Part III:
Access to Health Care Coverage

Breast and Cervical Cancer Treatment

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) was created by Congress in 1990 under the Breast and Cervical Cancer Mortality Prevention Act (P.L. 101-354). Administered by the Centers for Disease Control and Prevention (CDC), the program was designed to provide screening for breast and cervical cancer to underinsured and uninsured women. While the program was authorized to provide screening, it was not authorized to use funds for treatment. Rather, states had to find a way in which to treat the women diagnosed.

Since the NBCCEDP's inception, it has served over 1.4 million women, diagnosing over 5,800 breast cancers, over 31,000 precancerous lesions, and over 500 cervical cancers.[1] However, due to financial constraints, the program reaches only 15 percent of the women eligible for screening. Currently, the NBCCEDP operates in all 50 states, 6 territories, the District of Columbia, and 12 American Indian/Alaska Native organizations.[2]

Despite the program's success, women's health advocates argued that some women diagnosed under the program were not receiving timely follow-up and treatment. Although states have created extensive networks through which women are referred to treatment, these systems are frequently disconnected. Treatment is often provided by physicians, hospitals, or managed care organizations on donated time or at a reduced cost.

According to the CDC, 92 percent of women screened and diagnosed through the program obtained treatment, the remaining 8 percent either refused treatment (2 percent), were lost to follow-up (1 percent), or data was unavailable (5 percent).[3] For women diagnosed with breast cancer, there is a median of eight days between the diagnosis and the initiation of treatment. The CDC currently does not collect data that follows women through the treatment process, including the actual length of treatment, whether or not those who initiated treatment received it through the full course of their illness, or if women received any necessary auxiliary services.[4]

A recent evaluation conducted for the CDC demonstrated that approaches used to secure treatment for patients were short-term, labor-intensive, and difficult to manage, calling the system "tenuous and fragile at best."[5] Practitioners and advocates share stories of women waiting six months to a year to initiate treatment. Those who do initiate care are often forced to incur serious debt in order to afford the treatment.[6]

If women do obtain care, the standard of care is often not met. According to advocates, once diagnosed through the NBCCEDP, women are forced to navigate a confusing health care system, and then they often do not have access to all the services necessary for a complete recovery, such as psychological counseling, physical therapy, or support groups. Further, many women opt for a radical mastectomy rather than breast conserving surgery, even if the cancer would be amenable to this type of treatment, becuase they cannot afford to pay for additional treatments such as chemotherapy or radiation. Surgical reconstruction is seldom a possibility for these women.[7]

Congressional Action

In an effort to remedy these problems, Congress enacted a bill (P.L. 106-354) to provide treatment to women diagnosed under the program. The new law gives states the option of providing Medicaid coverage to women diagnosed with breast or cervical cancer under the NBCCEDP. The law provides an enhanced federal match identical to the match provided under the State Children's Health Insurance Program, which ranges from 65 to 83.76 percent, depending upon the state.

The language is based on several bills (H.R. 1070, H.R. 4386, S. 662). H.R. 1070 was sponsored by Reps. Rick Lazio (R-NY) and Anna Eshoo (D-CA). H.R. 4386 was sponsored by Reps. Sue Myrick (R-NC), Pat Danner (D-MO), and Lazio. S. 662 was sponsored by the late Sen. John Chafee (R-RI) and Sen. Barbara Mikulski (D-MD).

Additionally, the 106th Congress improved Medicare coverage for screening Pap smears and pelvic exams. Under the new law (P.L. 106-554), Medicare is required to provide biennial coverage for screening Pap smears and pelvic exams for all women. Currently, Medicare covers a Pap smear once every three years. Women who are at risk of developing cervical cancer and those who have had an abnormal Pap smear in the past three

years are currently eligible for an annual Pap smear. The provision was part of the Medicare "givebacks" legislation, which was included in the final FY2001 Consolidated Appropriations Act (P.L. 106-554).

Notes

1 Centers for Disease Control and Prevention (CDC), "Ten Years of Progress: The National Breast and Cervical Cancer Early Detection Program" <http://www.cdc.gov/cancer/nbccedp/anniversary.htm> (8/30/00).

2 CDC, "The National Breast and Cervical Cancer Early Detection Program At-A-Glance 2000" <http://www.cdc.gov/cancer/nbccedp/about.htm> (8/9/00).

3 Dr. Nancy Lee of the National Center for Chronic Disease Prevention and Health Promotion at the CDC, testimony before the House Commerce Subcommittee on Health and Environment, July 21, 1999, p. 3.

4 House Commerce Committee, *Breast and Cervical Cancer Federally Funded Screening Programs* (Washington: Government Printing Office, 1999), p. 24.

5 Lowell Sever, Ph.D. and Paula Lantz, Ph.D., et al., "Follow-up and Treatment Issues in the National Breast and Cervical Cancer Early Detection Program: Study Design and Research Results" (joint study by Batteile Centers for Public Health Research and Evaluation and the University of Michigan School of Public Health, Jan. 1998).

6 Fran Visco of the National Breast Cancer Coalition, testimony before the House Commerce Subcommittee on Health and Environment, July 21, 1999, p. 2.

7 Dr. Stanley Klausner of Brookhaven Memorial Hospital, testimony before the House Commerce Subcommittee on Health and Environment, July 21, 1999, pp. 4-5.

Bone Mass Measurement

Osteoporosis, a disease characterized by weak, brittle bones, is a leading cause of injury and disability in older women. Eight million women are afflicted with the disease, which causes 1.5 million fractures annually.[1] The only accurate way to diagnose osteoporosis, predict future risk of fractures, and select the most appropriate treatment is through a bone mineral density (BMD) test or bone mass measurement.

Bone densitometry is often recommended for women at menopause who are trying to decide whether to start hormone replacement therapy because bone density loss is linked to a reduction in estrogen that occurs with menopause. Repeat BMD measurements can help monitor the amount of bone lost or evaluate the effectiveness of treatment over time.[2]

A variety of techniques for measuring bone density exists, including radiographic absorptiometry (RA), single photon and single x-ray absorptiometry (SPA/SXA), dual photon and dual x-ray absorptiometry (DPA/DXA), peripheral dual x-ray absorptiometry (PDXA), quantitative computed tomography (QCT), and ultrasound.[3] In addition to BMD tests, health care providers also assess a woman's risk for osteoporosis and fracture, as well as monitor therapy, using biochemical markers, which measure bone formation and resorption.[4]

A high degree of diagnostic accuracy makes DXA one of the preferred methods of BMD today.[5] DXA uses small amounts of radiation (much lower than that of a chest x-ray or CT scan) to measure bone density in the spine, hip, wrist, or heel. The test is quick, painless, and reliable, and can detect even the earliest stages of bone loss.[6]

The cost of DXA, which ranges from $100 to $300, is now covered under Medicare.[7] The Balanced Budget Act of 1997 (P.L. 105-33) included a provision that requires Medicare coverage of bone mass measurement every two years for those at high risk of developing osteoporosis, including estrogen-deficient women. The law also mandates coverage for individuals being monitored to determine their response to osteoporosis drug therapy. Recently, the National Osteoporosis Foundation recommended guidelines that all women aged 65 and over and postmenopausal women under age 65 who have one or more risk factors for osteoporosis undergo BMD testing.[8]

Additionally, under the Balanced Budget Refinement Act of 1999 (P.L. 106-113), Medicare was required to establish a new system to classify and pay for tests performed in an outpatient setting. Under the rule, which went into effect on July 1, 2000, all BMD tests have been placed under the same class (plain x-ray) and they are reimbursed at the same rate, $67. How-

Legislation

Osteoporosis Early Detection and Prevention Act of 1999/Early Detection and Prevention of Osteoporosis and Related Bone Diseases Act of 1999 (H.R. 925/S. 1106)—Reps. Carolyn Maloney (D-NY) and Connie Morella (R-MD) and Sens. Robert Torricelli (D-NJ) and Olympia Snowe (R-ME)

H.R. 925/S. 1106 would require private health insurance plans to cover bone mass measurement for qualified individuals who are at risk of developing osteoporosis.

Osteoporosis Federal Employee Health Benefits Standardization Act of 1999 (H.R. 933/S. 1152)—Rep. Connie Morella (R-MD) and Sen. Olympia Snowe (R-ME)

H.R. 933/S. 1152 would ensure that coverage of bone mass measurement is provided under the health benefits program for federal employees. Under the bill, the Federal Employees Health Benefits Program could not contract with a plan that does not include coverage for bone mass measurement.

