

TRENDS

Eroding Access Among Nonelderly U.S. Adults With Chronic Conditions: Ten Years Of Change

While the uninsured fared the worst, more adults with health coverage also found it hard to afford care by 2006.

by **Catherine Hoffman and Karyn Schwartz**

ABSTRACT: Both the connection to health care and its affordability worsened for many nonelderly U.S. adults living with chronic conditions between 1997 and 2006. This erosion varied by health insurance coverage, fundamental as it is to securing health services. Access to care among uninsured adults with chronic conditions deteriorated on all of our basic measures between 1997 and 2006. In addition, more of both the privately and publicly insured with chronic conditions went without health care because of its cost over this ten-year span, even while they were just as likely as or more likely than others to have a usual source of care over time. [*Health Affairs* 27, no. 5 (2008): w340–w348 (published online 22 July 2008; 10.1377/hlthaff.27.5.w340)]

MORE THAN 40 PERCENT of the U.S. population lives with one or more chronic conditions. However, because people with chronic conditions have greater health needs than others, they account for three-quarters of all personal medical care spending in this country.¹ And yet we know that many people with chronic conditions have problems getting health care, particularly if they have no health insurance coverage. Given the swings in the economy and family incomes in the past decade, as well as the growth in health care costs and the number of uninsured Americans, we measured whether the insurance disparities in access to care among those with chronic conditions have changed. We focused on nonelderly adults with chronic conditions, knowing that their greater need for and use of health ser-

vices make them sensitive to these changes. All of the research to date on access to care for this population was conducted before 2000, and no studies have measured changes in access to care among those with chronic conditions over this long of a period.

Background

The chances of having a chronic condition increase with age—particularly among the elderly, nearly all of whom have Medicare coverage. However, the majority (60 percent) of people with chronic conditions, about sixty-five million, are working-age adults.² Nonelderly adults with chronic conditions are more likely than others to have health insurance, partly because they know that their health needs will be greater, and so insurance is even more essential to them, but also because those who become disabled may qualify

Catherine Hoffman (hoffman@kff.org) is associate director and a senior researcher at the Kaiser Commission on Medicaid and the Uninsured, located in Washington, D.C. Karyn Schwartz is a senior policy analyst with the commission.

for Medicaid, and eventually Medicare. Still, about one in eight nonelderly adults with chronic conditions are uninsured (12 percent).³

Among nonelderly adults with chronic conditions, the uninsured are more likely than the privately insured to be in poor health and to have physical limitations.⁴ Despite their greater health needs, they have less access to care. Uninsured people who are newly diagnosed with a chronic condition are as likely as those with insurance are to receive recommendations for follow-up care; however, they are less likely to actually receive it—with fewer office visits and prescription medicines and more visits to the emergency department (ED).⁵

Uninsured people with chronic conditions are also twice as likely as their privately insured counterparts to either delay or forgo care altogether, including basic preventive care.⁶ For example, uninsured adults with diabetes are less likely than privately insured adults with diabetes to have regular eye exams or blood glucose monitoring.⁷ People with chronic conditions are also more likely to need specialist care. However, more of the uninsured have difficulty getting this level of care than those with private coverage.⁸ Recognizing these access-to-care differences, we were interested in determining whether the degree of the disparity had changed during the past decade.

Study Data And Methods

■ **Survey.** Using data from the National Health Interview Survey (NHIS), we tracked ten years of data (1997–2006). Basic access-to-care measures that could be reliably trended over this period included the following: (1) having no usual source of care (or the ED as a usual source of care), and, in the past year, (2) having no physician or health professional visit; (3) having no medical specialist visit; (4) forgoing medical care because it was unaffordable; and (5) forgoing prescription drugs

because they were unaffordable.

■ **Sample.** Adults in the NHIS are asked a series of questions about specific types of health conditions. We selected just those conditions that are chronic in nature—that is, those that typically last years, rather than months, and that have no cure. We subsampled nonelderly adults (ages 18–64) who reported being told by a doctor or other health professional that they had at least one of the following categories of chronic conditions:

heart disease (including angina, heart attack, other heart conditions or diseases), hypertension, stroke, diabetes (other than during pregnancy), pulmonary conditions including both emphysema and asthma (having had an asthma attack or episode in the past twelve months), and cancer or a malignancy. Although some types of cancer

are now curable, we included cancer as a chronic condition because many, if not most, people with cancer will undergo treatment and be monitored for relapse or metastasis over several years. They also incur relatively high medical expenses, which makes them particularly vulnerable if their insurance coverage or access to care is compromised. In fact, three of these conditions—heart disease, pulmonary conditions, and cancer—are among the five most costly medical conditions in the United States.⁹ In total, 76,080 nonelderly adults with at least one of these seven chronic conditions were included in our ten-year sample.

