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Issue Brief

A Look at Working-Age Caregivers' Roles, Health Concerns, and Need for Support

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ABSTRACT: The role of informal caregivers is becoming increasingly important as the U.S. population continues to age and cost-containment strategies promote shorter hospital stays. There are currently 16 million working-age adults caring for a sick or disabled family member, according to data from the Commonwealth Fund Biennial Health Insurance Survey. Caregivers are less likely to be working, more likely to miss days of work when they are employed, and more likely to lack health insurance coverage. This may leave them financially vulnerable and unable to obtain needed health care. Indeed, one-half of caregivers reported not getting care because of cost issues, and three of five caregivers experienced problems with medical bills. Polices to expand Medicaid and Medicare would improve caregivers' ability to access health care for themselves and their families, as well as help eliminate the financial strain of going without health insurance.

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Overview

Informal caregiving has become increasingly important as the U.S. population continues to age and cost-containment strategies promote shorter hospital stays. By providing care for sick or disabled family members, informal caregivers play a critical support role in the U.S. health care system. Based on data from the Commonwealth Fund Biennial Health Insurance Survey, nearly one of 10 working-age adults ages 19 to 64 is caring for a sick or disabled family member, for a total of 16 million caregivers in 2003.[1] Adding to their burden, more than 9 million of these caregivers have health problems of their own.

This study finds that caregivers are less likely than non-caregivers to be working, more likely to miss days of work when they are employed, and more likely to lack health insurance coverage. Such vulnerabilities can leave

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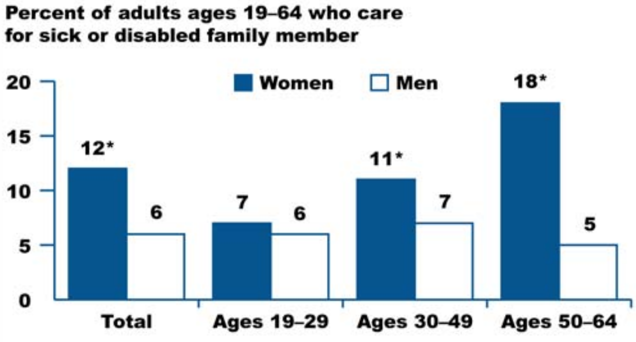
caregivers financially at risk and may make it difficult for them to obtain needed health care. One-half of all caregivers reported not getting needed care because of cost, compared with 35 percent of non-caregivers. Sixty percent of caregivers reported problems with their medical bills, compared with 39 percent of non-caregivers. This issue brief examines the implications of caregiving in terms of caregivers' personal health, work, insurance coverage, and ability to afford health care. It also provides targeted policy steps that could help lend greater assistance to caregivers and their families.

Who Are the Caregivers?

There are approximately 16 million caregivers ages 19 to 64 in the United States (Table 1) and more than 2 million over the age of 65 (data not shown). This analysis is limited to working-age caregivers in order to explore the implications of caregiving on employment, insurance coverage, and access to the health care system.

Women are more likely than men to be caregivers, with women composing approximately two-thirds of the total group (Table 1). About 12 percent of women, compared with 6 percent of men, said they were caring for a sick or disabled family member (Figure 1). Among women and men of all ages, women ages 50 to 64 are the group most likely to be caring for sick or disabled family members. Nearly one of five (18%) of these women reported being a caregiver—a rate two and a half times higher than reported by women ages 19 to 29. Previous studies have observed that daughters in mid-life provide the bulk of care to both their parents and in-laws.[2] In addition, women ages 50 to 64 may also take on caregiving responsibilities for their sick or disabled spouses.