Medicare Osteoporosis Measurement Act of 2000 (H.R. 3840/S. 2524)—Reps. Connie Morella (R-MD) and Shelley Berkley (D-NV) and Sen. Olympia Snowe (R-ME)

H.R. 3840/S. 2524 would expand Medicare coverage of bone mass measurement to all individuals at clinical risk of osteoporosis.

ever, prior to the new rule, Medicare reimbursed at different rates for BMD tests depending on the technology. For example, a DXA exam was reimbursed at $136.20, while a PDXA exam was reimbursed at $41.37. Advocates are concerned that the new rule will encourage hospitals to use cheaper and less effective technologies, while being reimbursed at the same rate as a more expensive technology.[9]

Notes

1 National Osteoporosis Foundation (NOF), "Osteoporosis Fast Facts" <http://www.nof.org/osteoporosis/stats.htm> (8/9/00).

2 NOF, "Osteoporosis: Bone Mass Measurement" <http://www.nof.org/osteoporosis/bonemass.htm> (8/9/00).

3 Ibid.

4 Christine Simonelli, M.D., "Practical Issues in Bone Mineral Density Testing," *Journal of the American Medical Women's Association* 55 (2000) 4: 228-233.

5 Dr. Leon Lenchik of the International Society for Clinical Densitometry, email communication with Women's Policy, Inc., Aug. 14, 2000; Dr. Simonelli, "Practical Issues in Bone Mineral Density Testing."

6 NOF, "Osteoporosis: Bone Mass Measurement."

7 Dr. Lenchik, email communication.

8 Dr. Simonelli, "Practical Issues in Bone Mineral Density Testing."

9 NOF, "Legislative Alert: Action Needed on Final Rule for Ambulatory Payment Classes," May 2000 <http://www.nof.org/advocacy/petition_congress/hcfaalertMay00.htm> (8/28/00).

Clinical Trials

For many years, research on women's health focused primarily on reproductive functions, with information on other health issues affecting women often derived by extrapolation from studies of men. Women have been greatly underrepresented in clinical research, which uses human subjects to translate discoveries in basic science into advances in medicine. Research on coronary heart disease, kidney transplants, alcoholism, tobacco use, and HIV/AIDS, until recently, has been particularly notable for its exclusion of women from clinical trials.

In 1986, the National Institutes of Health (NIH) adopted a policy of encouraging the inclusion of women in clinical trials; however, a 1990 General Accounting Office (GAO) report found that little had been done to implement that policy.[1] The report was requested by Rep. Henry Waxman (D-CA) and the co-chairs of the Congressional Caucus for Women's Issues (CCWI), Reps. Pat Schroeder (D-CO) and Olympia Snowe (R-ME). Additionally, the CCWI introduced the Women's Health Equity Act, which included a provision to establish an Office of Research on Women's Health at the NIH.

As a result, the NIH in September 1990 announced the creation of the NIH Office of Research on Women's Health (NIH-ORWH), which would oversee and coordinate the inclusion of women in clinical trials. In 1993, Congress enacted the NIH Revitalization Act (P.L. 103-43), which established guidelines on the inclusion of women and minorities in clinical trials and permanently established the NIH-ORWH.

Ten years after its initial report, the GAO examined the NIH's progress and found that while the NIH had made significant advances in the inclusion of women and minorities in clinical trials, the data from those trials was not being analyzed to reflect sex and gender differences.[2] The report was requested by Sens. Tom Harkin (D-IA), Barbara Mikulski (D-MD), and Olympia Snowe (R-ME) and Rep. Henry Waxman (D-CA). The NIH-ORWH responded to the GAO report by creating an NIH-wide Tracking and Inclusion Subcommittee to specifically oversee the adherence to the 1993 guidelines on the inclusion of women and minorities in clinical trials. Additionally, the NIH-ORWH posted a notice on its website clarifying the requirements for the inclusion of women and minorities in Phase III clinical trials, which test a new drug, a new combination of drugs, or a new surgical procedure in comparison to the current standard for treatment.[3]

Reimbursement Issues

Broad agreement exists among academic health centers, researchers, and managed care plans that insurers should not be responsible for the research costs of patients enrolled in clinical trials—extra tests, experimental treatment, hospitalization, or outpatient care that patients receive only because they are required by study protocols.[4] However, the National Center for Research Resources at the NIH and many researchers contend that insurers should pay the normal clinical costs for Category B patients regardless of the phase of the trial in which they are enrolled, since these costs would be incurred even if the patients were not participating in clinical trials. Category B patients are research participants who have an underlying illness and are hospitalized or are receiving outpatient care for medically necessary reasons—not simply because they are enrolled in a clinical trial.[5]

In many cases, these patients have serious illnesses for which the treatments are largely experimental. Because medical costs associated with these illnesses are often high, the refusal of insurers to pay can result in a major financial burden on either the academic health center or the patient. The possibility of losing coverage for all costs associated with an illness if they enroll in a clinical trial may lead some patients to decline to participate and thereby deprive them of potentially lifesaving treatments.[6]

Studies show that 1 percent of seniors participate in clinical trials. While 63 percent of cancer patients are over the age of 65, they make up only 33 percent of those enrolled in clinical trials. Additionally, older women constitute 44 percent of breast cancer patients, but only 1.6 percent of women aged 65 and over who participate in clinical trials for the disease.[7]

While the Health Care Financing Administration (HCFA), which oversees Medicare and Medicaid, has no formal policy on reimbursement for routine care

associated with clinical trials, a 1997 GAO report discovered that HCFA was unknowingly reimbursing for most routine care costs of Medicare beneficiaries in certain cancer clinical trials.[8] A recent Institute of Medicine report recommended that Medicare should reimburse routine care for patients in clinical trials in the same way it reimburses routine care for patients who are not participating in clinical trials. The report found that uncertainty about reimbursement contributed to difficulty in enrolling patients in clinical trials.[9]

Additionally, a 1999 GAO report found that health insurance policies generally exclude coverage for clinical trials, although some exceptions are made on a case-by-case basis. Insurers also reported wide variations in the way they review cases for approved clinical trial coverage.[10]

On June 7, 2000, the President issued an executive memorandum directing the Medicare program to reimburse providers for the cost of routine care associated with participation in clinical trials. The executive memorandum also directs the Medicare program to promote the participation of Medicare beneficiaries in clinical trials.[11]

Legislation

Improved Patient Access to Clinical Studies Act (S. 117/H.R. 2769)—Sen. Olympia Snowe (R-ME) and Rep. Nita Lowey (D-NY)

S. 117/H.R. 2769 would prohibit health plans from discriminating against enrollees who are participating in clinical research studies. Specifically, plans would be prohibited from denying, limiting, or imposing additional conditions on the coverage of items or services for persons enrolled in approved clinical studies, as long as those items and services would otherwise be covered under the plan.

Medicare Cancer Clinical Trial Coverage Act of 1999 (S. 784/H.R. 1388)—Sens. John Rockefeller (D-WV) and Connie Mack (R-FL) and Reps. Nancy Johnson (R-CT) and Ben Cardin (D-MD)

H.R. 1388/S. 784 would create a demonstration project to study and provide coverage of routine patient care costs for Medicare beneficiaries with cancer who are enrolled in a federally approved clinical trial.

Notes

1 General Accounting Office (GAO), *NIH: Problems on Implementing Policy on Women in Study Populations* (Washington: Government Printing Office, 1990).

2 GAO, *Women's Health: NIH Has Increased Efforts to Include Women In Research* (Washington: Government Printing Office, 2000).

3 Washington FAX, "NIH Responds to GAO Criticism About Insufficient Gender Analysis in Trials," Aug. 3, 2000 <http://www.washingtonfax.com> (8/3/00); National Cancer Institute, "Understanding Clinical Trials" <http://cancertrials.nci.nih.gov/understanding/basics/index.html#types> (8/29/00).

4 The Public Health Service, "The Impact of Managed Care on Clinical Research: A Preliminary Investigation," Jan. 1996 <http://www.ncrr.nih.gov/clinical/crpublic.htm> (8/10/00).

5 National Center for Research Resources, "NCRR Reporter," May/June 1996.

6 National Breast Cancer Coalition, "Legislative Priority #4: Increased Access to Clinical Trials," NBCC Briefing Paper <http://www.natlbcc.org/agenda/brief/p3.asp> (6/21/00).

7 The White House, "President Clinton Takes New Action to Encourage Participation in Clinical Trials" (press release, June 7, 2000) <http://www.whitehouse.gov/WH/New/html/20000607.html> (6/20/00).

8 GAO, *Cancer Clinical Trials: Medicare Reimbursement Denials* (Washington: Government Printing Office, 1997).

9 Institute of Medicine, *Extending Medicare Reimbursement in Clinical Trials* (Washington: National Academy Press, 2000).

