

Prescription Noncompliance due to Cost Among Adults With Disabilities in the United States

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Medicare prescription drug insurance is a recurrent focus of American health policy,¹ and a combination of rapidly escalating drug costs² and insurance industry trends^{3,4} have again thrust the issue to center stage. One of the more compelling rationales offered for expanding drug coverage is that affordability problems have clinical as well as economic consequences; that is, patients who have difficulty paying for medications are less likely to take them and can suffer adverse health effects as a result of noncompliance.^{5,6} Although this argument has intuitive appeal, no national data are available on cost-associated noncompliance, leading commentators to question both the scope of affordability problems and the remedies proposed to address them.⁷ In the present study, we sought to illuminate a critical aspect of the policy debate by developing the first national prevalence estimates of prescription noncompliance due to cost and resulting health problems among adults with disabilities, a population known to be heavy users of health care,^{8,9} including prescription drugs.^{9–11}

Medicare recipients with drug coverage are more likely to fill their prescriptions than those without coverage.^{12–14} Total and out-of-pocket drug costs are heavily skewed toward individuals with poor health or chronic conditions, even among recipients with drug coverage.¹⁵ Noncompliance with prescription regimens is a widely recognized clinical problem,¹⁶ particularly in the case of treatment of chronic illnesses such as hypertension,¹⁷ and it has been identified as an important predictor of emergency room visits¹⁸ and hospital admissions.^{19,20} Numerous studies have linked rates of noncompliance to (1) sociodemographic factors, including age,^{21–23} sex,¹⁷ and race/ethnicity²⁴; (2) socioeconomic factors, including insurance coverage²⁵ and out-of-pocket costs^{18,19}; and (3) treatment factors, including type²⁶ and number of drugs prescribed²⁷ and complexity of drug regi-

men.²¹ We examined the relative influences of these factors on self-reported noncompliance due to cost.

METHODS

Data Source

The Disability Supplement and the Disability Follow-Back Survey (DFS) are special supplements to the National Health Interview Survey (NHIS), a continuing probability survey of households representative of the civilian noninstitutionalized population of the United States.²⁸ The Disability Supplement was administered to all respondents at the same time they completed the 1994 and 1995 NHIS core surveys. The DFS was administered 6 to 18 months later to respondents who reported impairments, functional limitations, chronic conditions, or receipt of disability benefits in the core NHIS surveys or the Disability Supplement.²⁹ We used data from the adult supplement, which was administered to 25 805 respondents 18 years or older with disabilities (about 17% of the NHIS sample).

Adults selected for the DFS differed from the general population selected for the NHIS in predictable ways. They were older (according to weighted estimates, 35% of DFS adult respondents were 65 years or older, compared with 13% of NHIS adult respondents),

Objectives. This study estimated national prevalence rates of medication noncompliance due to cost and resulting health problems among adults with disabilities.

Methods. Analyses involved 25 805 respondents to the Disability Follow-Back Survey, a supplement to the 1994 and 1995 National Health Interview Surveys.

Results. Findings showed that about 1.3 million adults with disabilities did not take their medications as prescribed because of cost, and more than half reported health problems as a result. Severe disability, poor health, low income, lack of insurance, and a high number of prescriptions increased the odds of being noncompliant as a result of cost.

Conclusions. Prescription noncompliance due to cost is a serious problem for many adults with chronic disease or disability. Most would not be helped by any of the current proposals to expand Medicare drug coverage. (*Am J Public Health.* 2002;92:1120–1124)

had lower incomes (19% of DFS respondents had incomes at or below the poverty level, compared with 12% of NHIS respondents), and were in worse health (69% of DFS adult respondents rated their health as fair or poor, compared with 34% of NHIS respondents).

Data Analysis

We used a case–control design to examine risk factors associated with prescription noncompliance due to cost. We weighted all data so that they would be generalizable to the overall US population. SUDAAN statistical software was used to account for the clustered sample design of the NHIS and the lack of independence in the error terms.³⁰ Unadjusted and adjusted odds ratios (ORs) were calculated for demographic (age, sex, race/ethnicity), socioeconomic (income, health insurance coverage), and health and disability (self-assessed health status, severity of activity limitations, number of prescriptions) factors. Respondents who were not prescribed any medications and those who reported that they did not take their medications as prescribed for reasons other than cost were omitted from comparisons.