Figure 1. Women Ages 50 to 64 Report Highest Rate of Caring for Sick or Disabled Family Member



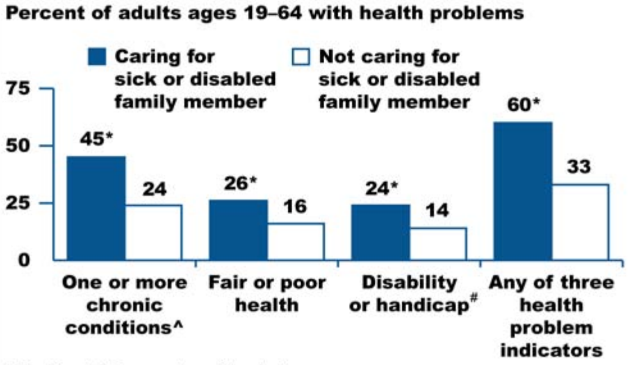
* Significant difference at p ≤ .01 or better.
Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

Caregivers disproportionately come from lower-income households.[3] Forty-four percent live in households under twice the federal poverty level, compared with one-third (33%) of non-caregivers (Table 1).

Double Burden: Caregiving and Health Problems

In addition to the burden of caring for sick or disabled family members, caregivers are also more likely than non-caregivers to have health problems of their own. Three-fifths of caregivers reported fair or poor health status, one or more chronic conditions, or a disability, compared with one-third of non-caregivers (Figure 2).[4] Caregivers reported chronic conditions at nearly twice the rate of non-caregivers (45% vs. 24%).

Figure 2. Caregivers Are More Likely than Non-Caregivers to Have Health Problems



* Significant difference at p ≤ .01 or better.
^ Chronic conditions include heart attack/disease, cancer, diabetes, or arthritis.
# Disability, handicap, or chronic disease that prevented full participation in daily work, housework, or other daily activities.
Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

Large segments of the U.S. population are either coping with their own health problems, a family member's poor health, or both. More than two of five (43%) women are either coping with personal health problems or caring for a sick or disabled family member (data not shown). Men fare only slightly better: more than one-third (35%) reported health problems of their own or a caregiving responsibility.

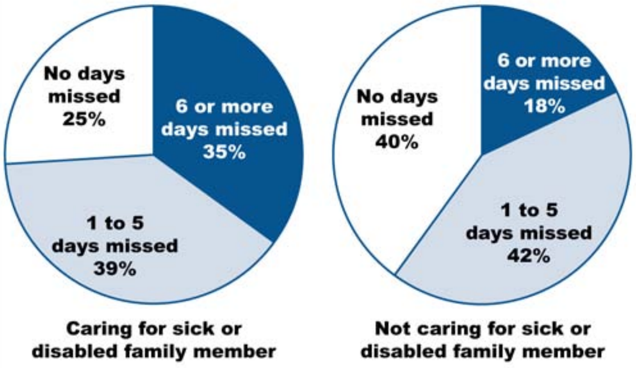
Impact of Caregiving on Employment Status, Sick Leave

The responsibility of caring for a sick or disabled family member may make it difficult to hold a full-time job. One-half (51%) of caregivers reported working full-time, compared with three-fifths of non-caregivers (Table 2).[5]

Working caregivers who have health problems of their own may experience increased needs for time off from work. The Fund's survey asked respondents how many days of work they missed because they or a family member was sick. Over one-third (35%) of employed caregivers reported missing more than one week of work during the year, compared with one-sixth (18%) of non-caregivers (Figure 3). Caregiving has a strong, independent effect on whether workers miss days of work. For caregivers, the odds of missing six or more days of work because they or a family member was sick is nearly twice that of non-caregivers, holding constant for gender, family structure, insurance coverage, health problems, income, and paid sick leave (Table 3).[6] Previous studies have found a reduction in caregivers' productivity at work because of factors including absenteeism, unscheduled time off, and lateness.[7,8]

Figure 3. When Caregivers Do Work, They Are More Likely than Non-Caregivers to Miss Work

Percent of employed adults ages 19–64 who missed work because self or family member was sick



Note: Significant difference between caring for sick or disabled family member and not caring for sick or disabled family member at p ≤ .01 or better.

Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

Caregivers at Risk for Lacking Insurance Coverage

Many caregivers have low income and only tenuous connections to the workforce, leaving them at risk of lacking health insurance. One-third (34%) of caregivers are uninsured for at least some period during the year, compared with one-quarter (26%) of people without such responsibilities (Table 2). Lack of coverage may affect both the ability of caregivers to seek care for themselves and to provide adequate care for their ailing family members.

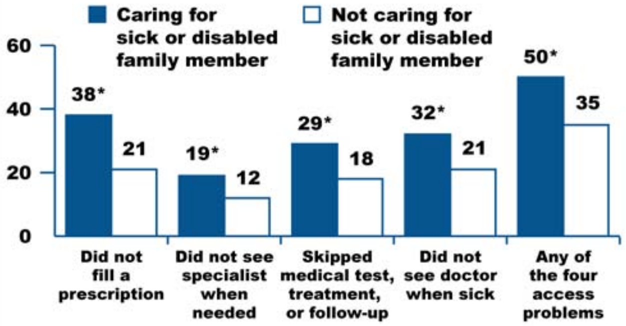
Health Care Affordability Problems

Lack of insurance coverage, low income, and the financial burden of providing care can make it difficult for caregivers to afford health care. The survey asked respondents if, in the past year, they: had not filled a prescription; had failed to see a specialist when they or a doctor thought it was needed; had skipped a recommended medical test, treatment, or follow-up visit; or had a medical problem but did not visit a doctor or clinic. Caregivers were more likely than non-caregivers to report each of these four access problems. In fact, one-half of all caregivers reported experiencing at least one cost-related access problem, compared with 35 percent of non-caregivers (Figure 4).

Although the analysis did not show an independent effect of caregiving on access problems, individuals with characteristics more common among caregivers than non-caregivers—being female, lacking coverage, having health problems, and being of lower-income status—were found to be at higher risk of experiencing access problems.

Figure 4. Caregivers Face Problems Accessing Health Care Services Because of Cost

Percent of adults ages 19–64 reporting the following problems because of cost



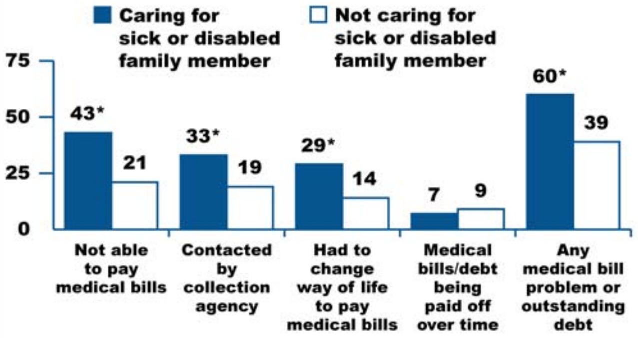
* Significant difference at p ≤ .01 or better.
Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

Caring for a sick or disabled family member can potentially increase the caregiver's exposure to medical bills. Health care costs of sick or disabled family members, such as insurance copayments and premiums, uncovered prescription medication costs, and medical equipment expenses, may be shared or assumed entirely by the caregiver.[9] Respondents were asked whether in the past year they had difficulty paying or were unable to pay their bills, had been contacted by a collection agency concerning outstanding medical bills, or had to change their lives significantly in order to meet their obligations. People who reported none of these medical bill problems were asked if they were currently paying off medical debt incurred in the past three years. Medical bill problems or medical debt could include those incurred by another family member.

The survey found that caregivers reported disproportionately high rates of medical bill problems. Three of five (60%) caregivers reported medical bill problems or medical debt, compared with two of five (39%) non-caregivers (Figure 5). In fact, caregiving has an independent effect on medical bill problems or medical debt. The odds of medical bill problems or medical debt for caregivers is one-and-a-half times that of non-caregivers, holding constant for gender, family structure, insurance, health, and income (Table 3). In addition, each of these variables also has an independent effect. Adults who were female, had dependent children, lacked coverage, had health problems, and were of lower-income status were at higher risk of experiencing medical bill problems or medical debt.