10 GAO, *NIH Clinical Trials: Various Factors Affect Patient Participation* (Washington: Government Printing Office, 1999).

11 The White House, "President Clinton Takes New Action to Encourage Participation in Clinical Trials."

Contraceptive Drugs and Services

Access to contraceptives is a crucial determinant of women's health. Contraceptive use prevents millions of abortions and unplanned births in the United States each year, yet prescription contraceptive devices and services are not routinely covered by most private health plans. This omission places some women at an economic disadvantage and poses health risks for them and their families.

Traditional indemnity (or fee-for-service) health care plans have generally covered medically necessary diagnostic and treatment services but not those services characterized as preventive in nature. These are the health plans least likely to provide contraceptive coverage.

The growth of managed care has expanded coverage of contraceptive services, but the majority of plans still do not cover all of the most commonly used contraceptives. Moreover, the newer types of managed care plans, such as preferred provider organizations (PPOs) and point of service (POS) plans, are considerably less likely to offer contraceptive coverage than are health maintenance organizations (HMOs). According to a 1998 Alan Guttmacher Institute (AGI) survey:

- Half of all indemnity plans and PPOs, 20 percent of POS networks, and 7 percent of HMOs cover no reversible forms of contraception. However, the majority of indemnity plans and HMOs cover both surgical abortions and sterilization.
- Fifteen percent of indemnity plans and PPOs and less than 40 percent of HMOs or POS networks routinely allow women to choose from the five most commonly used reversible contraceptive methods (oral contraceptives, the IUD, diaphragm, Norplant, and Depo Provera).
- Although 97 percent of indemnity plans cover prescription drugs in general, only 33 percent include oral contraceptives in that coverage. The vast majority of HMOs that cover prescription drugs include coverage of oral contraceptives.[1]

A more recent employer survey by the Kaiser Family Foundation/Hospital Research and Educational Trust found that 60 percent of individuals enrolled in indemnity plans had contraceptive coverage, compared to 62 percent of individuals in PPOs, 75 percent of individuals in POS plans, and 87 percent of individuals in HMOs.[2]

One important consequence of the lack of contraceptive coverage is that women spend more out-of-pocket for health care services than men. According to the Agency for Healthcare Research and Quality, women paid an average of $480 per year in out-of-pocket expenses, compared with men, who spent an average of $374 per year.[3]

A 1998 Kaiser Family Foundation study found that three-quarters of Americans support legislation to require contraceptive coverage, with 78 percent of women expressing support for such policies compared to 66 percent of men. Additionally, 73 percent of those surveyed said that they would support contraceptive coverage even if it raises their insurance premiums by $1 to $5 per month. Eighty-two percent of those surveyed believe that contraceptive coverage should include all FDA-approved methods.[4]

Another AGI study found that the addition of contraceptive coverage to a health plan would cost $21.40 per year per employee. Of that amount, employers would be responsible for $17.12 and employees would be responsible for $4.28. The cost of adding contraceptive coverage would result in an increase of less than 1 percent in employers' costs.[5]

In addition to the cost-effective nature of contraceptive coverage, family planning provides a significant health benefit for women as well. By helping women to adequately space their families, contraceptives contribute to healthier pregnancies and births. They also reduce rates of maternal complications, low birthweights, and infant mortality.

As of December 2000, 13 states had enacted legislation requiring health insurance plans to cover prescription contraceptives if they also cover other prescription drugs; however, the range of services covered varies. According to the Kaiser Family Foundation, all of the state laws cover contraceptive drugs and devices, many states require coverage for birth control-related services, some states only require insurers to offer health plans that cover contraception, several states only require HMOs to cover contraceptive drugs, and sev-

eral other states simply require HMOs to cover family planning services without defining what those services would include.[6]

In December 2000, the Equal Employment Opportunity Commission (EEOC) ruled that it was unlawful for an employer to exclude coverage for prescription contraceptives when it provided coverage for other prescription drugs. The EEOC determined that exclusion of such coverage violated Title VII of the Civil Rights Act of 1964, as amended by the Pregnancy Discrimination Act (PDA), which requires equal treatment of women "affected by pregnancy, childbirth, or related medical conditions." In 1991, the U.S. Supreme Court determined that the PDA prohibits discrimination based on a woman's ability to get pregnant, as well as the pregnancy itself.[7] As such, the EEOC determined that the exclusion of contraceptive coverage constituted "prohibited sex discrimination since prescription contraceptives are available only for women."[8]

Congressional Action

A District of Columbia's (D.C.) City Council-approved bill to require health insurance plans that provide coverage to city employees to cover contraceptives if they also cover other prescription drugs became the subject of controversy when the House considered its FY2001 D.C. appropriations bill (H.R. 4942) in July 2000. As approved by the House Appropriations Committee, H.R. 4942 would have prohibited D.C. from implementing the City Council bill, unless it was rewritten to include a conscience clause that would allow an exemption for religious beliefs and moral convictions.

After D.C. Mayor Anthony Williams pocket vetoed the D.C. City Council bill, the House approved an amendment by Del. Eleanor Holmes Norton (D-DC) to strike the language that would prevent D.C. from implementing the bill. However, as passed by the House, the FY2001 D.C. spending bill directed the D.C. City Council to rewrite a contraceptive coverage bill that includes a conscience clause. The Senate-passed bill did not include language regarding the city's contraceptive coverage bill.

The final bill (P.L. 106-522) retained the House language requiring the D.C. City Council to rewrite the contraceptive coverage bill to include a conscience clause.

Legislation

Equity in Prescription Insurance and Contraceptive Coverage Act of 1999 (S. 1200/H.R. 2120)—Sens. Olympia Snowe (R-ME) and Harry Reid (D-NV) and Reps. James Greenwood (R-PA) and Nita Lowey (D-NY)

S. 1200/H.R. 2120 would require health insurance plans that already cover prescription drugs to cover FDA-approved prescription contraceptives and devices. It also would require plans that cover basic health care services to also cover medical and counseling services to promote the effective use of those contraceptives.

Additionally, after a protracted battle, the 105th Congress enacted legislation to require plans participating in the Federal Employees Health Benefits Program to cover prescription contraceptives if they also cover other prescription drugs. The provision was included in the FY1999 Treasury, Postal Service, and General Government appropriations bill (P.L. 105-277). The 106th Congress renewed the provision during the FY2000 and FY2001 appropriations process.

Notes

1 Rachel Benson Gold, "The Need for and Cost of Mandating Private Insurance Coverage of Contraceptives," *The Guttmacher Report on Public Policy* 1 (Aug. 1998) 4 <http://www.agi-usa.org/pubs/journal/gr01045.html> (6/14/00).

2 The Kaiser Family Foundation, "Coverage of Gynecological Care and Contraceptives" (fact sheet, 2000), p. 1.

3 Agency for Healthcare Research and Quality (AHRQ), *Medical Expenditure Panel Survey, 1996* (Rockville: AHRQ, 1997); Amy Taylor of AHRQ, telephone interview with Women's Policy, Inc., Aug. 15, 2000.

4 Kaiser Family Foundation, "State Policies on Access to Gynecological Care and Contraception" (issue brief, 2000), p. 4.

5 Jacqueline Darroch, "Cost to Employer Health Plans of Covering Contraceptives: Summary, Methodology and Background," June 1998 <http://www.agi-usa.org/pubs/kaiser_0698.html> (6/14/00).

6 Kaiser Family Foundation, "Update: State Policies on Access to Gynecological Care and Contraception" (issue brief, 2000), pp. 3-4.

7 Equal Employment Opportunity Commission (EEOC), "Decision on Coverage of Contraception" <http://www.eeoc.gov/docs/decision-contraception.html> (12/13/00).

8 EEOC, "EEOC Issues Decision on Two Charges Challenging the Denial of Health Insurance Coverage for Prescription Contraceptives" (press release, Dec. 13, 2000) <http://www.eeoc.gov/press/12-13-00.html> (12/13/00).

Family Caregivers/Long-term Care

Family caregivers are those who have primary responsibility for a relative who—due to physical or mental limitations—is dependent upon others for assistance with daily activities. Caregivers assist with tasks such as bathing, grooming, eating, meal preparation, housework, running errands, and administering prescriptions and other medical care.

