ when web surfers use certain search terms.

In terms of impact, however, nothing compares to the Susan G. Komen for the Cure campaign against breast cancer. Founded in 1982 when the words "breast" and "breast cancer" were rarely spoken in public, the Komen organization has grown into a global behemoth that says it has invested almost \$2 billion in breast cancer research, outreach, advocacy and community programs in more than 50 countries.

Almost single-handedly, the Komen organization has succeeded in putting breast cancer on the women's health map. It has done so in part by mastering the phenomenon known as cause marketing, enlisting for-profit supporters to join in its promotions. Komen has signed up more than 100 corporate financial backers — banks, manufacturers, food companies, retailers, clothiers and assorted others — and licensed them to use Komen's trademarked pink ribbon logo.

The logo has become so familiar that many people may be surprised to learn that although breast cancer is the most commonly diagnosed cancer among women, lung cancer is the leading cause of female cancer deaths, according to the CDC. It's also true that more American women die of heart disease than of all cancers combined. That makes heart disease "the no. 1 misunderstood [women's health] risk," in Schnieders' view. Awareness of that risk "is still not what it should be among medical professionals as well as the public," said Weisman.

The American Heart Association (AHA) has been striving to raise awareness since 2004, when it launched Go Red for Women, its own cause-marketing drive complete with corporate sponsors and logo. But in the public consciousness, the AHA's red dress symbol has yet to catch up

with the pink ribbon, and Go Red's single signature event — National Wear Red Day, every first Friday in February — has received comparatively modest amounts of media and public attention.

The AHA has been behind the times, according to Phyllis Greenberger, president and chief execu-

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— Phyllis Greenberger

tive of the Society for Women's Health Research (SWHR), a national non-profit organization based in Washington, D.C. that funds, advocates and tracks research on sex differences in health and disease. In publicizing the facts about women and heart disease, her own organization was ahead of the AHA by five years, Greenberger said.

Heart disease remains a top priority for the organization, and women need to know three things about it, Greenberger said: "One, they are as vulnerable as men if not more so. Two, their symptoms can be different. And three, they need to be more aggressive" in describing their symptoms and insisting that doctors listen to them. Women's heart disease symptoms are subtler than men's, and women tend to have heart attacks at later ages, Greenberger said, but "they can still get them in their 30s and 40s."

By no means are female health differences limited to heart disease and female cancers. According to SWHR, women are at greater risk than men for a host of ailments that include osteoarthritis, anxiety, depression, fibromyalgia, irritable bowel syndrome, restless leg syndrome, Alzheimer's disease, osteoporosis, stroke, urinary incontinence, certain autoimmune diseases, thyroid disease, migraines and eating disorders.

"There's very little understanding why there are these disease disparities," Greenberger said. "There are more questions than there are answers with practically all of these conditions." In her view, even though women tend to live longer than men, women live with so much more chronic disease that they aren't really any healthier than men.

What's more, the longevity gap between the

genders has been slowly closing, from seven years in 1980 to five years in 2010, with life expectancy at birth now 76 years for men and 81 years for women.⁵ Anne Coleman, administrator of St. Vincent Women's Hospital, expects the gap to narrow further, the result of early detection and treatment of heart disease in both men and women.

WOMEN'S HOSPITALS

St. Vincent is one of a growing number of specialized women's hospitals. No one keeps official count, but an Internet search turns up some three dozen women's hospitals of various sizes across the country. Among them are a handful that began as narrowly focused maternity hospitals of the 19th century and many others that were founded

during the past couple of decades. St. Vincent is among the few Catholic facilities.

St. Vincent also is among the relative newcomers, dating to 2003, when Indiana-based St. Vincent Health acquired a 20-year-old, for-profit women's hospital from Hospital Corporation of America. Over the 10 years since, the hospital has grown to 178 beds from 45, and the staff has tripled to 750 people, Coleman said. The expansion has been necessary "to accommodate the growth in patient volume."

Maternity services are the common denominator of today's women's hospitals and the major focus of most of them, including at St. Vincent, where more than 4,000 babies are born every year, according to Coleman. Like other women's

'EQUALITY' UNRELATED TO HEALTH

When it comes to health, American women aren't created equal. They differ not only from men, but also among themselves, with women of color in general and black women in particular less healthy by many measures than the female population as a whole. The evidence is plentiful, the questions numerous, the answers elusive.

