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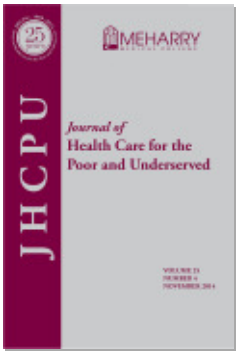

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Journal of Health Care for the Poor and Underserved, Volume 25, Number 4, November 2014, pp. 1507-1513 (Article)

Published by Johns Hopkins University Press
DOI: *https://doi.org/10.1353/hpu.2014.0154*

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[3.149.229.253] Project MUSE (2024-04-26 14:40 GMT)

Women as Health Care Decision-Makers: Implications for Health Care Coverage in the United States

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Abstract: Women in the United States make approximately 80% of the health care decisions for their families, yet often go without health care coverage themselves. The implementation of the Affordable Care Act provides an historical opportunity for women to gain health care coverage for themselves and their families. The focus of this commentary is on women's leadership roles in the context of health care decision-making and Affordable Care Act education and outreach, and implications for reaching broader health and social goals.

Key words: Women, health care, insurance, health care reform, decision-making, Affordable Care Act.

Four years after the passage of the Affordable Care Act in 2010, and more than two years after the Supreme Court ruling upholding the constitutionality of this law, the prospect of health care coverage for millions of Americans who have been uninsured or underinsured for years is becoming a reality. The focus has turned, in large part, to implementing the law's signature pieces: a Marketplace of affordable private plans that launched on October 1, 2013, with coverage that began on January 1, 2014. Through the Health Insurance Marketplace available online at HealthCare.gov, individual consumers can compare different health insurance plans and select one based on their income and their needs, as well as determine their eligibility for expanded Medicaid coverage. To date, 27 states and the District of Columbia have opted to expand Medicaid eligibility based on income, household size, and other circumstances. In most cases, individuals without employer-sponsored health coverage must enroll in a health insurance plan for themselves and their families *via* the Health Insurance Marketplace or, if eligible,

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apply and enroll in Medicaid or the Children's Health Insurance Program (CHIP). This health care plan decision is one that will fall to women in a large majority of households.

According to the U.S. Department of Labor, women make approximately 80% of the health care decisions for their families and are more likely than men to be caregivers to family members.[1–3] Other researchers have also cited this significant decision-making role of women: for example, a 2008 American Academy of Family Physicians (AAFP) national survey found that 90% were responsible for health care decision-making for themselves and/or family members.[4] Recognizing this key role that so many U.S. women—particularly mothers—play in their families has gained the attention of those involved in the Obama Administration's Affordable Care Act outreach and education efforts.[5–8]

What do we know about this influential health care decision-making role that so many U.S. women play, particularly women with limited resources, in the context of the historical Affordable Care Act? The focus of this commentary is on women's leadership roles in the context of health care decision-making and how this responsibility can evolve with Affordable Care Act education and outreach, leading to more Americans having health insurance coverage.

Women and Lack of Health Insurance Coverage

Although women often serve as primary health care decision-makers, many lack basic health insurance for themselves and their families. In 2011, more than 48.6 million people in the U.S. lacked health insurance, 44.7% of whom had household incomes below 150% of the Federal poverty level. Of those living below 150% of the Federal poverty level, more than one in three (9.3 million) lacked health insurance.[9] Reasons vary, but often come down to cost, health insurance eligibility limitations, system barriers such as lack of extended clinic hours and transportation, and lack of time given other job and household responsibilities.[10] Moreover, women who were uninsured or receiving Medicaid benefits reported spending less on other basic necessities in order to cover health care costs. According to recent findings from the 2013 Kaiser Family Foundation's Women's Health Survey, uninsured women were significantly less likely than others to report receiving screenings for blood pressure, cholesterol, cervical cancer, breast cancer or colon cancer than their insured counterparts. In addition, uninsured women were significantly more likely than women who were privately insured or covered by Medicaid to put off or postpone preventive health services because of the burden of health care costs.[2,4] These findings build upon Kaiser's 2008 Women's Health Survey, which noted that younger women (those aged 18–44) and women of color were more likely to delay care than women aged 45–64 and White women, respectively. Preventive health care, including education, screening, and counseling, also varies for women of different racial and ethnic groups. In 2010, non-Hispanic American Indian/Alaska Native and non-Hispanic women of multiple races were less likely than women of other races and ethnic groups to have had routine breast cancer and Pap smear screenings based on U.S. Preventive Services Task Force recommendations.[11] These data expose a sad irony: that the health care decision that many of these women must make is to go without care.

Women as Health Care Decision-makers and Breadwinners

According to the aforementioned AAFP 2008 national survey, 70% of female respondents reported that they were responsible for their own health care decisions, 27% for decisions affecting their children, 20% for their spouse or partner, and 6% held primary responsibility for an adult relative's health care decisions.[4] Survey data from an earlier 2005 Kaiser Family Foundation report illustrate similar findings: women with children under the age of 18 were more likely than husbands and partners to select a child's doctor, take a child to doctor's appointments, ensure their children receive recommended care, and make decisions about their children's health insurance.[10]