Most often, caregivers are unpaid family members who provide care on a long-term basis. Caregiving responsibilities disproportionately fall upon women. In fact, 7 out of 10 unpaid caregivers are women.[1] Many individuals, particularly the elderly, rely on family members because it is determined that they do not require "skilled" care and therefore do not qualify for Medicare home health care benefits. The General Accounting Office found that 60 percent of disabled elderly individuals relied on unpaid caregiving.[2]

Although caregiving is not considered "skilled" care, the responsibilities often can exceed those of a full-time job. Research also has shown that the average American woman spends 18 years of her life caring for an elderly relative. Most caregivers spend an average of 69 hours per week in that role; two-thirds work full- or part-time jobs in addition to providing family care. Most caregivers also are simultaneously caring for their own children.[3]

Caregiving responsibilities disproportionately fall upon women. In fact, 7 out of 10 unpaid caregivers are women.

Family caregivers contribute significantly to the American health care system. A study published in the March/April 1999 issue of *Health Affairs Magazine* found that family caregivers provide $196 billion in services annually. Comparatively, $32 billion is spent on private home health providers and $83 billion is spent on nursing home care.[4] Additionally, three-quarters of nursing home residents aged 65 and older are women and two-thirds of home health care users are women.[5]

Many of the personal costs to family caregivers are not quantified. Research has shown an increased likelihood of depression and anxiety among caregivers seeking to balance a variety of responsibilities. Chances for physical injury also are increased, as much of the work of caregiving involves lifting and other physical strain.[6] One study found that elderly caregivers had a 63 percent higher death rate than individuals who do not provide care.[7]

Additionally, as women live an average of seven years longer than men, they often require long-term care themselves.

Congressional Action

Congress has endeavored to provide some assistance for family caregivers. For instance, under the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191), taxpayers who itemize their deductions can deduct certain expenses related to long-term caregiving if those expenses and other medical costs combined exceed 7.5 percent of the taxpayer's adjusted gross income.[8]

In addition, a caregiver can claim an elderly relative as a dependent and claim a personal exemption if a range of criteria is met. The caregiver and the recipient of care must live in the same home, the caregiver must provide at least 50 percent of the financial support for the relative, and the annual income of the care receiver cannot exceed the personal exemption amount, which is about $3,000. As many elderly individuals receive Social Security and pension benefits in excess of that amount, few can be claimed as dependents.[9]

During the 106th Congress, the President and several Members of Congress advanced proposals for expanding assistance to family caregivers. In his FY2000 budget proposal, the President proposed a $125 million initiative called the National Family Caregiver Support Program, which would provide information services for caregivers, assist caregivers in gaining access to such services, provide individual counseling or support groups for caregivers, offer respite care, and provide other long-term care arrangements. In addition to providing information and services, the proposal included a targeted $1,000 tax credit for people in need of long-term care or their caregivers. In his FY2001 budget plan, the President called for increasing that tax credit to $3,000.

Provisions designed to benefit long-term caregivers were included in a tax bill (H.R. 2488) approved by Congress in August 1999. Under the bill, employers would have been able to deduct the cost of providing long-term care insurance for their employees. In addition, the measure would have expanded the personal exemption for an individual who cares for an elderly relative at home and allowed the deduction of more care-related costs. However, based on objections to unrelated provisions also included in the package, the President vetoed the bill in September 1999.

The 106th Congress enacted legislation (P.L. 106-265) to assist federal and military employees and retirees with the purchase of long-term care insurance. The new law allows federal and military employees and retirees to purchase long-term care insurance at group rates, which usually are significantly lower than the rates for individually-purchased plans. Long-term care insurance policies can be purchased to help cover a range of situations, including private in-home nursing care, family caregivers, and assisted living facilities. The Office of Personnel Management (OPM) is authorized to negotiate with long-term care insurers for benefits, in much the same way that OPM currently negotiates with health insurers on behalf of workers enrolled in the Federal Employees Health Benefits Program.

The 106th Congress also enacted legislation (P.L. 106-501) to reauthorize the Older Americans Act. Included in that bill was a provision to establish the National Family Caregiver Support Program. The program was appropriated $125 million under the FY2001 Labor, Health and Human Services, and Education spending bill (P.L. 106-554).

A number of legislative proposals aimed at providing long-term care and aiding family caregivers were introduced in the 106th Congress. For a listing, see Appendix II.

Notes

1 William Scanlon of the General Accounting Office, testimony before the Senate Special Committee on Aging, Sept. 13, 2000, p. 6.
2 Ibid., p. 2.
3 Older Women's League, "Women and Long-Term Care" (fact sheet, 1999).
4 National Alzheimer's Association, "State-by-State Study Shows U.S. Health Care System Benefits from $196 Billion in Services from Family Caregivers" (press release, March 3, 1999) <http://www.alz.org/media/news/1999/Cstate_study.htm> (6/26/00).
5 Scanlon, testimony, p. 6.
6 National Alzheimer's Association, "Study Shows U.S. Health Care System Benefits."
7 Carol Levine, "Night Shift," *Ms.* 10 (2000) 5: 42-46.
8 AARP, "Long-Term Care," *The Public Policy Agenda 2000* (Washington: AARP, 2000), p. 7-12.
9 Ibid.

Genetic Discrimination

Medical research is rapidly expanding knowledge about the role of genetics in diseases from cancer to Alzheimer's to heart disease. Researchers continue to discover new genes in the human body and identify how genes are involved in a variety of medical conditions. In fact, in July 2000, researchers announced that they had mapped the entire human genome.[1]

With this knowledge comes the possibility of developing more effective treatments, as well as developing genetic tests to identify individuals at risk for certain diseases. These individuals could then participate in early detection screenings, potentially saving both lives and medical costs. However, few practitioners or consumers are adequately informed about the limitations of genetic testing. In the absence of safeguards, some fear that genetic information could be used to deny individuals health and life insurance or employment opportunities.

Over the past few years, scientists have identified genes that may predispose individuals to cancers of the colon, breast, and ovary, as well as Huntington's disease, amyotrophic lateral sclerosis, and some forms of Alzheimer's disease.[2] Additionally, scientists have discovered over 100 alterations in the inherited BRCA1 and BRCA2 genes, known to cause breast cancer. This discovery has focused public attention on the role of genetics in breast cancer and raised for the first time the possibility of screening a segment of the population for a cancer predisposition mutation. Women who have inherited the BRCA1 mutation have a 50 to 85 percent risk of developing breast cancer in their lifetime. Scientists believe that BRCA1 and BRCA2 mutations account for 30 to 70 percent of all inherited breast cancer cases.[3]

The possibility of screening women for these mutations, however, also points out the limitations of genetic testing. Only 5 to 10 percent of all breast cancers are hereditary.[4] Thus, a negative test result does not guarantee that an individual will not develop cancer. Further, a positive test result for a gene implicated in a certain medical condition does not guarantee that an individual will develop the disease.

A genetics test does not take into account factors such as exposure to environmental compounds, diet, behavior, and infectious agents that also influence the development and course of a disease. Finally, there are no comprehensive criteria in place to monitor the quality or assess the scientific validity of genetic tests, or to ensure that adequate counseling is provided along with the tests.

Studies have shown that there is a risk of discrimination against those who have a genetic predisposition for a disease. A 1998 study by the National Center for Genome Resources at the National Institutes of Health (NIH) found that 63 percent of respondents probably or definitely would not take a genetics test if employers could access the results. The study also found that 85 percent of respondents thought that health insurers should be barred from accessing genetic information.[5] Another survey by the American Management Association found that one-fifth of employers take family medical histories of employees and applicants.[6] Additionally, during genetic testing studies at the NIH, nearly 32 percent of eligible individuals offered a test for breast cancer risk declined to take it; most cited concerns about health insurance discrimination.[7]

Although discrimination on the basis of genetic information may not yet be systemic, as scientists characterize the genetic connections of more diseases and develop screening tests, the potential for genetic discrimination may continue to increase. As of August 2000, 37 states had laws prohibiting insurance discrimination on the basis of genetic information, and 24 states had laws regarding genetic discrimination in the workplace.[8] But even in those states, large employers who develop self-funded insurance plans are exempt from such regulations.

The 104th Congress addressed the issue of genetic discrimination in the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191). The law prohibits group health plans from using genetic information to deny coverage, but does not protect people who need individual health insurance, such as the self-employed. The law also does not prohibit insurance companies from raising their rates based on genetic tests.

The Balanced Budget Act of 1997 (P.L. 105-33) addressed the effects of genetic discrimination by prohibiting managed care plans participating in Medicare and Medicaid, as well as certain Medigap insurance plans, from discriminating in enrollment or coverage on the basis of genetic information.

During the 106th Congress, legislation to prohibit genetic discrimination was included in the Senate-passed patients' bill of rights (S. 1344), but the bill stalled in a House-Senate conference. The language included in the Senate bill is identical to legislation (H.R. 306/S. 543) sponsored by Rep. Louise Slaughter (D-NY) and Sen. Olympia Snowe (R-ME).

