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# An Overview: Expanding the Women's Health Research Frontier

Marsha G. Davenport, M.D., M.P.H.

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*The articles featured in this issue are focused on health topics that are important to improving the health of women across the life span. Cancer and other chronic diseases will need to continue to be the focus for research efforts in the future. However, additional research on women's health must go beyond the biomedical model and encompass issues related to the cultural aspects of health. Further, there is a great need for health services researchers and others to expand the frontier of policy research to explore the development of innovative health care delivery systems to improve the health and health status of all women.*

## BACKGROUND

The health of women of all ages is a priority for the Nation. With the release of the Department of Health and Human Services' (DHHS) Healthy People 2010 report (U.S. Department of Health and Human Services, 2000), there is a national focus on (1) increasing the quality and years of healthy life and (2) eliminating health disparities. The emphasis for goal two of Healthy People 2010, eliminating health disparities, is to target factors such as sex, race/ethnicity, poverty, and disability, for example, to conquer differences in health status across the population in the United States. Thus, the Federal Government, in partnership with State and

local governments, community organizations, and advocacy groups is engaged in efforts to eliminate health disparities.

Historically, health disparities have existed for a number of individuals or groups who have been considered vulnerable populations. Women of all ages are one such group. In 1983, the United States Public Health Service Task Force on Women's Health was convened. This Task Force was charged with reviewing and evaluating the role of DHHS in women's health (U.S. Department of Health and Human Services, 1985). A major recommendation put forth by the Task Force was to increase women's participation in research studies, especially in clinical trials, that were funded by the Federal Government. Further, the Task Force recommended expanding women's health research in the biomedical and behavioral health arenas.

In 1987, in response to these recommendations, the National Institutes of Health (NIH) developed a policy for including women in clinical trials. However, it was not until 1990, that NIH established the Office of Research on Women's Health (ORWH) (Pinn and Chunko, 1999). Recognizing the importance of the Federal Government to address the health needs of women and other vulnerable populations, ORWH was challenged with three mandates. First, ORWH was asked to identify the gaps in knowledge for diseases and conditions for women and to increase research in these particular areas. As part of this effort, ORWH was to develop a women's

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The author is with the Office of Strategic Planning, Centers for Medicare & Medicaid Services (CMS) (formerly known as the Health Care Financing Administration). The views expressed in this article are those of the author and do not necessarily reflect the views of CMS.

health research agenda for NIH. Secondly, ORWH was to ensure that clinical trials, as well as all other NIH-funded research, included appropriate representation of women. This was and still is a key role for ORWH. Prior to this time, women had not been included routinely in studies, therefore, little was known about diseases, conditions, and medications affecting women outside of their reproductive health. ORWH's third mandate was to develop and direct appropriate research and academic initiatives resulting in an increase in the number of women pursuing biomedical careers (Pinn and Chunko, 1999).

Following the creation of ORWH, other Federal agencies developed a focus on women's health issues, including CMS. In 1998, CMS established the Women's Health Workgroup to assist in the coordination of the agency's women's health programs and policies, educational and outreach efforts, and research and demonstration projects (Davenport et al., 2000). Today, almost every Federal agency has staff who are dedicated to improving the health of women of all ages. Various Federal agencies work closely with the DHHS' Office on Women's Health to provide leadership and coordination of women's health activities (Jones, 1999).

Women's health is an important aspect of every program administered by CMS, including Medicare, Medicaid, and the State Children's Health Insurance Program (SCHIP). For the Medicare program alone, women comprise over 50 percent of beneficiaries (Health Care Financing Administration, 2000). The Medicare, Medicaid, and SCHIP programs are critical for providing access to quality health care for all of the beneficiaries and for women, in particular. Moreover, research studies identifying areas where new coverage policies and benefits are needed are crucial for CMS to do its job.

Policy and coverage decisions frequently require the support of evidence-based studies. Without research findings to demonstrate the efficacy and potential benefit of providing an innovative medical procedure or device, access to new technologies that might improve health care and eliminate disparities would be limited.

