Are caregivers adherent to their own medications?

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Abstract

Objective: To explore caregiver adherence to chronic medications and predictors of appropriate medication use.

Design: Descriptive, nonexperimental, cross-sectional study.

Setting: United States in May 2009.

Participants: 2,000 adults randomly selected from a large national consumer panel.

Intervention: Web-based survey of community pharmacy patients.

Main outcome measure: Self-reported medication adherence.

Results: 21% of those invited (3,775) responded to the survey invitation. Of the 2,000 individuals who were eligible to participate, 38% described themselves as caregivers. Among caregivers, 45% agreed that they were more likely to forget their own medications than medications for their caregivees. Caregivers were 10% more likely to forget to take their medications, 11% more likely to stop taking medications if they felt well, and 13% more likely to forget to refill their medications than noncaregivers ($P < 0.001$ for all). In fully adjusted models, caregivers had 36% greater odds (95% CI 0.52–0.79) of reporting that they were nonadherent compared with noncaregivers and increased medication use among caregivees was associated with worse adherence among caregivers ($P < 0.05$).

Conclusion: Medication nonadherence was common in this population, and caregivers were more likely to report poor medication adherence than noncaregivers. Considering that caregivers often engage health professionals, physicians and pharmacists may choose to screen for caregiving status. Pharmacists are uniquely positioned to intervene to enhance appropriate medication adherence.

Keywords: Caregivers, medication adherence, chronic disease.

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Patients frequently do not adhere to effective, essential chronic medications, resulting in substantial morbidity and mortality.[1–4] Annual excess health care costs resulting from medication nonadherence in the United States have been estimated at approximately $290 billion.[5] As a result, efforts to improve adherence have been widely publicized by the Institute of Medicine and others as an important public health priority.[6] However, interventions to improve adherence have demonstrated limited success,[7] and only the strategies that most comprehensively engage patients tend to succeed. A better understanding of the specific patient populations at greatest risk of medication nonadherence, and possible barriers to their appropriate medication use, can offer potential targets for future interventions.

More than 65 million Americans (28.5%) describe themselves as caregivers,[8,9] and that total may continue to increase as the population ages[8] and health insurance premiums rise. Informal or family caregivers may face particular barriers when attempting to adhere to chronic therapy because of the emotional and financial burdens of caregiving. Numerous studies have shown that caregivers experience greater psychological stress, morbidity, and mortality than noncaregivers.[9–12]

At a Glance

Synopsis: Medication nonadherence was common in a population of survey respondents self-identifying as caregivers, and caregivers were more likely to report poor medication adherence than noncaregivers. Nearly one-half of caregivers agreed that they were more likely to forget their own medications than the medications of their caregivees. Moreover, more than 50% of caregivers reported that if cost was a problem, they would forgo their own medications rather than medications for their caregivee. Compared with noncaregivers, caregivers were 10% more likely to forget to take their medications, 11% more likely to stop taking medications if they felt well, and 13% more likely to forget to refill their medications.

Analysis: *Caregiving is common in the United States, and if this population is disproportionately failing to appropriately manage their chronic diseases, interventions are needed to provide them with additional support. A dose-response relationship appeared to exist between caregiving burden and willingness to sacrifice for the caregivee; caregivers who managed incrementally more prescriptions for their caregivees were increasingly likely to report that they sacrificed their own health care needs in favor of those of the person for whom they cared. Because the caregiver likely interacts with the same pharmacist for their own care and that of their caregivee, pharmacists may be most aware of the caregiver's burden and optimally positioned to intervene and support appropriate medication use.*

Limited and dated evidence suggests that caregivers are less adherent to their own chronic medications.[13] The burden of caregiving may limit caregivers' ability to attend to their health and remember to take their medications. In contrast, caregivers often are responsible for purchasing medications for their caregivees and may have more opportunities to purchase their own medications.

Objective

Considering the large proportion of Americans who serve as caregivers, nonadherence in this population could be a central contributor to poor health and excess health care costs. A better understanding of medication adherence in this population may offer insight into their preventive health behaviors and could provide an important target for interventions to improve medication use and population health. Accordingly, we surveyed a national sample of community pharmacy users to evaluate caregiver adherence to chronic medication therapy.

Methods

We conducted a cross-sectional Internet survey of 2,000 community pharmacy patients. Survey participants were selected from the e-Rewards consumer panel.[14] The panel includes approximately 3 million consumers and has been demographically balanced to reflect the total U.S. population with regard to age, gender, annual household income, ethnicity, and geographic distribution of the population (aligned with U.S. Census regions). To be included in the study, respondents must have been aged 20 years or older and purchased at least one medication a month at a community pharmacy in the previous year.