Legislation

Genetic Information Nondiscrimination in Health Insurance Act of 1999 (H.R. 306/ S. 543)—Rep. Louise Slaughter (D-NY) and Sen. Olympia Snowe (R-ME)

H.R. 306/S. 543 would prohibit group and individual health insurance plans from using predictive genetic information to discriminate against individuals. Health insurers would be prohibited from using predictive genetic information as a condition of eligibility and to adjust premiums. Additionally, health insurers would be prohibited from requesting or requiring predictive genetic information concerning an individual or family member.

Genetic Nondiscrimination in Health Insurance and Employment Act of 1999 (S. 1322/H.R. 2457)—Sen. Tom Daschle (D-SD) and Rep. Louise Slaughter (D-NY)

S. 1322/H.R. 2457 would prohibit the use of genetic information by employers and health insurers to discriminate against individuals. The measures would cover all genetic information including an individual's family history. Under the bills, employers would be prohibited from collecting and disseminating genetic information without an individual's consent.

Additionally, on February 8, 2000, the President issued an executive order prohibiting federal agencies from using genetic discrimination information in any hiring or promotion action.[9]

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Mammography Screening

Mammography screening is one of the few effective means of breast cancer detection currently available. While government and private educational campaigns have led to steady increases in the use of mammograms, there have been sharp divisions in the scientific community about the age at which screening should begin. A highly publicized debate between the National Cancer Institute (NCI) at the National Institutes of Health (NIH) and the American Cancer Society (ACS) was resolved in March 1997 when the NCI joined the ACS in endorsing regular mammography screenings for women aged 40 and over. Since that time, policymakers have moved quickly to expand public and private insurance coverage for the procedure.

During a mammogram, a woman's breast is exposed to a low dose of radiation to create an image of its internal structure. A mammogram can find roughly 90 percent of breast cancer tumors in women over 50 and detect them as much as two years earlier than a breast self-examination. In part because of the density of younger women's breasts, mammograms may miss up to 25 percent of invasive breast cancers in this age group.[1]

Screening mammography—performed when a woman has no symptoms of breast cancer—has repeatedly been shown to reduce breast cancer mortality rates by up to 30 percent in women aged 50 to 69.

Screening mammography—performed when a woman has no symptoms of breast cancer—has repeatedly been shown to reduce breast cancer mortality rates by up to 30 percent in women aged 50 to 69. Breast cancer death rates in all women have decreased approximately 18 percent since 1990, a finding cancer researchers attribute to the increase in mammography screening.[2] According to the National Center for Health Statistics, in 1998, 66.9 percent of women aged 40 and over and 68.9 percent of women aged 50 and over reported having a mammogram within the past two years.[3]

The number of women aged 50 and over who have received at least one mammogram increased from 61 percent in 1994 to 69 percent in 1998. Certain populations are far less likely to be screened, however, including those with low incomes or limited education and those older than 65. Fifty-three percent of women living below the poverty line reported receiving a mammogram within the last year, compared with 72 percent of women living above the poverty line.[4]

However, according to a recent NCI and Health Care Financing Administration (HCFA) survey, only 57 percent of women aged 65 and older know about recommendations to have a mammogram every one or two years.[5] This also is the population that is at greatest risk of breast cancer; 77 percent of breast cancers occur in women over 50.

The cost of mammograms and limited access to health care are among the major barriers to regular screening for low-income and older women. A mammogram typically costs $100, with newer technologies costing more. Although coverage under private insurance plans varies widely, most insurers will provide full or partial coverage for an annual screening.

The Balanced Budget Act of 1997 (P.L. 105-33) expanded mammography coverage under Medicare to include annual mammograms—with no deductible—for women aged 40 and older. Under previous law, annual mammograms were covered under Medicare for women aged 50-64. For women under 50 and over 65, the program covered a mammogram every two years. Under current law, Medicare pays 80 percent of the cost of a mammogram for beneficiaries aged 40 and older.

In addition, many medically underserved women have received free or low-cost mammography screenings through the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program. Enacted in 1990, the CDC program now provides support and technical guidance to all 50 states, U.S. territories, and the District of Columbia.[6]

Mammograms for Women in Their 40s

While a broad consensus has existed for many years on the benefits of annual screening for women over 50, the research on whether routine mammography decreases cancer mortality for younger women is less

conclusive. As a result, the NCI and the ACS have differed over the years in their recommendations about the age at which women should begin mammography screening.

The NCI first recommended annual mammography for women over 50 in 1977. At that time, however, it stated that the only time a woman between the ages of 40 and 49 merited a mammogram was when she had a personal or family history of breast cancer. In 1983, the ACS came out in support of regular screening for women in their 40s. The NCI followed suit in 1989, in part to eliminate the confusion caused by the conflicting recommendations.[7]

But the debate over mammograms for women under 50 has continued. Although more than half a million women have participated in randomized clinical trials on the value of mammography screening over the past 30 years, researchers argue that these studies have failed to show a clear decrease in mortality rates in women under 50.[8] Researchers also have expressed concern about the fact that women in their 40s who are screened annually have about a 30 percent chance of receiving a "false positive" result.[9]

Due to these concerns, the NCI rescinded its guidelines in 1993, rekindling the controversy over the age at which mammography should begin. Absent conclusive scientific evidence, the NCI said, women in their 40s should review the facts with their health care providers and make their own decision.[10]

In 1996, following the release of new data showing a 17 percent reduction in breast cancer deaths among women in their 40s who had regular mammograms, the NIH agreed to convene an independent consensus panel to review the research literature and report to the National Cancer Advisory Board, which was preparing to review federal mammography screening guidelines.[11] In late January 1997, the panel issued a draft report, which concluded that existing data did not warrant a recommendation that all women in their 40s have regular mammograms.[12]

The panel's findings came under immediate attack from other researchers who said the group had overemphasized mammography's risks while paying too little attention to the data that showed benefits.[13] The Senate expressed its disapproval of the panel's recommendations in February 1997, when it voted unanimously (98-0) to strongly urge the National Cancer Advisory Board to consider reissuing its 1993 guidelines recommending mammography for women in their 40s. In March 1997, the Board agreed to recommend again that women in that age range have a mammogram every one to two years, citing the 1995 data.[14]

On the same day that the NCI adopted its new guidelines, the President announced a series of executive orders on the issue. He instructed HCFA to send a letter to state Medicaid directors encouraging them to cover annual mammography screenings beginning at age 40 and informing them that the federal government would provide matching payments for these services. He also directed the Office of Personnel Management to require all federal employee health plans to provide such coverage.[15]

Adding to the controversy over mammography screening, a recent study by Canadian researchers that followed nearly 40,000 women aged 50-59 found that clinical breast exams were equally as effective at detecting breast cancer as mammograms. Under the study, half the women received clincial breast exams alone and the other half received both clinical breast exams and mammograms. After a 13-year period, equal numbers in both groups had died of breast cancer.[16]

Additionally, a study published in the *Journal of the National Cancer Institute* found that the cumulative risk of a false-positive mammogram over time varies depending on a woman's risk and factors related to screening technologies. The study reviewed the medical records of 2,227 women aged 40-69 who had at least one screening mammogram. The study found that by the ninth mammogram the risk of a false-positive can be as low as 5 percent for women at low-risk for breast cancer and as high as 10 percent for women with a number of known risk factors.[17] Both these studies point to the need for improved screening methods.

Congressional Action

The 106th Congress enacted legislation (P.L. 106-554) to provide additional Medicare payments to health care providers, which included provisions pertaining to mammography screening. Under the new law, two new payment rates for new technologies applied to screening mammography will be established beginning in 2002. For technologies that directly take digital images, the payment rate will be equal to 150 percent of

the payment for bilateral diagnostic mammography. For technologies that convert images, the payment rate will be increased by $15. Additionally, the Secretary of Health and Human Services will be required to determine if a new code is necessary. The provisions were part of the Medicare "givebacks" legislation, which was included in the FY2001 Consolidated Appropriations Act (P.L. 106-554).

A number of legislative proposals aimed at improving women's access to mammography were introduced during the 106th Congress. For a listing, see Appendix II.

Notes

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Mastectomy Hospital Stays

The shift to managed care has created dramatic reductions in the length of hospital stays. Concerns raised by the health and consumer advocacy communities have prompted incremental steps toward regulating coverage in private sector plans. Public outrage over "drive-by deliveries," in which women were dismissed from hospitals less than 24 hours after giving birth, led to the passage in the 104th Congress of a bill (P.L. 104-204) mandating coverage of a hospital stay for at least 48 hours after delivery. This same legislative strategy is now being applied to the issue of breast cancer surgery, primarily mastectomies.