Figure 5. Caregivers Have High Rates of Medical Bill Problems and Accrued Medical Debt

Percent of adults ages 19–64 who had the following problems in the past year



* Significant difference at p ≤ .01 or better.
Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

Lack of Confidence in the Health Care System

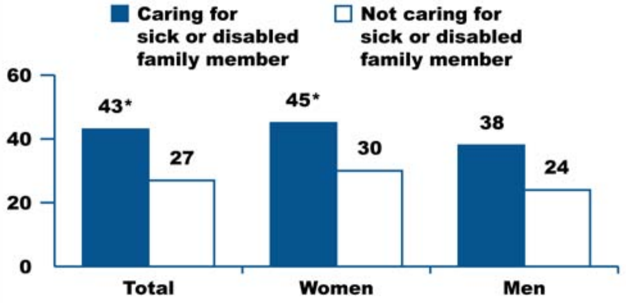
Caregivers, coping with their own personal health problems and the needs of the people they care for, expressed heightened anxiety about the U.S. health care system. More than two of five (43%) adults caring for a sick or disabled family member, compared with one-quarter (27%) of non-caregivers, said they were not too confident or not at all confident they would receive high-quality care when needed in the future (Figure 6). This level of worry is particularly pronounced for female caregivers: 45 percent of female caregivers, versus 38 percent of male caregivers, reported not being confident they would receive quality care.

Conclusion and Policy Implications

Sickness and disability exact enormous costs on the health care system each year, but the burden

Figure 6. Caregivers Express Less Confidence in Future Ability to Obtain High-Quality Care

Percent of adults ages 19–64 who are not too confident or not at all confident they will be able to obtain high-quality care when needed in the future



* Significant difference at p ≤ .01 or better.

Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

placed on the families of those in poor health is less well documented. This study finds that an estimated 16 million working-age adults are currently caring for a sick or disabled family member. Caregivers are less likely to be working and, if they do work, are far more likely to take time off from work than are those without caregiving responsibilities. Because employment is the primary source of health insurance in the United States, this leaves caregivers at risk of lacking coverage. Caregivers report higher rates of health problems than noncaregivers, and they are also more likely to have cost-related access problems and problems paying medical bills. While caregivers provide a critical, vital function in society, they pay a price in terms of their financial security and overall well-being.

Caregivers have received some forms of policy support, such as the Family and Medical Leave Act of 1993 and the Family Caregiver Support Program under the Older Americans Act of 2001.[10,11] Advocacy groups are currently seeking legislation in more than 20 states to guarantee workers are paid sick days or family leave to care for themselves and ill family members.[12] Policymakers might consider additional ways to ease their financial burden. Extending health insurance coverage to low-income people is an obvious first step toward relieving cost burdens and improving access to health care. Medicaid and Medicare cover disabled individuals, but often exclude their caregivers.[13] Policy options to extend coverage include expanding Medicaid and the State Children's Health Insurance Program to low-income caregivers of sick or disabled children and adults, as well as allowing a Medicare buy-in for individuals caring for a Medicare beneficiary. In addition, employers may find that providing better support for working caregivers, through health insurance or paid sick leave, could reduce emotional and physical stress and increase productivity among working caregivers. Better protection against the financial hardships created by disability and caregiving could also be addressed through tax policy (e.g., tax credits for expenses in excess of 5 percent of income, or 10 percent in higher tax brackets). These are modest changes that would provide caregivers meaningful and affordable access to a health care system they help to support through their care of ailing or disabled loved ones.

NOTES

[1] The Commonwealth Fund Biennial Health Insurance Survey asked respondents, ages 19 and older, whether they were currently caring for a sick or disabled relative, including a child, spouse or partner, parent, or other family member. Other estimates of number of caregivers in the U.S. vary depending on the base population of both caretakers and care recipients, as well as the definition of caregiving. A 1998 national survey, Long-Term Care from the Caregiver's Perspective, found that 16 percent of adults, ages 18 and older, were providing care to a family member or friend at the time of the survey, and 23 percent said they had provided care in the prior year. See K. Donelan et al., "Challenged to Care: Informal Caregivers in a Changing Health System," *Health Affairs* 21 (July/August 2002): 222–31.