■ **Health insurance status.** To clearly differentiate health insurance experience, we constructed three insurance categories: privately insured (including employer-sponsored and nongroup insurance), Medicaid (including any adults with coverage through the State Children's Health Insurance Program, or SCHIP), and uninsured. Medicare beneficiaries were excluded. The privately insured and Medicaid groups included only the nonelderly who had health insurance throughout the past

“Uninsured people with chronic conditions are twice as likely as their privately insured counterparts to either delay or forgo care altogether.”

twelve months. The uninsured group included only those who said that they had been uninsured throughout the past twelve months.

■ **Analysis.** We first looked at the unadjusted trends for each of the three insurance groups in our five access measures over the entire ten-year period. To test the change in health access disparities over time, however, we wanted to adjust for important confounding factors, so we chose to compare the endpoints, using pooled years 1997–98 and 2005–06. For simplicity, when discussing the results of our analysis, we refer to 1997 when discussing 1997–98 and 2006 when discussing 2005–06. Our logistic regression models controlled for health insurance category, year endpoints, and their interaction—in addition to controlling for age, sex, race/ethnicity, education, poverty level, marital status, health status, and functional and work limitations.¹⁰

From the logistic regression model, we report adjusted predicted probabilities of having an access problem, depending on whether a person was privately insured, had Medicaid, or was uninsured in each of the two endpoint periods. To directly test for significant changes between the two time periods for each insurance group, we then ran separate logistic regressions on each access measure for each insurance group—with the *p* value of the

coefficient derived for the year variable (2005–06 versus 1997–98) indicating whether there was a statistically different change over time. All data were analyzed using Stata 9 survey commands to account for the complex survey design.¹¹

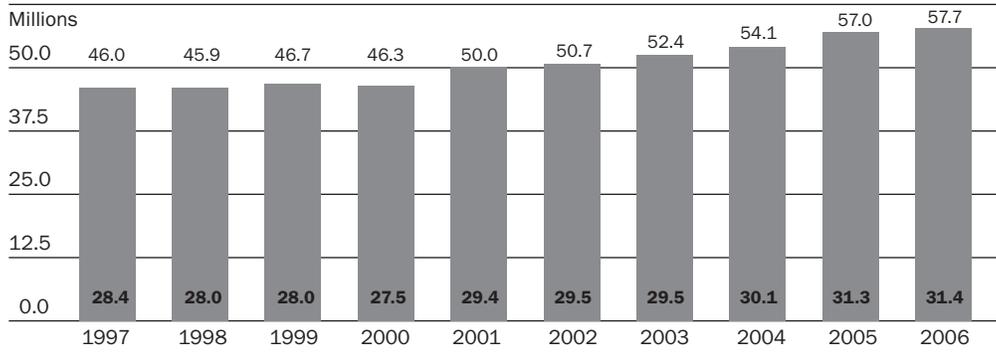
Study Results

The number of nonelderly adults who report having one or more of seven major chronic conditions has been increasing—to a total of 58 million by 2006 (Exhibit 1). The percentage of adults with these chronic conditions has also been growing, from 28 percent in 1997 to 31 percent by 2006. Hypertension, diabetes, emphysema, and cancer rates all increased statistically, while heart disease, stroke, and asthma prevalence did not change.¹²

Between 1997 and 2006 the profile of nonelderly adults with these highly prevalent chronic conditions changed: more were older, from racial or ethnic minority groups, college educated, unmarried, and male. More were from higher-income families (at least 400 percent of the federal poverty level), but fewer were privately insured. About 13 percent of nonelderly adults with these conditions were uninsured in both 1997 and 2006.

Self-reported overall health status declined among nonelderly adults with chronic condi-

EXHIBIT 1
Nonelderly U.S. Adults Reporting At Least One Of Seven Major Chronic Conditions, 1997–2006



SOURCE: Authors' analysis of data from the National Health Interview Survey, various years.