From this frame, a random sample of 17,900 consumers, with an age and sex distribution that matched the e-Rewards panel, was selected and invited to participate via a single e-mail sent between May 27 and May 29, 2009. The e-mail included an invitation for consumers to visit a website to participate in the survey, where they were further screened for eligibility. Individuals younger than 20 years or who had purchased no medications for themselves or others at any community pharmacy were considered ineligible.

Survey instrument

The survey instrument was developed in an iterative fashion by the study authors, additional employees of CVS Caremark, and a survey consulting firm, IntelliQresearch (survey available upon request from corresponding author). The survey sought to gain an understanding of many facets of patient behavior regarding medication use and adherence, and caregiver behavior was one of the prespecified areas of inquiry. The survey was piloted for face validity and to assess survey length with 10 patients, resulting in minor revisions, but no formal validity or reliability testing was performed.

The survey instrument included questions related to general health management, prescription drug use, medication adherence, and caregiving. The general health management section included questions about annual physicals, general

health status, diet, and exercise. The prescription drug use section focused on the number of prescriptions purchased monthly by the respondent and for which conditions the prescriptions were indicated. If the respondent self-identified as the primary caregiver for another person, these questions also were asked about the caregivee's prescription medications. We chose to allow respondents to self-identify as caregivers even if they cared for their children. In addition, we captured information on the caregivee, in order to assess the full spectrum of medication use in caregivers. We chose to include parents caring for children at home as caregivers because the routines that are central to appropriate medication adherence can be altered when a child is sick. As a result, parents caring for children may be at particular risk of nonadherence at times that could be identified and targeted by pharmacists if the child's illness requires the caregiver to present to the pharmacy to purchase a prescription medication for that child.

The medication adherence section included the six questions from the modified Morisky scale[15] and questions about the impact of drug and health care costs on medication adherence. Finally, the subset of respondents who reported being caregivers were asked about the burden of caregiving and the relative priorities of caregiving responsibilities versus self-management.

All response options were closed ended and included various multiple-choice formats. Questions about events included both general category (e.g., often, sometimes, never) and precategorized frequency (e.g., none, one time, two times) formats. Questions about caregiver perceptions used a five-point Likert-type scale (1, strongly agree, to 5, strongly disagree). Completion of the interview averaged approximately 19 minutes.

Analysis

We used descriptive statistics to evaluate caregiver and noncaregiver sociodemographic and health characteristics, medication purchasing behavior for caregivers, and caregiver perceptions about health behaviors. We used chi-square tests to compare caregiver and noncaregiver reports of medication adherence, cost-related nonadherence, and participation in other healthy behaviors.

Multivariable logistic regression was used to evaluate the relation between caregiver status and other patient characteristics with reported medication adherence. The Morisky index was used to determine adherence. Scores of 0 or 1 indicated adherent behavior, while scores of 2 or greater indicated nonadherence. We also used logistic regression to assess the relation between caregiver burden and other patient characteristics through patients' responses to the question, "Do you sacrifice your own health care needs for the needs of your family." Responses of "somewhat" and "strongly" agree were combined, while responses of "somewhat" or "strongly" disagree were combined with "neither agree or disagree" for this analysis. This study was approved by the Brigham and Women's Hospital Institutional Review Board. All analyses were performed with SAS version 10.1 (SAS Institute, Cary, NC).

Results

A total of 3,775 (21.1%) people responded to the invitation. We excluded 696 individuals who responded after the survey had closed. Of the remaining 3,079 respondents, a total of 1,079 were deemed ineligible for the survey by reporting the following: age younger than 20 years (n = 7), purchasing no prescription medications for self or family on a monthly basis (n = 964), or never using a community pharmacy for purchasing prescriptions (n = 108). The remaining 2,000 completed the survey questionnaire and are included in this analysis; a usable response rate was 12%. Survey respondents were older (19% vs. 13% older than 65 years), more likely to be women (76% vs. 70%), and less likely to have an income less than $50,000 (51% vs. 62%) or to be black (12% vs. 20%) than nonrespondents, respectively.