In this issue of the *Health Care Financing Review*, the spotlight is on health concerns and research findings that have an impact on women of all ages, from young girls to older women. This is the first issue of the *Review* dedicated to women's health, and it contains four articles focusing on health topics for women across the life span. These articles include topics on the use of preventive health services for girls from birth to age 21 through Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program; mammography utilization for Medicare beneficiaries in fee-for-service (FFS) as well as in managed care; and health care access concerns for women with low incomes.

### **EPSDT**

In 1967, the Medicaid program was expanded to provide access to more comprehensive care, especially preventive care, for children and young persons under age 21 (Herz, Chawla, and Gavin, 1998). Twelve years ago, the Omnibus Budget and Reconciliation Act of 1989 addressed the need to increase participation of States in the EPSDT programs (Herz, Chawla, and Gavin, 1998).

Providing appropriate preventive care is key to improving one's health at any age. The article by Adams featured in this issue, analyzed the impact of physician's fees on access to preventive services for children and young adults who participat-

ed in the EPSDT program. The findings suggested that there is a need to increase participation of physicians in Medicaid and in the EPSDT programs in poorer parts of the country. The author recommended that certain States make this effort a priority. It was noted in this study of four States, that Michigan was the only State that was able to develop a fee schedule for Medicaid preventive services comparable with the private sector, which helped to improve physician participation in this program.

### **Access to Health Care**

Even with programs such as Medicare, Medicaid, and SCHIP, there is still considerable concern about beneficiaries not having access to health care. This concern is so prevalent that not only is access to care one of the Healthy People 2010 focus areas, but it is also one of the 10 Leading Health Indicators (U.S. Department of Health and Human Services, 2000). Moreover, if there is a problem accessing the health care system with some form of insurance coverage, then there is a far greater problem for those persons without health insurance.

In this issue, Almeida, Dubay, and Brown studied factors related to low income. They analyzed data from the 1997 National Survey of America's Families—a telephone household survey of approximately 100,000 children and their families, including adults under age 65. The findings support the growing concern that there is a large group of individuals, primarily women and children, who are uninsured in this country and are less likely to receive health care services. The authors suggested that future research examine factors unrelated to finances that may serve as barriers to access. One might begin by studying the interaction of culture and the role it plays on health-seeking behaviors, irrespective of insurance status.

### **Breast Cancer and Mammography Utilization**

In Spring 1995, CMS launched a consumer information campaign for its Medicare beneficiaries emphasizing the need for mammograms among older women. CMS continues to support these educational and outreach efforts as we strive to reduce morbidity and mortality due to breast cancer among Medicare beneficiaries. The CMS national mammography campaign message for beneficiaries is "Get a Mammogram, Not Once, But for a Lifetime."

However, further research on mammography utilization and vehicles for increasing mammography utilization rates are crucial to improving the health of female beneficiaries. In addition, research on mammography utilization assists CMS in monitoring progress on not only the Healthy People 2010 goals and objectives, but also other goals such as the Health Plan Employer Data and Information System® measures and the Government Performance Results Act.

As previously noted, CMS has monitored mammography utilization rates since 1995 in the FFS sector as part of its outreach campaign. More recent outreach efforts have included women who participate in managed care plans.

However, the first national biennial rates reported in 1995 were based on Medicare FFS data from 1992-1993. The report noted that for all women over age 65, the biennial mammography utilization rate was 37 percent for the period studied (Health Care Financing Administration, 1995). The most recent biennial mammography utilization rates for FFS were reported from 1998-1999 data. Approximately 63 percent of aged, female Medicare beneficiaries in FFS received a mammogram during this time period (Griggs and McCall,

2001). Also, approximately 49.1 percent of women who were dually eligible for both Medicare and Medicaid, were found to be less likely to obtain a screening mammogram. Racial/ethnic differences were also reported. White women were more likely than women of all other racial/ethnic groups studied, to receive a screening mammogram (Griggs and McCall, 2001). Though most of the early work on mammography focused on the Medicare population, CMS is currently funding extramural research studies to determine mammography utilization rates and the use of additional cancer-related preventive services in non-aged women from selected States in the Medicaid program.