NOTES: For a list of the conditions examined, see text. Numbers at the bottom of each bar indicate the percentage of the population reporting at least one condition in each year.

tions over this period: 23.2 percent reported being in either fair or poor health in 2006, compared to 20.9 percent in 1997. Functional status, however, remained the same. Only 2 percent reported having problems with activities of daily living (ADLs), but 22 percent reported work limitations.¹³

Among nonelderly adults with these major chronic conditions, large differences in access to care between the uninsured and the insured persisted and even increased over the ten-year period. After confounding factors were adjusted for, Medicaid and privately insured nonelderly adults had similar levels of access to care—with both groups having much better access than the uninsured.

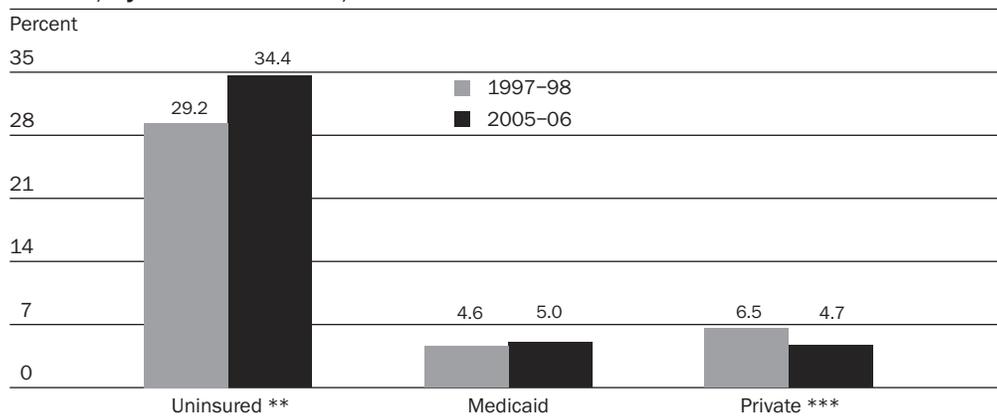
■ **Access to a usual source of care and regular health care.** *No usual source of care.* The uninsured with chronic conditions were more than four times as likely not to have a usual source of care compared to both the privately insured and those with Medicaid in 1997. By 2006 the disparity had widened even further (Exhibit 2). In 2006, after social, economic, and health differences were controlled for, 34.4 percent of uninsured nonelderly adults with chronic conditions reported not having a

usual source of care, compared to about 5 percent of the insured (4.7 percent for private; 5.0 percent for Medicaid). The chances of having a usual source of care actually improved over time among the privately insured with chronic conditions, did not change significantly among those with Medicaid, but worsened for the uninsured (adjusted: 34.4 percent by 2006 compared to 29.2 percent in 1997).

No doctor or health professional visit in past year. The disparity between the uninsured and insured in annual doctor visits is also large and growing. The share of insured nonelderly adults with chronic conditions who reported not having seen a health care provider in the past year either did not significantly change (for Medicaid) or actually decreased (privately insured) between 1997 and 2006. However, the share of the uninsured with chronic conditions who had not seen a provider grew over time (Exhibit 3). After adjusting, 25.8 percent of the uninsured in 2006 reported not having a doctor visit in the past year, compared to 21.3 percent in 1997.

No medical specialist visit in past year. Not everyone who is diagnosed with a chronic condition will require a specialist to manage their care.

EXHIBIT 2 Probability That Nonelderly Adults With Chronic Conditions Reported No Usual Source Of Care, By Insurance Status, 1997–2006

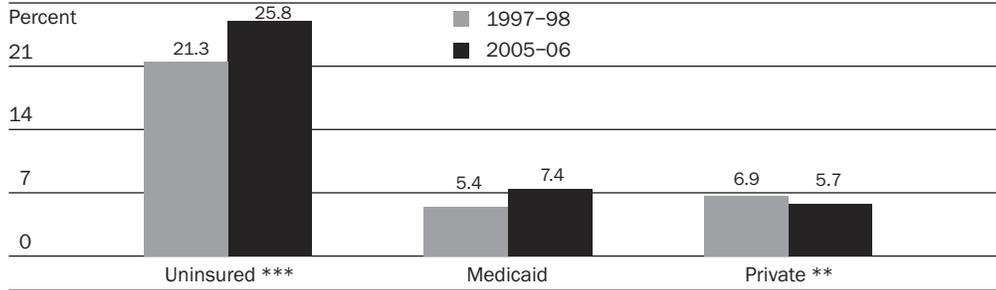


SOURCE: Authors' analysis of data from the National Health Interview Survey, various years.