The latest data from the Centers for Disease Control and Prevention (CDC) on the leading causes of female death suggest some of the major and most perplexing of these intra-gender disparities. The numbers show, for instance, that while heart disease is the leading killer of women overall, as well as black and white women, with cancer a close second, the reverse is true of Hispanic, Native American and Asian women. That was the first observation offered by Janine Austin Clayton, MD, director of the Office of Research on Women's Health at the National Institutes of Health, when she was asked for her professional analysis of the rankings.

Next she called attention to what she described as "huge" differences in kidney disease, which takes a greater toll on

black women than women of all of the other groups, and diabetes, with death rates higher for all other ethnic groups than for whites. She also found it signifi-

Access and utilization are especially problematic for Hispanic and Native American women.

cant that hypertension is responsible for 2 percent of black women's deaths but doesn't rank among the 10 top causes for any other group except Asians.

"We don't know why [all of] this is," Clayton said. "... Obesity clearly has something to do with it."

Obesity — implicated in hypertension, kidney disease and diabetes — is especially prevalent among black women. The CDC recently estimated that 41.4 percent of black women are obese, compared with 33.5 percent of Hispanic women and 26.3 percent of white women.¹

Without suggesting any causality,

the Office of Minority Health of the U.S. Department of Health and Human Services calculates further that:

- 9.5 percent of black women are diabetic, compared with 9.3 percent of Hispanic and 5.4 percent of white women
- 44.3 percent of black women have hypertension, compared with 28.1 percent of white and 27.8 percent of Mexican-American women
- Black women enter treatment for end-stage kidney disease half again as often as Hispanic women and at twice the rate of white women

The Office of Minority Health also reports that black women are more likely to die of cancer than women of any other racial group; that they have 25 times the rate of AIDS infection than do white women; and they are less likely to be diagnosed with breast cancer than white women are, but more likely to die of it.²

These broad national numbers are subject to considerable geographical variation. The Kaiser Family Foundation found that out when it analyzed women's health, group by group and state by state, in 25 different ways under three general headings — health status, access to and



hospitals today, St. Vincent delivers babies as just one aspect of a continuum of maternity care that includes everything from prenatal childbirth classes to postnatal breast-feeding support groups.

Coleman noted that women are typically the primary health care decision-makers for themselves and for their families as well, and childbirth is often the way they — and then their families — enter the health care system. So, she said, “We want to make that [childbirth] experience for women and their families a great one.”

In keeping with the birth-to-death perspective of contemporary women's health theory and practice, St. Vincent offers maternity care in the larger context of a broad array of women-specific

services not related to childbirth. These include breast and gynecological surgeries; mammograms, Pap smears and bone density tests; and age-appropriate exercise classes taught by a nurse practitioner.

Although women's hospitals serve only women, they do not necessarily limit themselves to services only women use. St. Vincent, for instance, also features on-site colonoscopy, endoscopy and podiatry. Either directly or through the health care systems to which they belong, various other women's hospitals offer their patients such major specialties as radiology, dermatology, plastic surgery, endocrinology, cardiology and psychiatry.

It all adds up to Coleman's definition of a women's hospital as a place “designed to take care of

utilization of health care, and the social and economic determinants of health, a category that included income and education.³

In most of those 25 respects, Kaiser found minority women as a group were worse off than white women in almost every state, though more so in some states than in others. The study concurred with the national data in concluding that black women have consistently higher rates of chronic illnesses. It also concluded, among other things, that access and utilization are especially problematic for Hispanic and Native American women and that white women have higher rates of smoking and “serious psychological distress.”

The Kaiser Family Foundation offered its findings matter-of-factly and refrained from theorizing about them except to suggest, “Health is shaped by many factors, from the biological to the social and political.”

Clayton agreed that socioeconomic status is an important factor behind the different health outcomes of women of different ethnicities and races. But, she added, “Even when you correct for

income, years of education and poverty ... it doesn't explain everything. That means we have to do more work to understand this.”

Susan Wood, Ph.D., executive director of the Jacobs Institute of Women's Health at George Washington University in Washington, D.C., was of similar mind. Health disparities among women result from “many variables,” some biological and some socioeconomic, but “not that much is known” about them, she said.

One reason, she contended, is that “there's a real problem with the inclusion of minority women in clinical trials,” black women being especially difficult to recruit.