The trend of decreasing post-mastectomy hospitalization was first brought to national attention by a Connecticut surgeon who clashed with health maintenance organizations (HMOs) in her area regarding covered hospital stays for her patients. These HMOs had adopted guidelines developed in 1995 by an accounting and consulting firm that suggested that mastectomies without complications could be performed on an outpatient basis.[1]

While cost containment measures have abbreviated average hospital stays for all surgeries, the length of stays following mastectomies have decreased more rapidly than for other surgeries on the whole. According to a 1997 study of hospitalization by the Connecticut Office of Health Care Access, hospital stays for all surgical procedures in that state dropped by 23 percent over the previous five years. In this same period, stays for mastectomies dropped by more than 42 percent.[2] The National Center for Health Statistics found that the average length of stay for women aged 45-64 who were diagnosed with breast cancer increased from 2.7 days in 1996 to 3.5 days in 1997. However, the average length of stay for women aged 65-74 years who were diagnosed with breast cancer decreased from 2.9 days in 1996 to 2.4 days in 1997. Additionally, the average length of stay in a hospital for any procedure across the United States has decreased from 6.3 days in 1985 to 4.9 days in 1998. [3]

Many women's health advocates argue that reducing hospital stays places undue physical and emotional burdens on women. Following a mastectomy, plastic drains are generally placed in the incision and must be emptied of blood and cleaned every few hours for days after the surgery. Most women need painkillers and antibiotic treatment to prevent infection. Because of pain and weakness, it may be difficult for a woman to manage her own medication schedule and the maintenance of drains immediately following surgery.[4]

Some doctors suggest that the security and comfort of a familiar environment may speed some women's recovery and that shorter stays for mastectomy patients may be advisable under certain circumstances. These include an absence of medical complications, thorough patient education about aftercare prior to the procedure, and family or friends who are willing to assist in aftercare.[5] Proponents of legislation to require minimum hospital stays argue that while it requires insurers to cover a minimum stay, doctors and patients may still decide together if a shorter stay is appropriate in a given situation.

Congressional Action

Insurers strongly oppose legislative efforts to create minimum stays, arguing that it is inappropriate for Congress to mandate benefits and levels of coverage. In November 1996, the American Association of Health Plans announced that their members would cover at least a one-night hospital stay for women who undergo mastectomies.[6] However, during consideration of the Balanced Budget Act of 1997 (P.L. 105-33), the House approved a provision that would have required managed care organizations participating in Medicare to cover the length of an inpatient hospital stay that the attending physician or health care provider deemed medically appropriate. The provision was dropped in conference with the Senate.

In February 1997, Secretary of Health and Human Services Donna Shalala issued an executive directive to the 350 managed care plans contracting with Medicare. It prohibits them from requiring outpatient surgery, or other limitations on the length of hospital stays, for Medicare beneficiaries undergoing surgery for the treatment of breast cancer.[7]

Legislation

Breast Cancer Patient Protection Act (H.R. 116/S. 681)—Rep. Rosa DeLauro (D-CT) and Sen. Tom Daschle (D-SD)

H.R. 116/S. 681 would require insurance companies to provide at least 48 hours of inpatient hospital care following a mastectomy and a minimum of 24 hours following a lymph node dissection for the treatment of breast cancer.

Women's Health and Cancer Rights Act of 1999 (S. 115/H.R. 383)—Sens. Olympia Snowe (R-ME) and Dianne Feinstein (D-CA) and Rep. Sue Kelly (R-NY)

H.R. 383/S. 115 would require insurance companies to provide inpatient hospital care following a mastectomy and lymph node dissection for a period of time to be determined by the physician in consultation with the patient.

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Mental Health Services

According to a 1999 U.S. Surgeon General's report, an estimated 44 million people in the United States suffer from some form of mental disorder each year, roughly 20 percent of the adult population. The report also estimates that direct medical costs from mental illness totaled $69 billion in 1996.[1] Fortunately, many of these illnesses can be treated successfully.

Many neurobiological disorders—most notably depression, anxiety disorders (including phobias and panic disorders), and eating disorders—disproportionately affect women. A number of factors associated with neurobiological disorders—particularly depression—include heredity, biochemistry, behavioral responses, high stress work or circumstances, domestic violence, sexual abuse, lower income, and single parenthood. However, experts continue to debate the relative significance of these factors. Further research on individual and social indicators that contribute to depression and other neurobiological disorders is needed.[2]

Major depression is one of the most prevalent psychiatric disturbances affecting women. Approximately twice as many women as men suffer from depression.[3] One out of seven women will suffer from depression in her lifetime.[4] Additionally, the National Institute of Mental Health (NIMH) at the National Institutes of Health estimates that 20 percent of women have at least one episode of depression that should be treated.[5]

Symptoms of major depression include persistent sadness, disruption in sleep patterns, changes in appetite and energy level, loss of interest in daily activities, and impairment of cognitive functions. Major depression can cause severe impairment in social and physical functioning and is a major precipitating factor in suicide. It has been associated with higher medical costs, greater disability, poor self-care and adherence to medical regimens, and increased morbidity and mortality.[6] According to the American Psychological Association, depression in women is misdiagnosed 30 to 50 percent of the time.[7]

Depression occurs most frequently in women aged 25-44, with postpartum depression affecting roughly 10 percent of new mothers.[8] Researchers also are seeing a rise in depression among adolescent women. A 1999 NIMH study of adolescent girls transitioning through high school to early adulthood found that 37 percent of the girls experienced a major depressive episode that had a negative impact on their school performance and their intimate romantic relationships during this time period. Additionally, 47 percent of the girls had experienced depression at some point in their lifetime.[9]

In most cases, a combination of psychotherapy and medication can successfully treat clinical depression in a matter of months. The advent of new medications has brought new hope to long-term sufferers of mental illness. The NIMH states that more than 80 percent of individuals suffering from clinical depression respond positively to antidepressants.[10] However, according to the American Psychological Association, 70 percent of the prescriptions prescribed for antidepressants are prescribed for women, often with improper diagnosing.[11]

Research

The NIMH is currently undertaking research on women and depression that will focus on life stresses. Data from another NIMH-sponsored study indicates that stressful life experiences may play a role in recurring episodes of depression. Additionally, the NIMH is investigating the role of hormones and depression in women and the mechanisms that contribute to postpartum depression.[12]

Congressional Action

Legislation addressing the need for better coverage of mental health services was passed in 1996 under the FY1997 Veterans Affairs, Housing and Urban Development, and Related Agencies appropriations bill (P.L. 104-204). Insurers that offer mental health care coverage are required to set similar coverage limits on annual and lifetime coverage for mental and physical illnesses. The law allows employers to purchase plans with different coverage limits for physical and mental disorders if a plan offering similar coverage raises costs by 1 percent or more. Businesses with fewer than 50 employees are exempt from the law's requirement.

A recent General Accounting Office (GAO) report examined compliance with the Mental Health Parity Act of 1996 and found that 86 percent of health plans were in compliance with the 1996 law. According to

the GAO, 14 percent of plans were noncompliant, compared to 55 percent of plans that were noncompliant before the law was enacted. However, of the plans that were compliant, 87 percent limited mental health benefits to a greater extent than medical benefits.[13]

The Balanced Budget Act of 1997 (P.L. 105-33) included a provision, as part of the $24 billion State Children's Health Insurance Program, that requires state health plans to expand health coverage and services to include mental health benefits for low-income, uninsured children.

Legislation

Mental Health Equitable Treatment Act of 1999 (S. 796)—Sens. Pete Domenici (R-NM) and Paul Wellstone (D-MN)

S. 796 would prohibit health plans from imposing limitation or financial requirements on the coverage of mental health benefits if similar benefits are not imposed on medical and surgical benefits. The bill would limit mental health coverage to severe biologically-based mental illnesses.

Mental Health and Substance Abuse Parity Amendments of 1999 (H.R. 1515)—Reps. Marge Roukema (R-NJ) and Bob Wise (D-WV)

H.R. 1515 would prohibit health plans from imposing treatment limitations or financial requirements on the coverage of mental health benefits and on the coverage of substance abuse and chemical dependency benefits if similar benefits or requirements are not imposed on medical and surgical benefits. The bill does not define mental illness.

Mental Health Parity Enhancement Act of 1999 (H.R. 2445)—Reps. Carolyn Maloney (D-NY) and Benjamin Gilman (R-NY)

H.R. 2445 would clarify that health insurance plans may not impose limitations on the number of visits allowed for mental health, nor may they impose any other limitations on covered mental health benefits.