NOTES: Predicted probabilities were adjusted for age, race/ethnicity, education, poverty level, sex, marital status, health status, problems with activities of daily living (ADLs) and with instrumental activities of daily living (IADLs), and work limitations. Statistical significance denotes difference from 1997–98 to 2005–06.

** $p < 0.05$ *** $p < 0.01$

EXHIBIT 3
Probability That Nonelderly Adults With Chronic Conditions Reported No Doctor Or Health Professional Visit In The Past Year, By Insurance Status, 1997–2006



SOURCE: Authors' analysis of data from the National Health Interview Survey, various years.

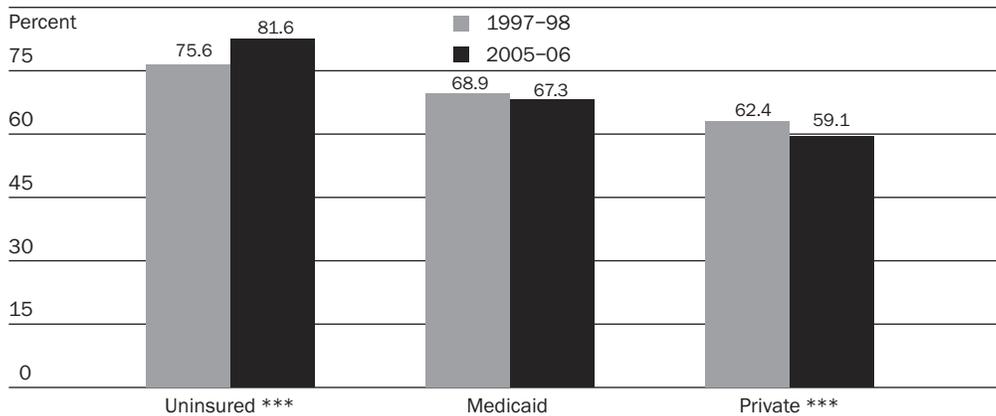
NOTES: Predicted probabilities were adjusted for age, race/ethnicity, education, poverty level, sex, marital status, health status, problems with activities of daily living (ADLs) and with instrumental activities of daily living (IADLs), and work limitations. Statistical significance denotes difference from 1997–98 to 2005–06.

** $p < 0.05$ *** $p < 0.01$

For many, their primary care physicians, some of whom have subspecialized in the care of specific conditions, can manage their preventive and routine care needs. In fact, the majority of nonelderly adults with chronic conditions in our sample reported that they had not seen a medical specialist in the past year. The uninsured are much less likely than the insured to have seen a specialist, however (Ex-

hibit 4). Between 1997 and 2006, the use of medical specialists remained the same for those with Medicaid and increased among the privately insured. The proportion of uninsured nonelderly adults with chronic conditions who had not seen a medical specialist in the previous year increased significantly over time—from 75.6 percent to 81.6 percent. Both Medicaid and privately insured nonelderly

EXHIBIT 4
Probability That Nonelderly Adults With Chronic Conditions Reported No Medical Specialist Visit In The Past Year, By Insurance Status, 1997–2006



SOURCE: Authors' analysis of data from the National Health Interview Survey, various years.

NOTES: Predicted probabilities were adjusted for age, race/ethnicity, education, poverty level, sex, marital status, health status, problems with activities of daily living (ADLs) and with instrumental activities of daily living (IADLs), and work limitations. Statistical significance denotes difference from 1997–98 to 2005–06.

*** $p < 0.01$

adults continue to be more likely than the uninsured to use medical specialists, and the large gap between the privately insured and uninsured widened from a difference of thirteen percentage points in 1997 to twenty-three percentage points by 2006.

■ Affordability and access problems.

Unmet need for medical care because of cost. Going without needed medical care because it is unaffordable is common among the uninsured, reported by more than 30 percent of the uninsured with chronic conditions—a rate at least four times higher than among those with health insurance (Exhibit 5). We found that more of both the uninsured and privately insured reported unmet needs because of cost in 2006 than in 1997, while nonelderly Medicaid adults were the least likely to have unmet medical needs because of cost, and the problem did not worsen for them over time.