Wood attributes their reluctance to long-held, deep-seated fears, the result of black men having been used as research subjects in unethical experiments that left them sick. “There's still a negative feeling in the black community that clinical trials aren't safe and they're going to be guinea pigs, and there aren't enough ethnic and minority people doing trials and recommending their patients to be in trials,” she said.

—Susan C. Thomson

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the woman that's taking care of everybody else." As a Catholic hospital, St. Vincent also pursues a larger mission, implicit in this statement on the hospital's web page: "We are committed to offering you a more personal and complete approach — caring for you mind, body and spirit."

The mind aspect of that three-part equation is, to a degree, an aspect of Schnieders' wide-ranging practice at the hospital. She hears from women who are depressed, and she understands about women and stress. "I think women have a lot of stress because they take on too many responsibilities, and they're not good about saying no," she said.

Weisman includes mental health issues like depression and anxiety among the problems warranting consideration in what others have described as an emerging "bio-psycho-social" view of women's health. "It recognizes that women's health problems are not only biological . . . They stem also from the social circumstances in which women live and the stresses they're exposed to," she said.

Similarly, in its strategic plan, the NIH's Office of Research on Women's Health acknowledges that health outcomes "are influenced by biological sex, gender identity, as well as development, cultural, environmental, and socioeconomic factors."⁶

The document emphasizes even more, however, the importance of "biological sex differences" as determinants of health and disease, and it lists increasing research into these topics among its top goals.

As Janine Austin Clayton, MD, the agency's director, put it: Women are different down to their very chromosomes, and "sex is inherent in every cell" of their bodies. She said these "basic biological differences" can be clinically important, explaining, for instance, the different ways men and women may metabolize the same drugs.

RESEARCH

NIH established the Office of Research on Women's Health to ensure that women were adequately represented in federal clinical studies. That goal largely has been achieved. When last counted in fiscal 2012, women made up 49 percent of participants in studies other than those limited by design to a single gender, Clayton said.

Elsewhere at the NIH, the Women's Health Initiative continues, under the leadership of Jacques Rossouw, MD. The primary focus remains on the

causes and prevention of disease in postmenopausal women, he said.

The Women's Health Initiative is following up with the still-living 93,000 women who took part in the original studies and who are now between the ages of 65 and 97. "They are the survivors," Rossouw noted, and research questions remain: What determines healthy aging? How do some women avoid cardiovascular disease? In search of answers, the group is asking these women about their diets and their activity levels. "We think physical activity is very important in determining survival," said Rossouw.

Also, he said, "Right now we're very interested in hip fracture and atrial fibrillation, which are very common in older women. These conditions have not been studied very extensively."

To that list of "hot topics" in women's health, Rossouw adds hormone replacement therapy, for the issue still has not been completely resolved. "Everyone agrees [HRT] is not a good idea for older women," he said. But because it is known to be helpful for controlling hot flashes, HRT might make sense for "younger women, those close to menopause," he said. The questions are: What are the risks for these women? And might the therapy protect them from heart disease in the long run?

HEALTH REFORM

In the short run, the Affordable Care Act (ACA) is phasing in with important advances for women's health care. It forbids insurers from charging women more than men for the same coverage, and it requires them to offer certain screenings, including those for breast and cervical cancer, without co-pays or deductibles. Weisman applauded the ACA as "the first time in this country we have had a focus on prevention." What's more, she said, the new free services are based on evidence that they will "keep people healthier longer and help prevent the development of disease down the road."

With these ACA provisions falling into place, many leading proponents of women's health have turned their eyes to Jan. 1, 2014. That's when the state-based insurance exchanges — virtual marketplaces where uninsured individuals and small businesses can compare and buy health coverage — are due to be up and running.

Concerned that the exchanges deliver on the benefits the ACA has promised women, three health advocacy groups have issued a "checklist" urging exchange planners to, for instance:

- Develop benefits packages that meet wom-



en's health needs

- Monitor the implementation of women's free preventive services

- Educate women about the exchanges

- Clearly explain to women the new insurance plans' benefits, including out-of-pocket costs.⁷

It's the checklist's premise that "women's health is a major determinant of our nation's health and the health of future generations," in part because women use more health care than men and "take major responsibility for coordinating care for family members."

Said the Jacobs Institute's Wood, "There's a whole host of things in [the ACA] that will benefit women, and it's important, moving forward, to make sure it's implemented right."

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