Additionally, in May 1999, the President issued an executive order requiring plans participating in the Federal Employees Health Benefits Program to provide mental health benefits that are equal or comparable to physical health benefits.[14] Plans cannot set limits on the number of inpatient days for mental illness if they do not set similar limits for physical illness. Additionally, the executive order bars higher co-payments for mental health care than for physical health care.

The 106th Congress also addressed the issue of postpartum depression. On October 10, 2000, the House approved a resolution (H. J. Res. 163) expressing the sense of the House regarding postpartum depression. Sponsored by Reps. Jack Kingston (R-GA) and Lois Capps (D-CA), the resolution expressed support for providing all new mothers and fathers with complete information about postpartum depression, encouraged all ob-gyns to inquire prenatally about any psychiatric problems the mother may have experienced, encouraged all ob-gyns to screen new mothers for postpartum depression prior to discharge from the hospital, recommended that appropriate health care professionals be trained in screening for postpartum depression, and recommended that the NIMH undertake additional research on postpartum depression. The Senate did not consider a similar resolution.

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Obstetricians-Gynecologists

One result of the dramatic shift toward managed care over the past decade has been the development of the role of the primary care physician as a "gatekeeper" who serves as an entry point into the health care system while playing a variety of other roles in providing for a patient's care: delivering preventive services, treating common illnesses, and taking primary responsibility for the patient's general well-being and long-term continuity of care.

According to a 1999 American College of Obstetricians and Gynecologists (ACOG)/Princeton poll, 60 percent of all ob-gyns in managed care plans reported that their patients were either limited or barred from seeing an ob-gyn without prior authorization. Twenty-eight percent of ob-gyns reported that their pregnant patients had to go through a gatekeeper prior to seeing them. Additionally, nearly 75 percent of ob-gyns surveyed reported that their patients had to return to their primary care physician prior to receiving follow-up care.[1]

In contrast with other primary care specialists, ob-gyns are the only physicians specifically trained to provide comprehensive primary care for women. Primary care training recently has been expanded in ob-gyn residency programs and must encompass the following: taking comprehensive histories that include medical, nutritional, sexual, family, genetic, and social behavior data; assessing health risks; appropriately screening patients of various ages and under specific circumstances; diagnosing and treating common non-reproductive illnesses affecting women; managing the health care of patients in a continuous manner through all the reproductive and post-reproductive years; knowledge of the behavioral and societal factors that influence health among women of differing socioeconomic and cultural backgrounds; and knowledge of behavioral medicine and psychosocial problems, including domestic violence, sexual assault, and substance abuse.[2]

Furthermore, women examined by ob-gyns, as compared to other types of primary care physicians, are more likely to receive certain primary care preventive services such as pelvic exams, Pap tests, clinical breast exams, and referrals for mammograms. Eighty-one percent of women whose regular provider is an ob-gyn received a clinical breast exam in the past year, compared to 68 percent of women who saw another type of provider.[3] Additionally, of those women who sought care from an ob-gyn, 94 percent received a pelvic exam compared to 35 percent of women who received care from other health care practitioners. Ninety-four percent of women who sought care from an ob-gyn received a Pap smear compared to 33 percent of women who received care from other providers.[4]

In addition, many ob-gyns manage non-reproductive health concerns (such as hypertension, cardiovascular diseases, diabetes, and asthma) for women, including pregnant women.

Direct Access

Surveys consistently show that women consider ob-gyns to be important providers of health care. A 1998 survey found that 82 percent of Americans support direct access to ob-gyns, and 63 percent of Americans would support direct access even if their health insurance costs were to increase as a result.[5] A 1998 cost analysis found that requiring managed care organizations to allow direct access to ob-gyns would raise an individual's health insurance premium by only 12 cents a year.[6] The Congressional Budget Office estimated that direct access to ob-gyns would cost $1 million in the first year, or 0.1 percent of an individual's insurance premiums.[7]

Federal and state regulations have adopted several approaches to address this issue. As of December 2000, 38 states and the District of Columbia had implemented laws to require insurers to either allow women direct access to ob-gyns or to designate an ob-gyn as their primary care provider.[8]

In response to these actions, 22 of the nation's largest health care plans formed the Coalition for Affordable Quality Healthcare and pledged to provide direct access to ob-gyn services, in addition to a number of other services.[9]

Congressional Action

In 1997, Congress addressed the issue of access to ob-gyns in the debate over the balanced budget. A provision in the House version of the Balanced Budget Act

(P.L. 105-33) would have required managed care plans participating in Medicaid to allow a Medicaid recipient to choose an ob-gyn as her primary care provider or to allow her direct access to an ob-gyn, or a participating health care professional practicing in collaboration with an ob-gyn, without prior authorization. The provision was dropped during conference.

The 106th Congress revisited the issue of direct access during its debate on managed care reform. Both the House-passed and Senate-passed bills (H.R. 2990/S. 1344) included language allowing women direct access. The House-passed bill contained a stronger version of the provision. The House language would have applied to all health care plans and would have required those plans to allow women direct access to health care professionals specializing in obstetrics and gynecology for gynecological care and pregnancy-related services.

The Senate-passed version (S. 1344) would have applied to health plans regulated by ERISA and would have required those plans to allow women direct access to a physician who specializes in obstetrics and gynecology for obstetric care and related follow-up obstetrical care or routine gynecological care.

Advocates preferred the House-passed version because it applied to all health plans, allowed women access to a range of health care professionals, and more broadly defined gynecological care. However, the legislation stalled in a House-Senate conference.

Additionally, the Senate-passed version of the FY2001 Labor, Health and Human Services, and Education appropriations bill (S. 2533) included a compromise version of the patients' bill of rights. The amendment, offered by Sen. Don Nickles (R-OK), included a direct access provision; however, the language was dropped during a House-Senate conference.

The President issued an executive order in 1998 requiring the Health Care Financing Administration (HCFA), which oversees Medicare and Medicaid, to implement the Consumer Bill of Rights and Responsibilities. As directed, HCFA issued a proposed rule that would, among other things, ensure women enrolled in Medicare and Medicaid direct access to ob-gyns for routine and preventive health care services.[10]

Legislation

Women's Access to Care Act (S. 697)—Sens. Barbara Boxer (D-CA) and Olympia Snowe (R-ME)

S. 697 would require that group health insurance plans allow women to choose obstetrician-gynecologists as primary care physicians, or allow women direct access to ob-gyns, without prior authorization by separate primary care physicians.

Access to Women's Health Care Act of 1999 (H.R. 1806)—Reps. Nita Lowey (D-NY) and Rick Lazio (R-NY)

H.R. 1806 would require that groups and individual health insurance plans allow women to choose obstetrician-gynecologists as primary care physicians, or allow women direct access to ob-gyns, or to participating health care professionals practicing in collaboration with ob-gyns, without prior authorization by separate primary care physicians.

Notes

1 American College of Obstetricians and Gynecologists (ACOG), "Direct Access Talking Points" <http://www.acog.org/from_home /departments/dept_notice.cfm?recno=11&bulletin=545> (8/9/00).

2 American Medical Association, *Graduate Medical Education Directory, 1999-2000* (Chicago: AMA, 1999), pp. 155-156.

3 The Kaiser Family Foundation, "Coverage of Gynecological Care and Contraceptives" (fact sheet, 2000), p. 1.

4 The Kaiser Family Foundation, "State Policies on Access to Gynecological Care and Contraception" (fact sheet, 2000), p. 1.

5 Ibid., p. 2.

6 ACOG, "Direct Access Talking Points."

7 Ibid.

8 ACOG Department of State Legislative and Regulatory Activities, "State Insurance Mandates for OB-GYN Primary Care/Direct Access, 1994-2000," 2000.

9 Coalition for Affordable Quality Healthcare, "Progress Report," July 12, 2000 <http://www.caqh.org/progress4.html> (11/27/00).

10 The White House, "Memorandum for the Secretary of Defense, the Secretary of Labor, the Secretary of Health and Human Services, the Secretary of Veterans Affairs, and the Director of the Office of Personnel Management: Federal Agency Compliance with the Patient Bill of Rights," Feb. 20, 1998 <http://www.pub.whitehouse.gov/urires/I2R?urn:pdi://oma.eop.gov.us/1998/2/25/10.text.1> (9/18/00).