Unmet need for prescription medicines because of cost. Significantly more nonelderly adults with chronic conditions across all insurance groups reported going without prescription drugs because they could not afford them in 2006 than in 1997 (Exhibit 6). The share of the privately insured who were not able to afford prescrip-

tions nearly doubled over this period. However, as with other access measures, the uninsured were still far more likely than those with either Medicaid or private insurance to forgo prescription drugs because of their cost. By 2006, a third of uninsured nonelderly adults with chronic conditions said that they went without prescribed medications, up from 25 percent in 1997.

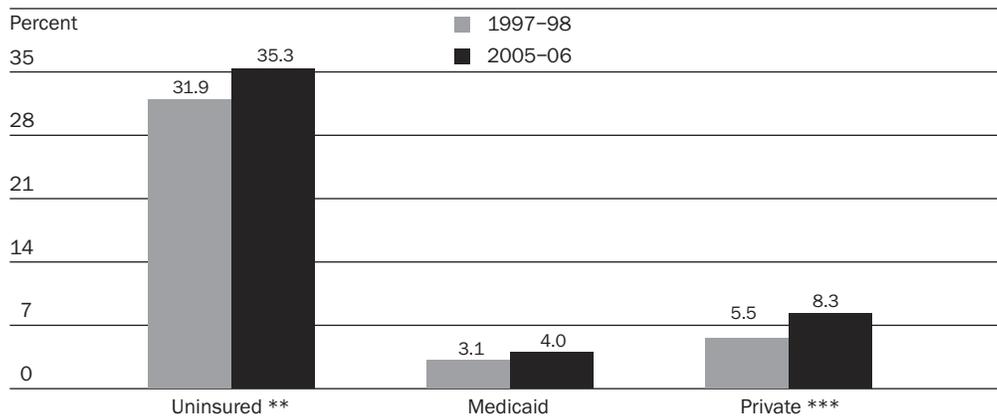
Discussion

By all of our measures, access to care among the uninsured with chronic conditions deteriorated between 1997 and 2006. However, we found that more of those with health insurance were also going without needed care because of its cost. Across all insurance groups, more nonelderly adults with chronic conditions reported needing prescription drugs but not getting them because of cost over this period.

These results might not be unique to nonelderly adults with chronic conditions, but instead could be reflecting broader trends in access to care. Over this period, rising numbers of uninsured people have strained the country's safety-net providers, while physicians have decreased the amount of charity

EXHIBIT 5

Probability That Nonelderly Adults With Chronic Conditions Reported Unmet Need For Medical Care Because Of Cost During The Past Year, By Insurance Status, 1997–2006



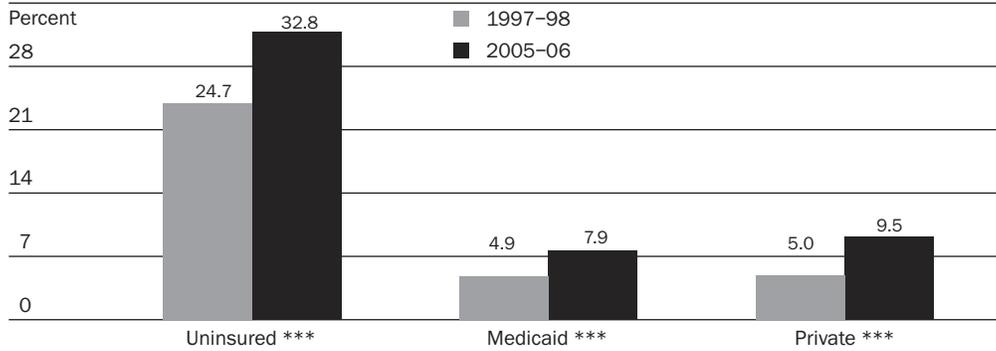
SOURCE: Authors' analysis of data from the National Health Interview Survey, various years.

NOTES: Predicted probabilities were adjusted for age, race/ethnicity, education, poverty level, sex, marital status, health status, problems with activities of daily living (ADLs) and with instrumental activities of daily living (IADLs), and work limitations.

Statistical significance denotes difference from 1997–98 to 2005–06.

** $p = 0.05$ *** $p < 0.01$

EXHIBIT 6
Probability That Nonelderly Adults With Chronic Conditions Reported Unmet Need For Prescription Drugs Because Of Cost During The Past Year, By Insurance Status, 1997–2006



SOURCE: Authors' analysis of data from the National Health Interview Survey, various years.