Moreover, as coverage policies change or are expanded, the role of research becomes even more important. The most recent example of a major health care policy change affecting women's health is the Breast and Cervical Cancer Prevention and Treatment Act of 2000. This Act was passed in October 2000, and amends Title XIX of the Social Security Act. It provides funding for States to expand the eligibility criteria for the Medicaid program to cover all treatment related to breast or cervical cancer that was diagnosed as a result of the woman's participation in the Centers for Disease Control and Prevention Breast and Cervical Cancer Screening Program. Any woman diagnosed with breast or cervical cancer through this program, who does not have insurance, can become a Medicaid beneficiary with full benefits while she is undergoing her cancer treatment.

Reducing morbidity and mortality resulting from breast cancer continues to be a priority for women's health researchers. Therefore, it is quite appropriate that two articles featured in this issue address mammography use. Each article con-

tributes a different perspective on this very important health topic. The article by Barr, Reisine, Wang, Holmboe, Cohen, Van Hoof, and Meehan, looked at the impact of beneficiaries' health beliefs as well as characteristics of the health plans on mammography use for women in managed care. Using a mail survey of Medicare beneficiaries in a particular managed care plan, Barr and colleagues studied 492 women and found that 78.6 percent of these women reported having had a mammogram in the past 2 years. Problems with access to services were found to be minimal. Of interest, was the finding that such factors as health status, fear of breast cancer, and education were not identified as significant predictors of mammography use.

In contrast, the Sabogal, Merrill, and Packel article studied women who were in Medicare FFS over a 7-year period in California. They analyzed rates for repeated mammography utilization over that 7-year timeframe. In their article, the authors developed a classification system to identify non-screeners, regular screeners, and irregular screeners for the 7-year period. Non-screeners were defined as women who did not receive any mammograms in the 7 years. While regular screeners were defined as those women who received mammograms without skipping 2 years in a row. By comparison, the irregular screeners were defined as women who had at least one mammogram during the study period. Among their findings, the authors noted that when non-screeners were compared with screeners (regular and irregular), they were more likely to be women who were older and non-white. They also noted that older women were more likely to be irregular screeners.

## RESEARCH LIMITATIONS

As with any study, there are limitations of the findings based on one or more factors. In this issue, some of the limitations that readers should consider relate to methods of data collection, sample sizes, and response rates.

The data collection methods varied across the four studies focusing on women's health topics in this issue. The authors of the studies that have used Medicare data have reported some of the well-known limitations. For example, if one analyzes Medicare administrative claims files, as reported in the article by Sabogal, Merrill, and Packel, there will be underreporting of mammography utilization due to the exclusion of the encounter data from the managed care plans. Underreporting can also be a result of the format of the questionnaire used in a survey. Several of the articles in this issue used surveys in their research. It is important to keep in mind the questionnaire design when interpreting the findings from surveys. A recent study (Siegel, Qualters, and Mowery, 2001), reported that a change in the Behavioral Risk Factor Surveillance System questionnaire resulted in lower rates of self-reported mammography use when compared with data from previous years.

Another factor related to underreporting is the quality of the data obtained. When a self-report survey instrument is employed, the findings become subject to recall bias. Providing prompts related to specific conditions as part of the questionnaire can be a helpful tool in minimizing recall bias (Siegel, Qualters, and Mowery, 2001; Hennekens and Buring, 1987).

Overcoming or limiting the impact of bias in research is a major challenge. One method for diminishing the impact of bias

in a study is to have sufficient sample sizes for the analyses. Yet another important mechanism to overcome bias is to have a very high response rate. Response rates for several studies featured in this issue hovered around 70 percent. Nonetheless, the findings from these studies are informative and are supported with tight confidence intervals and rigorous statistical levels of significance (Hulley and Cummings, 1998).