Prescription Drug Coverage for Older Women

Medicare has provided older individuals with health care coverage for 35 years. However, when the program was created in 1965, prescription drug coverage was not included. Currently, Medicare covers prescription drugs when they are provided during an inpatient stay at a hospital or nursing facility and when the drugs cannot be self-administered. As a result, Medicare beneficiaries are forced to either seek supplemental coverage for prescription drugs, incur debt to pay for prescription drugs, or forgo certain medications. According to the Kaiser Family Foundation, 16 percent of older individuals report that they did not fill a prescription because of the cost; 21 percent say that they gave up things to pay for prescription drugs; and 9 percent say that they gave up basic necessities to pay for their prescriptions.[1] In 1999, 35 percent of Medicare beneficiaries had no prescription drug coverage.[2]

Women are particularly affected. According to the Older Women's League, women constitute 58 percent of the Medicare population at age 65, and 71 percent of the Medicare population at age 85.[3] Minority women constitute 60 percent of all minority Medicare beneficiaries.[4] Seventeen million women use prescription drugs regularly, and an estimated seven million women served by Medicare lack prescription drug coverage.[5]

Studies show that older women are particularly vulnerable because women live an average of seven years longer than men and report more chronic conditions that require prescription drugs than men. A 1999 study found that 73 percent of older women on Medicare reported two or more chronic conditions, compared to 65 percent of older men.[6] According to AARP, 11 percent of older women reported having one or more severe limitations in activities of daily living, compared to 7 percent of men.[7]

As a result, women pay more in out-of-pocket health care costs than men. In 1999, older women spent $2,520 in out-of-pocket expenses, while older men paid $2,320.[8] Estimates show that women spent an average of $430 a year in out-of-pocket prescription costs, compared to $380 a year for men.[9]

In addition, the cost of prescription drugs is rising. In 2000, spending on prescription drugs increased by an estimated 11 percent, and it has tripled since 1990.[10] A July 2000 study found that spending on prescription drugs increased a record 17.4 percent in 1999, with average prescription prices rising 18 percent for women aged 70-79 and 20 percent for women over 80, compared with a 9 percent increase for men aged 70-79 and 11 percent for men over 80.[11]

Not only are women paying more in out-of-pocket expenses for prescription drugs, but these women also are more likely to be poor. AARP estimates that women constitute three-quarters of poor Medicare beneficiaries, defined as having an income below 200 percent of the poverty line. Of that number, 17 percent are minority women.[12]

A study by the Department of Health and Human Services (HHS) found that seniors without drug coverage not only lack insurance, but do not have access to the discounts and rebates that insured individuals receive.[13] The Kaiser Family Foundation found that insured individuals paid an average of $6 per prescription for generic drugs and $10 per prescription for brand name drugs. Uninsured individuals paid an average of $31 per prescription.[14] Additionally, the HHS study found that the percent of Medicare beneficiaries without drug coverage who reported not being able to afford a drug was about five times higher than those with coverage.[15] In 1996, women who did not have prescription drug coverage used 24 percent fewer prescriptions than women who had coverage.[16]

According to another survey, 76 percent of Americans support providing prescription drug coverage under Medicare. Sixty-two percent of Americans would support expanding Medicare to provide such coverage directly, while 32 percent would support government subsidies for seniors to purchase private health insurance to cover prescription drugs.[17]

Congressional Action

The 106th Congress debated prescription drug coverage at length. While Republicans and Democrats agreed on the need for a prescription drug benefit for seniors, there was disagreement about how to best implement the benefit. Some argued that the benefit should be included in the Medicare program, but only if the pro-

gram as a whole was reformed. Others prefered to enact a separate prescription drug benefit through government-subsidized private plans.

While the House passed a Republican-sponsored plan (H.R. 4680) that would have allowed seniors to purchase prescription drug coverage through private insurance plans or Medicare+Choice managed care plans, the Senate never considered similar legislation, leaving the issue to be decided by the 107th Congress.

A number of legislative proposals pertaining to prescription drug coverage for seniors were introduced in the 106th Congress. For a listing, see Appendix II.

Notes

1 The Kaiser Family Foundation, "The Public and Prescription Drugs" (Kaiser Public Opinion Update, 2000), p. 1.
2 Peter Fox, Ph.D., *Prescription Drug Coverage: Cost Management Issues for Medicare* (Washington: AARP, 2000) <http://research.aarp.org/health/2000_09_cost_1.html> (9/19/00).
3 Older Women's League (OWL), *Prescription for Change: Why Women Need a Medicare Drug Benefit* (Washington: OWL, 2000), p. 1
4 Lisa A. Foley and Mary Jo Gibson, *Older Women's Access to Health Care: Potential Impact of Medicare Reform* (Washington: AARP Public Policy Institute, 2000), p. 2.
5 OWL, *Prescription for Change*, p. 7.
6 The Kaiser Family Foundation, "Medicare and Women" (fact sheet, 1999).
7 Foley and Gibson, "Older Women's Access to Health Care: Potential Impact of Medicare Reform," p. 5.
8 Ibid., p. 10.
9 OWL, *Prescription for Change*, p. 3.
10 The Kaiser Family Foundation, "Medicare and Prescription Drugs" (fact sheet, 2000), p. 1.
11 American Health Line, "Spending on Prescription Drugs Rises 17.4% in 1999, Study Finds," June 27, 2000, quoted in Kaiser Daily Update <http://www.kff.org/docs/ahl/ahl2.html> (6/27/00).
12 Foley and Gibson, "Older Women's Access to Health Care: Potential Impact of Medicare Reform," p. 4.
13 The White House, "President Clinton Releases New Prescription Drug Coverage and Pricing Study" (press release, Apr. 20, 2000).
14 The Kaiser Family Foundation, *Prescription Drug Trends: A Chartbook* (Menlo Park: The Kaiser Family Foundation, 2000), p. 10.
15 The White House, "President Clinton Releases New Prescription Drug Coverage and Pricing Study."
16 OWL, *Prescription for Change*, p. 3.
17 The Kaiser Family Foundation, "The Public and Prescription Drugs," p. 1.

Reconstructive Breast Surgery

The American Cancer Society estimated that 182,000 new cases of breast cancer would be diagnosed in the United States in 2000.[1] Treatment for breast cancer may include two or more of the following: lumpectomy and removal of lymph nodes under the arms; mastectomy and removal of lymph nodes under the arms; radiation; and/or chemotherapy.

- In 1996, the last year for which data is available, 85,000 women underwent mastectomies as part of their treatment for breast cancer.[2]
- According to the American Society of Plastic Surgeons (ASPS) in 1999, 82,975 women underwent reconstructive surgery after mastectomies.[3]

For many women with breast cancer, reconstructive surgery is an integral part of the healing process, both physically and mentally. However, the daunting financial burden associated with reconstructive surgery and the concern that the surgery will not be covered by insurance policies provides further obstacles on the road to recovery.

By 1998, 29 states had enacted laws mandating insurance coverage for breast reconstruction after a mastectomy.[4] Despite state efforts to legislate insurance coverage of breast reconstructive surgery, many advocates felt that federal legislation was needed since many women were covered by plans regulated under the federal Employee Retirement Income Security Act (ERISA), not state law.

Congressional Action

As a result, Congress enacted the Women's Health and Cancer Rights Act of 1998 (P.L. 105-277). The bill was included in the FY1999 omnibus appropriations measure. The law requires insurance policies to cover reconstructive breast surgery if they cover mastectomies. Reconstructive surgery is defined as all stages of reconstruction of the breast on which the mastectomy was performed; surgery and reconstruction of the other breast to produce a symmetrical appearance; and prostheses and treatment for physical complications associated with a mastectomy.

In the 106th Congress, an effort was made to further enforce the coverage of reconstructive breast surgery by health insurers; however, the legislation was never considered by either the House or the Senate.

Legislation

Women's Health and Cancer Rights Conforming Amendments of 1999/Breast Reconstruction Implementation Act of 1999 (H.R. 3224/S. 1679)—Reps. Sue Kelly (R-NY) and Karen Thurman (D-FL) and Sen. Joe Biden (D-DE)

H.R. 3224/S. 1679 would provide a civil monetary penalty against those health plans that fail to provide coverage for breast reconstruction after breast cancer surgery. This change is intended to ensure compliance with the Women's Health and Cancer Rights Act of 1998.

Notes

1 American Cancer Society (ACS), "Cancer Facts and Figures 2000" <http://www.cancer.org/statistics/cff2000/selected_toc.html> (8/9/00).

2 ACS, email communication with Women's Policy, Inc., Aug. 12, 2000.

3 American Society of Plastic Surgeons (ASPS), National Clearinghouse of Plastic Surgery Statistics, "1999 Plastic Surgery Procedural Statistics: Reconstructive Procedures" <http://www.plasticsurgery.org/mediacentr/totalrec99a.htm> (8/9/00).

4 ASPS, "State Laws – Breast Reconstruction" <http://www.plasticsurgery.org/advocacy/brstlaws.htm> (8/9/00).