To manage these responsibilities, women may need to take time off from work or have flexible work schedules to attend to family needs. These are options that many low-income women simply do not have. As Salganicoff and colleagues note, women earning less than 200% of the Federal poverty level reported fewer employer-sponsored benefits and less flexibility in their workday to manage health-related family issues.[10,24] Women, especially mothers, are also much more likely than men to work part-time, and part-time work generally confers fewer benefits.[12] Women are also more likely to provide care for a chronically ill, disabled, or elderly relative, which can require extensive health care management, knowledge, and time. One national study found that 12% of women and 8% of men provide primary family caregiver responsibilities.[10] These findings are well supported in the literature: a number of studies of youth with chronic diseases identified mothers and stepmothers as primary caregivers in the context of disease management.[13,14] For older adults, about two-thirds of caregivers are women.[15] A recent study on care transitions for older adults with limitations found that 48.8% of caregivers were wives or daughters, compared with 25.1% husbands and sons. Additionally, wives and daughters were less likely than other caregivers to be relieved of this responsibility by transitioning older adults into other settings for care.[16]

Increasingly, the primary breadwinner role is also being assumed by women, adding to their critical role in families as caregivers and decision-makers. A recent Pew Research Center study examining U.S. Census Bureau data from the 2011 American Community Survey found that in 40% of households with children under the age of 18, women hold the primary or sole breadwinner role.[18] Of note, more than 60% of these families are headed by single mothers, a subgroup that is often more likely to be poor.[18] Study authors cite a variety of factors that may contribute to this finding, including the most recent 2008 economic downturn. More women are taking on an increasing number of roles and responsibilities without being given additional resources.

The Affordable Care Act and Implications for Women: A Two-Way Street

Up until now, women without the financial means to cover the costs of health care simply went without care and often put their family members' health care needs ahead of their own. Under the Affordable Care Act, women themselves are better covered. In addition to more affordable coverage options, including Marketplace insurance plans and Medicaid expansion in a majority of States and the District of Columbia, women

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also have access to a variety of services at no cost. In fact, 22 preventive care services specifically aimed at women are required to be covered by insurers with no cost-sharing, including well-woman visits, FDA-approved contraception, breast and cervical cancer screening, domestic violence screening and counseling, and osteoporosis screening. Knowing they have these services covered can be the impetus that provides women with the peace of mind to help themselves, help others within their own families, and help the broader community around them. Potentially, this has huge implications for the success of the Affordable Care Act: it is exciting that the same women who are currently uninsured and underinsured are among those who have the most to gain. Rather than limit their influence because of economic limitations, women are in a unique position to look at their health care decision-making experience as a new source of clout. Women can share health care information with those around them including their families, their communities, and beyond, while at the same time, gaining access to the important services that they need.

A variety of outreach and education efforts that target women as both informed consumers and health care decision-makers are increasingly important along this new two-way street. According to the Pew Internet Project, women increasingly are turning to social media for health care information and sharing their health care experiences, recommendations, and decisions with other women in situations similar to their own.[17] Not surprisingly, women in health care decision-making roles are also a trusted resource for health information. According to Enroll America, a nonpartisan 501(c)(3) organization dedicated to increasing the numbers of uninsured Americans who enroll in health coverage through the Affordable Care Act, "Moms" are the most effective messengers when it comes to health information for their families. Results from a recent national study funded by Enroll America revealed that among young uninsured adult males, ages 18–29, a mom or spouse is one of the first people to turn to for insurance information.[19] This may be even more relevant for women in low-income communities, where individuals tend to turn to family networks and community ties for support and sources of trusted information.[20] People turn to trusted sources when making decisions about health and health care, and the decision to enroll in the Marketplace is likely be no different.

Efforts during the first open enrollment engaged women in Affordable Care Act outreach and education. For example, as part of one cross-sector effort to mobilize women as education and outreach leaders, "Wellness Wonder Teams" sponsored by the group MomsRising fanned out across the country with a goal to inform family, friends, and the general public about the affordable health care options and other opportunities under the new health care law.[21] At the same time, women bloggers, women's magazines, and other women's groups used communication and outreach strategies to become more involved with promotion and outreach within their communities.[19,22] Additionally, in July 2013, the U.S. Department of Health and Human Services issued an innovative challenge seeking the public's help to create educational tools focused on outreach and enrollment, as well as women's preventive services covered through the Affordable Care Act.[23] More initiatives at the community and local levels such as these are needed for future open enrollment periods. As the 2013 Kaiser Family Foundation's

Women's Health Survey noted, 74% of women are aware that the Affordable Care Act requires nearly all Americans to have health insurance, but only 57% of women are aware of the requirement for most insurance plans to cover the full cost of many preventive services.[24] It is important to continue to empower women to enroll themselves and their families in affordable health care coverage and to understand how to take advantage of their new benefits.

Discussion

Over the next 10 years, the Congressional Budget Office has projected that 24 million people will obtain health insurance coverage through the Marketplace and additional substantial numbers of people will obtain coverage through Medicaid expansion. The goal for the first open enrollment was set at seven million individuals between October 1, 2013 and March 31, 2014.[5] As of May 1, 2014, over eight million individuals had signed up for private insurance in the Marketplace, and an additional 4.8 million people enrolled in Medicaid and CHIP.[25] The influential role that women played in achieving this goal should continue to be recognized and encouraged. It will be important to track how women's roles in health care decision-making continue to evolve in the months and years to come in this unprecedented leadership opportunity.

The implementation of the Affordable Care Act can afford underserved women new health care opportunities and choices: opportunities to receive preventive health care services at no cost, choices in health care coverage, choice of primary care providers, and choice of contraceptives to help with family planning, if they so desire, to name a few. The Affordable Care Act can empower all women, but particularly uninsured women, as a trusted voice. Through their important caregiving and decision-making roles, women can continue to help others obtain health care coverage and services and, in turn, help themselves.

Disclaimer

The views expressed in this commentary are those of the authors and do not necessarily represent the official position of the U.S. Department of Health and Human Services, the Health Resources and Services Administration; Altarum Institute; or Virginia Polytechnic Institute.

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