NOTES: Predicted probabilities were adjusted for age, race/ethnicity, education, poverty level, sex, marital status, health status, problems with activities of daily living (ADLs) or with instrumental activities of daily living (IADLs), and work limitations. Statistical significance denotes difference from 1997–98 to 2005–06.

*** $p < 0.01$

care they provide.¹⁴ At the same time, the combined effect of a fluctuating economy, stagnant family incomes, and unchecked growth in health care costs put ever greater demands on family budgets.

As health care grew less affordable, access to care might have been jeopardized for many, especially the uninsured who are poorer. The financial burden of rising health costs on families' budgets has been growing. Between 2001 and 2004, the share of those with out-of-pocket health spending that consumed more than 10 percent of their family income grew from 15.9 percent to 17.7 percent of the nonelderly population, topping forty-five million people by 2004.¹⁵

Out-of-pocket health care spending is much higher than average among those with chronic conditions, creating even greater financial barriers to care. Having a single chronic condition increases a person's annual out-of-pocket health spending by more than 70 percent; having two conditions increases it threefold.¹⁶ These larger medical bills relative to family incomes are far more likely to be a burden on people with chronic conditions. For example, almost 40 percent of nonelderly diabetics and 33 percent of people with heart dis-

ease incurred out-of-pocket health care spending that consumed more than 10 percent of their family income in 2003.¹⁷

Our finding that access to care has deteriorated for many nonelderly adults with chronic conditions is particularly worrisome because this is a group of people with complex health needs requiring lifelong attention. Continuity in their care is essential to managing symptoms, preventing complications and comorbidities, and saving health dollars.

More than one-third of the uninsured with chronic conditions are having problems getting the care they need because of its cost. Because those with chronic conditions account for a disproportionately large share of personal health spending, the consequences of any forgone care among the chronically ill can be very costly. Preventable complications, comorbidities, and avoidable hospitalizations generate sizable direct expenses, as well as the indirect expenses of work-loss days and disability—all of which cost far more than regular exams or maintenance drugs.

The measures of access to care analyzed in this paper changed the least for nonelderly adults with chronic conditions covered by Medicaid—whose access to care (after other

socioeconomic and health factors are controlled for) is fairly similar to that of the privately insured. Medicaid recipients' access to a usual source of care and regular physician care did not change; nor did the small share who reported having unmet needs for medical care because of cost. However, they were not protected against rising prescription drug costs. This decline in access to prescription drugs seems to have occurred mostly after 2002, coinciding with a period when more states implemented drug copayments and limits on prescription drug use in their Medicaid programs.¹⁸

AS MEDICAL ADVANCES continue to save and prolong lives, sometimes turning potentially fatal health problems into chronic conditions, the number of people living with such conditions will also continue to grow. Controlling health system costs overall will require effective and efficient care for people with chronic conditions, because they use the majority of health care services in this country. These high costs put people with chronic conditions on the front lines to test major and even minor reforms of our health insurance system—a system that often excludes those with pre-existing conditions. Ensuring that more people living with chronic conditions, regardless of their health problems, have access to affordable health insurance coverage—which provides sufficient financial protection—is a well-evidenced first step toward improving access to care.

.....
Data from this paper were presented at a poster session of the AcademyHealth Annual Research Meeting, 9 June 2008, in Washington, D.C. The authors gratefully acknowledge Timothy Waidmann and Douglas Wissoker of the Urban Institute for their advice on computer programming and the statistical analysis. They also thank Diane Rowland for her helpful feedback on the analysis and final paper, as well as her personal support of their work.