Our sample of 2,000 respondents included 762 (38%) who described themselves as caregivers (Table 1). Approximately three-quarters of our total sample were women, and the sample included broad ranges in age, average annual income, and education level. Caregivers were more likely to be married or have a partner, were less likely to live alone, and were more likely to report full-time employment than noncaregivers. Caregivers tended to purchase fewer medications for themselves and were more likely to report that they were adversely affected by the economic downturn compared with noncaregivers (Table 1).

Caregivers most commonly reported that they care for a child (52%), spouse (42%), or parent (16%). When asked to report their own chronic diseases, the most common responses were hypertension (27%), allergies (27%), high cholesterol (22%), depression (19%), back pain (17%), arthritis (13%), thyroid disease (10%), diabetes (10%), asthma (10%), and heart disease (6%). Approximately 21% of caregivers reported taking three or more chronic medications per month. However, more than 66% of their caregivees required three or more prescription medications per month.

Caregivers commonly reported that they were more likely to forget to take their own medications than forget the medication needs of their caregivees; 45% somewhat or strongly agreed that they were more likely to forget their own medications (Figure 1). More than 50% of caregivers reported that if cost was a problem, they would forgo their own medications rather than medications for their caregivee. More than 46% of caregivers agreed with a statement that caring for their family was more important than caring for themselves, and more than 52% reported that they were more likely to sacrifice their own health than that of their caregivees. More than 53% of caregivers reported that managing the health of both themselves and their caregivees was stressful, and 52% reported eating to cope with the stress.

Caregivers were significantly more likely to report that they did not adhere to their chronic medications than noncaregivers (Table 2). Caregivers were 10% more likely to forget to take their medications, 11% more likely to stop taking medications if they felt well, and 13% more likely to forget to refill their medications than noncaregivers. Rates that caregivers and noncaregivers reported other healthy behaviors such as

Table 1. Caregiver, noncaregiver, and total sample characteristics

Demographics	Caregivers No. (%)	Noncaregivers No. (%)	Total %
n	762	1,238	
Age (years)			
20–34	191 (25.4)	214 (17.3)	20.3
35–54	364 (47.8)	350 (28.3)	35.7
55–64	129 (16.9)	375 (30.3)	25.2
≥65	78 (10.2)	299 (24.2)	18.9
Gender			
Women	582 (76.4)	930 (75.1)	75.6
Men	180 (23.6)	308 (24.9)	24.4
Marital status			
Married/partner	518 (68.0)	579 (46.8)	54.9
Single	111 (14.6)	356 (28.8)	23.4
Divorced	99 (13.0)	192 (15.5)	14.6
Widowed	29 (3.8)	100 (8.1)	6.5
Refused	5 (0.7)	11 (0.9)	0.8
Education			
Some high school	12 (1.6)	12 (1.0)	1.2
Completed high school	135 (17.7)	167 (13.5)	15.1
Some college	246 (32.3)	398 (32.2)	32.2
College	238 (31.2)	431 (34.8)	33.5
Postgraduate	125 (16.4)	228 (18.4)	17.7
Refused	6 (0.8)	2 (0.2)	0.4
Employment			
Working full time	360 (47.2)	495 (40.0)	42.8
Working part time	103 (13.5)	166 (13.4)	13.5
Retired	117 (15.4)	395 (31.9)	25.6
Seeking employment	78 (10.2)	91 (7.4)	8.5
Not seeking employment	86 (11.3)	78 (6.3)	8.2
Refused	18 (2.4)	13 (1.1)	1.6
Annual family income ($)			
<35,000	217 (28.5)	434 (35.1)	32.6
35,000–49,999	131 (17.2)	236 (19.1)	18.4
50,000–74,999	144 (18.9)	200 (16.2)	17.2
75,000–99,000	94 (12.3)	107 (8.6)	10.1
100,000–149,999	61 (8.0)	78 (6.3)	7.0
≥150,000	28 (3.7)	30 (2.4)	2.9
Don't know/refused	87 (11.4)	153 (12.4)	12.0
Living in household			
1 (living alone)	36 (4.7)	504 (40.7)	27.0
2	263 (34.5)	531 (42.9)	39.7
3	189 (24.8)	112 (9.1)	15.1
4	160 (21.0)	52 (4.2)	10.6
5	75 (9.8)	31 (2.5)	5.3
≥6	32 (4.2)	6 (0.5)	1.9
Refused	7 (0.9)	2 (0.2)	0.5
Medication purchasing			
Household medication purchasing			
All	458 (60.1)	745 (60.2)	60.2
Most	219 (28.7)	262 (21.2)	24.1
Some	85 (11.2)	231 (18.7)	15.8
Medication purchasing (self) per month			
1	298 (39.1)	365 (29.5)	33.2
2–3	254 (33.3)	455 (36.8)	35.5
≥4	210 (27.6)	418 (33.8)	31.4
Affected by recession			
No	47 (6.2)	100 (8.1)	7.4
Slightly	225 (29.5)	410 (33.1)	31.8
Somewhat	241 (31.6)	392 (31.7)	31.7
Very much	249 (32.7)	336 (27.1)	29.3

exercise, visiting their physician, and consuming a healthy diet were similar, as were proportions who described themselves as healthy.