[2] K. M. Robinson, "Family Caregiving: Who Provides the Care, and at What Cost?" *Nursing Economics* 15 (September/October 1997): 243–47.

[3] Low-income households defined as those under 200 percent of poverty, or $37,600 for a family of four in 2003. C. DeNavas-Walt, B. D. Proctor, and R. J. Mills, *Income, Poverty and Health Insurance Coverage in the United States: 2003* (Washington, D.C.: Current Population Reports, U.S. Census Bureau, August 2004).

[4] Chronic conditions included heart attack/heart disease, cancer, diabetes, and arthritis.

[5] This analysis indicates an association between caregiving and work status only.

[6] Health problems defined as fair or poor health, one or more chronic condition (heart attack/disease, cancer, diabetes, arthritis), or disability.

[7] R. Stone, G. L. Cafferata, and J. Sangl, "Caregivers of the Frail Elderly: A National Profile," *Gerontologist* 27 (October 1987): 616–26.

[8] C. L. Barnes, B. A. Given, and C. W. Given, "Parent Caregivers: A Comparison of Employed and Not Employed Daughters," *Social Work* 40 (May 1995): 375–81.

[9] K. M. Robinson, "Family Caregiving," 1997.

[10] The Family Medical Leave Act of 1993 allows eligible workers employed by private companies with 50 or more employees to take a total of 12 workweeks of unpaid leave during any 12-month period in order to care for an immediate family member (spouse, child, or parent) with a serious health condition. Refer to the U.S. Department of Labor for additional details: http://www.dol.gov/esa/whd/fmla/.

[11] The National Family Caregiver Support Program provides information about services, assistance with access to services, individual counseling, support groups and caregiver training, respite care, supplemental services such as adults day care, homemaker assistance, and home repair. See National Family Caregiver Support Program, http://www.aoa.gov/prof/aoaprog/caregiver/caregiver.asp.

[12] S. Greenhouse, "As Demands on Workers Grow, Groups Push for Paid Family and Sick Leave," *New York Times* (March 6, 2005): 23.

[13] Federal Medicaid law permits family members to become paid caregivers, but excludes those family members who are legally responsible for the care of an individual (e.g., spouses and parents/guardians of minor children). However, states have the option to pay these family members under certain exceptional circumstances. G. Smith, P. Doty, and J. O'Keeffe, *Supporting Informal Caregiving (under Medicaid),* National Family Caregiver Support Program, February 2004. Available at http://www.aoa.gov/prof/aoaprog/caregiver/careprof/progguidance/background/program_issues/Fin-Smith.pdf.

Table 1. Demographic Characteristics

Base: Adults ages 19–64

	Total	Caregiver	Non-Caregiver
Total in millions (estimated)	172.0	15.8	155.6
Percent distribution	100%	9%	90%
Age***			
19–29	24	16	24
30–49	50	50	50
50–64	27	34	26
Gender***			
Male	48	33	50
Female	52	67	50
Self-rated health status***			
Excellent	23	15	23
Very good	32	28	32
Good	28	31	28
Fair or poor	17	26	16
Chronic condition***			
Yes	26	45	24
No	74	55	76
Sicker***			
Yes	36	60	33
No	64	40	67
Race/Ethnicity**			
White	68	63	69
Black	11	15	11
Hispanic	14	15	13
Other	6	5	6
Family structure***			
Married, no children	25	26	25
Married, with children	35	30	35
Single, no children	28	24	28
Single, with children	12	20	12
Annual income***			
Less than $20,000	26	32	25
$20,000–$34,999	16	19	15
$35,000–$59,999	24	22	24
$60,000 or more	24	18	25
Less than $35,000	43	52	42
$35,000 or more	50	41	51
Poverty status***			
Below 100% FPL	15	18	15
100%–199% FPL	20	27	19
Below 200% FPL	35	44	33
200% or more FPL	57	47	59

Differences by caregiver status statistically significant at: *** $p \leq .001$; ** $p \leq .01$.