NOTES

1. C. Hoffman, D. Rice, and H. Sung, "Persons with Chronic Conditions: Their Prevalence and Costs," *Journal of the American Medical Association* 276, no. 18 (1996): 1473–1479; and W. Hwang et al., "Out-of-Pocket Medical Spending for Care of Chronic Conditions," *Health Affairs* 20, no. 6 (2001): 267–278.
2. Hwang et al., "Out-Of-Pocket Medical Spending."
3. H.T. Ha and M.C. Reed, "Options for Expanding Health Insurance for People with Chronic Conditions," Issue Brief no. 50 (Washington: Center for Studying Health System Change, 2002).
4. M.C. Reed and H.T. Tu, "Triple Jeopardy: Low Income, Chronically Ill, and Uninsured in America," Issue Brief no. 49 (Washington: HSC, 2002).
5. J. Hadley, "Insurance Coverage, Medical Care Use, and Short-Term Health Changes Following an Unintentional Injury or the Onset of a Chronic Condition," *Journal of the American Medical Association* 297, no. 10 (2007): 1073–1084.
6. Reed et al., "Triple Jeopardy"; M.B. Wenneker, J.S. Weissman, and A.M. Epstein, "The Association of Payer with Utilization of Cardiac Procedures in Massachusetts," *Journal of the American Medical Association* 264, no. 10 (1990): 1255–1260; J.G. Canto et al., "Payer Status and the Utilization of Hospital Resources in Acute Myocardial Infarction: A Report from the National Registry of Myocardial Infarction 2," *Archives of Internal Medicine* 160, no. 6 (2000): 817–823; R. Andersen et al., "Access of Vulnerable Groups to Antiretroviral Therapy among Persons in Care for HIV Disease in the United States," *Health Services Research* 35, no. 2 (2000): 389–416; J. Rabinowitz et al., "Relationship between Type of Insurance and Care During the Early Course of Psychosis," *American Journal of Psychiatry* 155, no. 10 (1998): 1392–1397; K.W. Hanson et al., "Uncovering the Health Challenges Facing People with Disabilities: The Role of Health Insurance," *Health Affairs* 22 (2003): w552–w565 (published online 19 November 2003; 10.1377/hlthaff.w3.552).
7. M.N. Stagnitti, "Medical Care and Treatment for Chronic Conditions, 2000," Statistical Brief no. 5 (Rockville, Md.: Agency for Healthcare Research and Quality, 2002).
8. A. Soni and S.C. Hill, "Getting Health Care from Specialists among Adults with Chronic Conditions, U.S. Civilian Noninstitutionalized Population, 2004," Statistical Brief no. 162 (Rockville, Md.: AHRQ, 2007).
9. G.L. Olin and J.A. Rhoades, "The Five Most Costly Medical Conditions, 1997 and 2002: Estimates for the U.S. Civilian Noninstitutionalized

- Population,” Statistical Brief no. 80 (Rockville, Md.: AHRQ, 2005).
10. Self-reported income in the NHIS data has a high rate of nonresponse; therefore, the National Center for Health Statistics uses a multiple imputation method and provides five income data sets for each year of publicly released data. For this analysis we found that income imputation had a negligible effect on our regression findings, so we used data on poverty level from only one of the public-use income files. Exhibit A-2, which shows the characteristics of our study population by each of these control variables, is included in the Technical Appendix, online at <http://content.healthaffairs.org/cgi/content/full/hlthaff.27.5.w340/DC2>.
 11. More information about the data and methods are available in the Technical Appendix; *ibid*.
 12. See Exhibit A-1; *ibid*.
 13. See Exhibit A-2; *ibid*.
 14. B.C. Strunk and P.J. Cunningham, “Treading Water: Americans’ Access to Needed Medical Care, 1997–2001,” Tracking Report no. 1 (Washington: HSC, 2002); P. Cunningham and J. May, “Insured Americans Drive Surge in Emergency Department Visits,” Issue Brief no. 70 (Washington: HSC, 2003); M.C. Reed, P.J. Cunningham, and J.J. Stoddard, “Physicians Pulling Back from Charity Care,” Issue Brief no. 42 (Washington: HSC, 2001); P.J. Cunningham and J.H. May, “A Growing Hole in the Safety Net: Physician Charity Care Declines Again,” Tracking Report no. 13 (Washington: HSC, 2006); and R. Hurley, L. Felland, and J. Lauer, “Community Health Centers Tackle Rising Demands and Expectations,” Issue Brief no. 116 (Washington: HSC, 2007).
 15. J.S. Banthin, P. Cunningham, and D.M. Bernard, “Financial Burden of Health Care, 2001–2004,” *Health Affairs* 27, no. 1 (2008): 188–195.
 16. Hwang et al., “Out-Of-Pocket Medical Spending.”
 17. J.S. Banthin and D.M. Bernard, “Changes in Financial Burdens for Health Care: National Estimates for the Population Younger than Sixty-five Years, 1996 to 2003,” *Journal of the American Medical Association* 296, no. 22 (2006): 2712–2719.
 18. J.S. Crowley, D. Ashner, and L. Elam, “State Medicaid Outpatient Prescription Drug Policies: Findings from a National Survey, 2005 Update” (Washington: Kaiser Commission on Medicaid and the Uninsured, 2005).