After adjusting for age, gender, number of unique medications taken monthly (a proxy for comorbidity),[16] education, income, and marital status, caregivers had 36% greater odds (95% CI 0.52–0.79) of reporting that they were nonadherent than noncaregivers (Table 3). Younger patients, patients taking more medications, patients with only a high school education, and full-time employees all reported significantly greater odds of being nonadherent (Table 3).

Among caregivers, multivariable analyses were used to evaluate characteristics that predicted whether the caregiver reported that he/she agreed with the statement, "I sometimes sacrifice my needs for the needs of my family" (Table 4). Each additional medication a caregivee was taking was associated with a 12% increase in the odds that the caregiver agreed that he/she was more likely to sacrifice his/her own needs. Women had more than two times greater odds of sacrificing personal needs, as did the youngest caregivers and caregivers who cared for children at home (Table 4). In addition, the lowest income patients were most likely to sacrifice personal needs; patients earning less than $35,000 annually reported more than two times greater odds of agreeing with the statement compared with those who earned greater than $75,000 annually.

Discussion

We surveyed a national cohort of consumers and found that caregivers have substantial barriers to their own medication adherence. Approximately one-half of caregivers reported that they were more likely to forgo their own medications than the medication needs of their caregivees, especially if cost was a problem, and that caring for their family was more important than caring for themselves. Moreover, caregivers were significantly more likely to report nonadherence to medications than patients who were not caregivers.

One might hypothesize that caregivers would be more familiar with the health care system, more facile with insurance reimbursement and the purchasing of medications, and make more contact with pharmacies, simplifying their own medication use. However, our findings suggest that the burden of caregiving is more closely related to medication use than any gains

Table 2. Healthy behaviors in caregivers and noncaregivers[a]

Morisky scale	Caregivers No. (%)	Noncaregivers No. (%)	*P*
Careless about taking medications as prescribed?	170 (22.3)	198 (16.0)	0.0004
Forget to take medications as prescribed?	373 (49.0)	486 (39.3)	<0.0001
If feel better, stop taking medications?	245 (32.2)	265 (21.4)	<0.0001
Know long-term benefits?	311 (40.8)	364 (29.4)	<0.0001
Forget to refill medications on time?	272 (35.7)	286 (23.1)	<0.0001
Health adherence			
Get yearly physical checkups?	662 (86.9)	1,097 (88.6)	0.297
Consider self healthy?	679 (89.1)	1,084 (87.6)	0.299
Try to stick to healthy diet?			
Always	146 (19.2)	287 (23.2)	0.167
Sometimes	549 (72.1)	858 (69.3)	
Seldom	60 (7.9)	82 (6.6)	
Never	7 (0.9)	11 (0.9)	
How many workout sessions per week?			
≥4	261 (34.3)	489 (38.7)	0.109
1–3	324 (42.5)	477 (38.5)	
<1/seldom/never	177 (23.2)	282 (22.8)	
Cost adherence			
How often decide not to fill a prescription because too expensive?			
Never	500 (65.6)	980 (79.2)	<0.0001
1 time	121 (15.9)	139 (11.2)	
≥2 times	141 (18.5)	119 (9.6)	
Skip dose to make prescription last longer			
Often	35 (4.6)	39 (3.2)	0.0147
Sometimes	170 (22.3)	226 (18.3)	
Never	557 (73.1)	973 (78.6)	

[a]Comparisons with *t* tests or chi-squared tests.