RESULTS

Almost 70% of the disabled adult population—about 28 million people—reported having been prescribed 1 or more medications

TABLE 1—Self-Reported Number of Prescriptions and Compliance Rates Among US Adults With Disabilities

	Estimated No. (%)
Medications prescribed	
None	12 161 (30.0)
1-2	12 400 (30.6)
3-5	10 846 (26.8)
6-9	3 961 (9.8)
≥10	1 139 (2.8)
Take medicine(s) as prescribed ^a	
All of the time	24 762 (86.8)
Most of the time	2 576 (9.0)
Some of the time	793 (2.8)
Rarely	210 (0.7)
Never	194 (0.7)

Note. Data are population estimates in 1000s derived from the National Center for Health Statistics.²⁹
^aAbout 2% of people who had one or more prescriptions (317 respondents) selected the “don’t know” response and were omitted from subsequent analyses.

(Table 1), and more than 85% of this group indicated that they always used their medications as prescribed. However, an estimated 3.8 million adults reported that they did not always use their medications as prescribed. These respondents were asked to select 1 or more of 8 reasons for their noncompliance (Table 2). About 1.3 million adults with disabilities cited 1 or more concerns related to cost (i.e., they did not get their prescription

filled, did not fill their prescription completely, did not refill their prescription, or used their medicine less often than prescribed because of cost). This subset of noncompliant respondents was the focus of all subsequent analyses.

Table 3 identifies specific factors associated with prescription noncompliance due to cost. Persons with incomes below the poverty level were at higher risk for cost-associated noncompliance than were persons with incomes above the poverty level (OR=1.6; 95% confidence interval [CI]=1.3, 2.0). Uninsured adults were nearly 4 times as likely to be noncompliant owing to cost as their counterparts with private insurance (OR=3.9; 95% CI=3.0, 5.1). Adults with private and public health insurance (i.e., supplemental Medicare coverage) exhibited relatively low rates of cost-associated noncompliance (OR=0.7; 95% CI=0.5, 1.0).

Individuals who described their health as fair or poor were more likely to be noncompliant than were those who rated their health as good, very good, or excellent (OR=1.4; 95% CI=1.1, 1.7). The relationship between severity of disability and cost-associated noncompliance appeared to be curvilinear, with the highest level of noncompliance among moderately impaired adults who were limited in, but did not require assistance with, 1 or more activities of daily living (OR=1.9; 95% CI=1.5, 2.5). Disabled adults who were prescribed 3 or more medications were more

likely than those who were prescribed 1 or 2 medications to report cost-associated noncompliance (3–5 medications: OR=1.4; 95% CI=1.1, 1.7; 6 or more medications: OR=1.6; 95% CI=1.2, 2.1).

Sex and race/ethnicity appeared to be only modestly related to cost-associated noncompliance, but there was a strong negative relationship between age and noncompliance: younger adults (those aged 18–34 years) were nearly 10 times more likely to be noncompliant as a result of cost than were members of the oldest cohort (those 75 years or older; OR=0.1; 95% CI=0.1, 0.2). However, members of younger cohorts were also less likely to be prescribed medications.

To clarify this relationship, we plotted the number of adults with prescriptions and the proportions reporting cost-associated noncompliance according to age group. Figure 1 shows that prescription rates increased with age: only 35% of disabled adults aged 18 to 24 years were prescribed medications, in comparison with 86% of adults aged 65 years or older. Among disabled adults with prescriptions, rates of cost-associated noncompliance peaked at about 10% for those aged 25 to 44 years and declined sharply in older age cohorts. Only about 2% of adults aged 65 to 74 years reported cost-associated noncompliance, and this rate dropped to below 1% among adults 75 years or older.

All noncompliant respondents were asked whether they had experienced any adverse health consequences (Table 4). Among those who were noncompliant owing to cost, more than half identified 1 or more resulting health problems. The most common problems involved exacerbation of conditions or symptoms; for example, nearly 350 000 people reported pain or discomfort resulting from cost-associated noncompliance. A relatively small proportion of respondents reported that noncompliance problems led directly to additional health care use: an estimated 66 000 people had to visit a doctor’s office or emergency room, and about 46 000 had to be hospitalized.