Note: Chronic conditions include heart attack/disease, cancer, diabetes, or arthritis; Sicker defined as fair/poor health, chronic condition, or disability.

Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

Table 2. Access and Medical Bill Problems, Confidence in Future Care, Insurance, and Work by Caregiving Responsibility

Base: Adults ages 19–64

	All Adults Ages 19–64			Men			Women		
	Total	Caregiver	Non-Caregiver	Total	Caregiver	Non-Caregiver	Total	Caregiver	Non-Caregiver
Total in millions (estimated)	172.0	15.8	155.6	82.9	5.3	77.4	89.1	10.5	78.2
Percent distribution	100%	9%	90%	100%	6%	93%	100%	12%	88%
Access problems in past year									
Went without needed care in past year because of costs:									
Did not fill prescription	23	38★★★	21	17	35★★★	15	29	40★★★	27
Did not get needed specialist care	13	19★★★	12	11	19★	10	15	20★★★	14
Skipped recommended test or follow-up	19	29★★★	18	14	27★★★	13	23	31★★★	22
Had a medical problem, did not visit doctor or clinic	22	32★★★	21	18	29★	17	25	34★★★	24
At least one of four access problems because of inability to pay	37	50★★★	35	31	44★★	30	42	53★★★	41
Medical bill problems in past year									
Problems paying or not able to pay medical bills	23	43★★★	21	17	39★★★	16	28	45★★★	26
Contacted by a collection agency for medical bills	21	33★★★	19	15	25★	14	26	37★★★	24
Had to change way of life to pay bills	15	29★★★	14	11	29★★★	10	18	28★★★	17
Any medical bill problem	32	52★★★	30	25	45★★★	24	39	56★★★	37
Medical bills/debt being paid off over time	9	7	9	7	NA	7	11	9	11
Any medical bill problem or outstanding debt	41	60★★★	39	32	47★★	31	50	66★★★	48
Confidence in ability to get high-quality care when needed									
Very confident	29	20★★★	30	32	27	32	26	17★★	27
Somewhat confident	40	34	41	40	30	41	40	36	41
Not too/not at all confident	28	43	27	25	38	24	31	45	30
Insurance stability									
Any time uninsured	26	34★★	26	27	34	26	26	34★★	25
Insured continuously	74	66	74	73	66	74	74	66	75
Adult work status									
Full-time	59	51★★★	60	70	69	70	49	43★★	50
Part-time	12	11	12	7	12	7	16	10	17
Not working	28	38	28	22	19	22	34	47	33
Worker productivity									
(Base: Employed adults, ages 19–64, total in millions [estimated])	122.5	9.9	112.2	64.2	NA	59.8	58.2	5.6	52.4
Missed work because self or family member sick									
0 days	38%	25%★★★	40%	47%	NA	48%	29%	21%★★★	30%
1–5 days	42	39	42	38	NA	38	47	43	47
6 or more days	19	35	18	15	NA	13	24	34	22

Differences by caregiver status statistically significant at: ★★★ $p \leq .001$; ★★ $p \leq .01$; ★ $p \leq .05$.

Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

Table 3. Effects of Caregiving and Other Factors on Sick Loss Days, Access Problems, and Medical Bill Problems

Based on Logistic Regression Models

Variables	**Six or more sick loss days from work**[1] (Base: working adults ages 19–64) **Odds ratio**	**Any cost-related access problems**[2] (Base: all adults ages 19–64) **Odds ratio**	**Any medical bill problems or medical debt**[3] (Base: all adults ages 19–64) **Odds ratio**
Caregiving status			
(ref = not caring for sick or disabled family member)			
Caring for sick or disabled family member	1.91★★	1.29	1.53★★
Gender			
(ref=male)			
Female	1.82★★★	1.64★★★	2.07★★★
Family structure			
(ref = married, no children)			
Single, with children	1.93★★	1.61★★	2.07★★★
Married, with children	1.79★★	1.27	1.98★★★
Single, no children	1.33	1.10	1.05
Insurance status			
(ref = insured all year)			
Any time uninsured	0.89	3.28★★★	2.62★★★
Health status			
(ref = No health problem[4])			
Health problem	2.06★★★	2.31★★★	2.65★★★
Poverty status			
(ref = 200% FPL or more)			
Less than 200% FPL	1.14	1.48★★★	1.66★★★
Paid sick leave			
(ref = yes, paid sick leave)			
No paid sick leave	0.74★	NA	NA