An additional consideration is the ability to interpret the findings to make policy decisions or to design future studies. Frequently, the study findings are not generalizable to the population as a whole. For example, analyses based on claims data will only include Medicare beneficiaries in the FFS. Therefore, a key limitation of the claims analyses is their inability to describe utilization patterns for Medicare beneficiaries who participate in managed care plans. In a similar fashion, using managed care plans as a sampling frame, as was done in the article by Barr and colleagues will limit the generalizability of the findings to beneficiaries who participate in managed care plans with comparable characteristics.

## FUTURE RESEARCH DIRECTIONS: BUILDING ON THE STRENGTHS

Expanding the research frontier requires building on the strengths that already exist in the field of women's health research. It means continuing to emphasize the need to eliminate sex bias in studies and to develop research tools that assist in this effort (Shelley, 1999). Future research must build on the knowledge that we have gained from such studies as the Women's Health Initiative. The Women's Health Initiative which began in 1983, has included well over 160,000 study participants.

The purpose of this extensive study was to expand the understanding of the well being of women (Healy, 1999). Yet this is not enough.

It is not enough without having a vision and understanding of the important challenges that are on the horizon. Among these challenges are broadening the knowledge base concerning sex differences in cardiovascular diseases, such as heart disease and stroke. Future research on cardiovascular diseases must focus on the epidemiology, clinical symptoms, prevention, appropriate treatment, and education for women, especially women who are at high risk.

In addition to cardiovascular diseases, more research is needed on diseases such as lupus, HIV/AIDS and incontinence. More needs to be known about the lasting effects of domestic violence and physical abuse. Another key area to target future research is studying the impact of eating disorders, whether it involves conditions such as anorexia or obesity, there are potentially long-term effects that are not clearly understood.

In conjunction with these biomedical studies, there must be additional studies analyzing the psychosocial aspects of health for women. Future research must address the impact of the complex roles women play as wife, mother, caretaker, worker, friend, etc., as well as other lifestyle factors on her health status. An important psychosocial aspect of health is culture. Recent efforts have been focused on delivering culturally competent health care. With the changing demographics in this country, the health care system must be ever more cognizant of the importance of culture in health. Cultural competence has been shown to be a significant factor in the success of policy and health care initia-

tives (Rorie, Paine, and Barger, 1996). Future research can build on this foundation and fill the gap in fostering culture as a key factor in providing competent health care to women.

Finally, an area of major importance for improving the health of women is research focused on analyzing changes in the health care delivery systems. The most recent policy change to the Medicaid program was described earlier in this article. This policy change resulted in an expansion of Medicaid eligibility criteria to include uninsured women who were diagnosed with breast or cervical cancer through the Centers for Disease Control and Prevention's screening program. Future research must track and monitor the impact of this recent expansion. Researchers must be ready to evaluate the impact of this major change in Medicaid policy. This should not be a missed opportunity to conduct the studies that would evaluate and shape the next generation of our health care delivery system.

## CONCLUSION

In summary, this issue of the *Review* provides findings from research studies that focus on health concerns that must be addressed in order to eliminate health disparities. Some of the most vulnerable populations (children, persons with disabilities, families with low incomes, racial/ethnic minorities, and women) are served by CMS's Medicare, Medicaid, and SCHIP programs. It is also clear that research on access, quality, and health outcomes that impact women's health are on the agenda as the Nation strives to eliminate health disparities and to increase the quality and years of healthy life.

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Reprint Requests: Marsha G. Davenport, M.D., M.P.H., Centers for Medicare & Medicaid Services, Office of Strategic Planning, 7500 Security Boulevard, C3-24-07, Baltimore, MD 21244-1850. E-mail: mdavenport@cms.hhs.gov