DISCUSSION

Our study showed that about 1.3 million adults with disabilities reported that the cost

TABLE 2—Reasons Given by Adults With Disabilities for Noncompliance

	Estimated No. (%)
Affordability	1280 (33.9)
Did not refill when ran out owing to cost	898 (23.7)
Use less often than prescribed to stretch out owing to cost	853 (22.6)
Did not get when first prescribed owing to cost	767 (20.2)
Did not get entire prescription filled owing to cost	741 (19.5)
Other	2483 (65.8)
Sometimes forget to use	1789 (47.4)
Don’t use as prescribed because of side effects	926 (24.5)
Don’t use because of perceived lack of need	826 (22.0)
Cannot pick up from drug store or get delivered	125 (3.3)
Total noncompliant ^a	3798 (100)

Note. Data are population estimates in 1000s derived from the National Center for Health Statistics.²⁹
^aCurrently prescribed one or more medications and does not always take as prescribed.

TABLE 3—Factors Associated With Prescription Noncompliance due to Cost Among Adults With Disabilities

	Estimated No. ^a (n = 25 836)	Noncompliant due to Cost, %	Unadjusted		Adjusted	
			OR	95% CI	OR	95% CI
Age, y						
18–34	2 787	20.8	1.00		1.00	
35–44	3 342	10.8	0.99	0.77, 1.27	0.95	0.73, 1.25
45–54	4 022	7.1	0.62	0.49, 0.80	0.59	0.45, 0.78
55–64	4 413	3.6	0.30	0.23, 0.40	0.28	0.20, 0.38
65–74	5 733	2.1	0.17	0.13, 0.24	0.21	0.14, 0.32
≥75	5 539	0.9	0.08	0.05, 0.12	0.10	0.07, 0.16
Sex						
Male	10 118	4.2	1.00		1.00	
Female	15 718	5.4	1.30	1.10, 1.53	1.20	0.99, 1.44
Race						
White	20 481	4.9	1.00		1.00	
Hispanic	1 695	3.7	0.75	0.57, 0.99	0.45	0.32, 0.64
Black	2 999	6.4	1.32	1.05, 1.67	0.87	0.65, 1.15
Other	662	4.1	0.84	0.47, 1.50	0.80	0.43, 1.47
Income at or below poverty level^b						
No	19 137	4.0	1.00		1.00	
Yes	4 167	8.8	2.34	1.94, 2.82	1.59	1.26, 2.02
Health insurance^c						
Private only	6 993	5.2	1.00		1.00	
Public only	7 787	5.3	1.02	0.83, 1.26	1.02	0.77, 1.34
Mix of private and public	9 409	1.6	0.30	0.23, 0.39	0.70	0.49, 0.98
Uninsured	1 548	21.3	4.90	3.87, 6.20	3.90	3.02, 5.05
Health status						
Excellent–good	13 863	7.9	1.00		1.00	
Fair–poor	11 782	6.0	1.53	1.31, 1.80	1.39	1.13, 1.72
Severity of disability^d						
No activity limitations	11 282	4.2	1.00		1.00	
Activity limit only	3 416	7.7	1.91	1.54, 2.37	1.93	1.48, 2.50
Assistance needed	11 138	4.9	1.18	0.98, 1.43	1.28	1.01, 1.63
No. of prescriptions						
1–2	11 112	4.9	1.00		1.00	
3–5	9 970	4.8	0.98	0.82, 1.17	1.37	1.11, 1.71
≥6	4 751	10.6	1.03	0.81, 1.32	1.62	1.19, 2.19

Note. Data are population estimates in 1000s derived from the National Center for Health Statistics (NCHS).²⁹ OR = odds ratio; CI = confidence interval.

^aTotal includes adults with disabilities who always took their medications as prescribed, plus adults with disabilities who did not take their medications as prescribed owing to cost concerns (respondents who were noncompliant solely for other reasons, as well as those who were not prescribed any medications, were omitted from this analysis).

^bFamily income data were missing for an estimated 9.8% of respondents and deleted in the multivariate model.

^cHealth insurance status based on NCHS recode; ambiguous categories (“private/unknown if public” and “public/unknown if private”) coded as “private only” or “public only.”

^dActivity limitation was assessed in 15 domains: bathing, dressing, eating, toileting, transferring, walking, getting outside, light housework, heavy housework, transportation, meal preparation, shopping for groceries, managing medications, managing money, and using the telephone.

uted to noncompliance. These prevalence figures are impressive; for several reasons, however, they probably underestimate the true scope of drug affordability problems among people with disabilities.