★★★ $p \leq .001$; ★★ $p \leq .01$; ★ $p \leq .05$.

Note: Models control for all variables unless otherwise indicated (NA).

[1] Sick loss days defined as reported days of missed work because self or family member was sick.

[2] Cost-related access problems include did not fill prescription, did not get needed specialist care, skipped recommended test or follow-up, or had medical problem but did not visit doctor or clinic because of cost within the last 12 months.

[3] Bill problems include not able to pay medical bills, contacted by a collection agency for medical bills, or had to change way of life significantly to pay bills within the last 12 months.

[4] No health problem defined as excellent/very good/good health status, no chronic condition (heart attack/disease, cancer, diabetes, or arthritis), and no disability; health problem defined as fair/poor health status, chronic condition, or disability.

Source: The Commonwealth Fund Biennial Health Insurance Survey (2003).

METHODOLOGY

The Commonwealth Fund Biennial Health Insurance Survey was conducted by Princeton Survey Research Associates International from September 3, 2003, through January 4, 2004. The survey consisted of 25-minute telephone interviews in either English or Spanish and was conducted among a random, nationally representative sample of 4,052 adults ages 19 and older living in the continental United States. To make the results representative of all adults ages 19 and older living in the continental United States, the data are weighted by age, sex, race/ethnicity, education, household size, geographic region, and telephone service interruption using the U.S. Census Bureau's 2003 Annual Social and Economic Supplement. The analytic sample consists of 3,261 adults ages 19 to 64. The 50 percent survey response rate was calculated consistent with standards of the American Association for Public Opinion Research.

A series of logistic regression models were estimated to examine the independent effects of caregiving, gender, family structure, insurance, health status, and poverty on sick-loss days, cost-related access problems, and medical bill problems or medical debt. The logistic regression model for sick-loss days also examined the independent effect of paid sick leave. Results presented in Table 3 show odds ratios for each variable holding all other variables shown in the table constant.

About the Authors

Alice Ho is a former research associate at The Commonwealth Fund, for whom she provided analytical and writing support for Fund publications and presentations. Previously she was an associate consultant in the Global Health Solutions division of Computer Sciences Corporation, where she conducted strategic planning for hospitals. She received her bachelor's degree in neuroscience from Brown University and is currently pursuing a law degree from New York University School of Law.

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Karen Davis, Ph.D., president of The Commonwealth Fund, is a nationally recognized economist with a distinguished career in public policy and research. Before joining the Fund, she served as chairman of the Department of Health Policy and Management at The Johns Hopkins Bloomberg School of Public Health, where she also held an appointment as professor of economics. She served as deputy assistant secretary for health policy in the Department of Health and Human Services from 1977 to 1980 and was the first woman to head a U.S. Public Health Service agency. A native of Oklahoma, she received her doctoral degree in economics from Rice University, which recognized her achievements with a Distinguished Alumna Award in 1991. Ms. Davis has published a number of significant books, monographs, and articles on health and social policy issues, including the landmark books *Health Care Cost Containment; Medicare Policy; National Health Insurance: Benefits, Costs, and Consequences;* and *Health and the War on Poverty*.

Michelle McEvoy Doty, Ph.D., is a senior analyst at The Commonwealth Fund, where she conducts research examining health care access and quality among vulnerable populations, as well as the extent to which lack of health insurance contributes to barriers to health care and inequities in quality of care. She received her M.P.H. and Ph.D. in public health from the University of California, Los Angeles.