First, our data did not allow us to estimate the number of people who take their medications as prescribed but do so at great personal cost. For some people with disabilities or chronic illnesses, limited incomes force a monthly choice between medication and food.³¹ Second, although only recently released to the research community, the surveys we examined are somewhat dated. Drug costs have skyrocketed in the period since the data were collected,² potentially threatening the health and economic security of many more adults with and without disabilities.^{6,32,33} Third, all compliance data were self-reported and thus subject to biases associated with such survey methods.³⁴ Indeed, underreporting of noncompliance is such a widely recognized problem²⁶ that many researchers use independent verification strategies such as pill counts³⁵ and electronic monitoring.³⁶

Despite these limitations, our analysis raises some provocative research and policy questions. As might be expected, income and insurance status were strong predictors of noncompliance due to cost. The magnitude of the insurance differences, however, was striking; after other risk factors had been controlled, disabled adults without insurance were nearly 4 times more likely than those with private insurance to report medication noncompliance due to cost.

The finding that people who were in poorer health or who took more medications were also at higher risk of cost-associated noncompliance was consistent with previous research. However, the curvilinear relationship found between severity of disability and noncompliance due to cost merits further investigation. The relatively lower rate of noncompliance among Hispanic adults with disabilities was unanticipated, and additional research is clearly needed to verify this relationship.

Our most remarkable finding from a public policy perspective was that cost-associated noncompliance was concentrated primarily in younger cohorts. This result seems to contradict much of the recent political commentary on drug affordability, although other studies

of the medicine(s) they were prescribed was so high that they could not afford to fill or refill their prescriptions or to take their medica-

tion as prescribed. More than half of this group identified 1 or more potentially serious and costly health problems that they attrib-

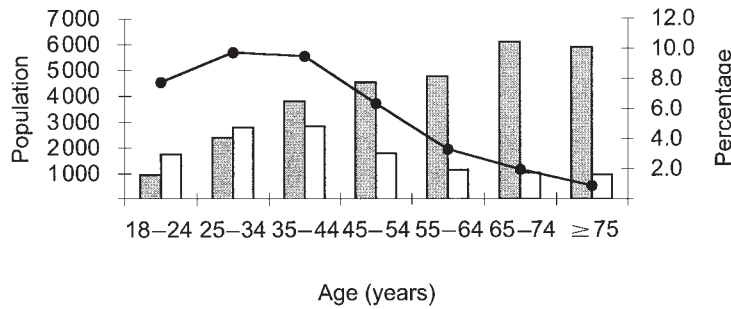


FIGURE 1—Number of disabled adults who had prescriptions and proportions noncompliant owing to cost, by age group.

TABLE 4—Reported Health Problems Attributed to Medication Noncompliance due to Cost Among Adults With Disabilities

	Estimated No. (%)
Experienced one or more problems owing to noncompliance	672 (52.5)
Pain or discomfort	349 (27.2)
Condition for which medicine prescribed got worse	267 (20.9)
Dizziness or fainting	159 (12.4)
Change in blood pressure, breathing, or other vital signs	154 (12.0)
Disorientation	93 (7.3)
Had to go to the doctor or emergency room	66 (5.2)
Other condition(s) got worse	64 (5.0)
Had to be admitted to the hospital	46 (3.6)
Overdose or withdrawal	37 (2.9)
Drug reaction	35 (2.8)
Other	152 (11.9)
Total noncompliant owing to cost	1280 (100)

Note. Data are population estimates in 1000s derived from the National Center for Health Statistics.²⁹

have also revealed a negative relationship between age and compliance.^{21,22} Additional research is needed, however, before we would concur with the conclusion of Park et al. that, in terms of medication compliance, “older is wiser.”²³

Indeed, at least for the population of adults with disabilities, the more appropriate adage might be “younger is poorer” (or, at least, “younger is less likely to be insured”). Most of the 1.3 million disabled adults identified in this study would not be helped by any of the current proposals to expand Medicare drug coverage, because only 27% received Medicare. If this population were included in the

policy debate and ways were found to increase prescription drug coverage for all adults with chronic illnesses and disabilities, much of the exacerbation of symptoms and conditions found in this study—and many of the associated health care expenditures—could be avoided. ■

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Note. The analyses, interpretations, and conclusions are those of the authors and do not necessarily reflect the views of the National Center for Health Statistics, the National Institute of Disability and Rehabilitation Research, Washington State University, or the University of Illinois.

Contributors

J. Kennedy designed the study, conducted the analyses, and wrote the article. C. Erb conducted the literature review, collaborated in analysis design and interpretation, and contributed to the writing of the article.

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