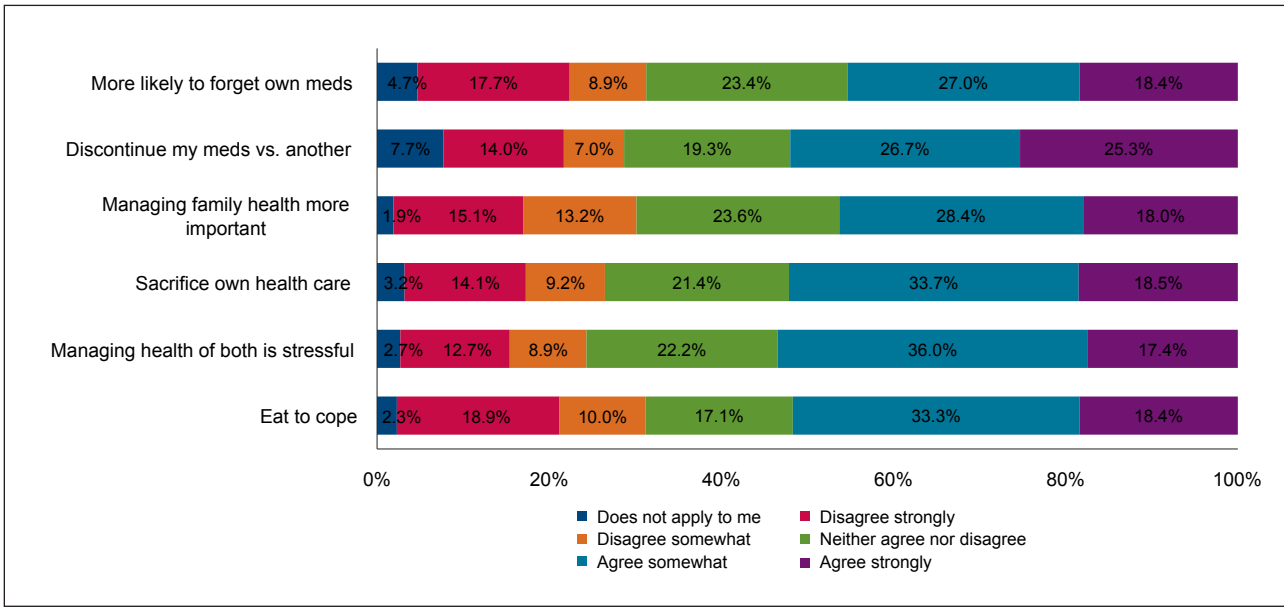

Figure 1. Caregiver perceptions about healthy behaviors

Table 3. Logisitc regression assessing correlates of medication adherence

Patient characteristic	Odds ratio (95% CI)
Caregiver	0.64 (0.52–0.79)[a]
Age (reference ≥55 years)	
20–34	0.35 (0.26–0.47)[a]
35–54	0.53 (0.42–0.68)[a]
Woman	1.18 (0.94–1.18)
Count of own medications	0.96 (0.93–0.99)[a]
Married	1.25 (0.99–1.57)
Education (reference college or higher)	
High school	0.72 (0.54–0.84)[a]
Some college	0.92 (0.73–1.16)
Full time vs. other employment	0.67 (0.54–0.84)[a]
Income (reference $75,000)	
<$35,000	0.90 (0.66–1.24)
$35,000–50,000	1.03 (0.75–1.41)
$50,000–75,000	0.87 (0.64– 1.19)

Outcome is dichotomous: adherent defined as Morisky index 0–1; nonadherent defined as Morisky index ≥2.
[a]Significant at $P < 0.05$.

Table 4. Among caregivers, predictors of agreeing with the statement, "I sacrifice my own needs for the needs of my family"[a]

Patient characteristic	Odds ratio (95% CI)
No. caregivees cared for by caregiver	1.10 (0.83–1.45)
No. caregivee prescription medications	1.12 (1.06–1.19)[b]
Age (reference ≥55 years)	
20–34	2.00 (1.19–3.37)[b]
35–54	1.87 (1.19–2.96)[b]
Gender (woman)	2.14 (1.43–3.21)[b]
No. own medications	0.96 (0.89–1.03)
Married vs. others (reference married)	1.17 (0.77–1.77)
Education (reference college or higher)	1.22 (0.75–1.98)
High school	1.22 (0.75–1.98)
Some college	0.93 (0.63–1.38)
Full time vs. other employment (reference full time)	1.42 (0.98–2.05)
Income (reference $75,000)	
<$35,000	2.12 (1.27–3.54)[b]
$35,000–50,000	1.05 (0.64–1.73)
$50,000–75,000	1.55 (0.96–2.51)

[a]Agree (includes strongly or somewhat agree) vs. disagree (includes neither, strongly, or somewhat disagree).
[b]Significant at $P < 0.05$.

in familiarity with the health care system. This conclusion is supported by the appearance of a dose–response relationship between caregiving burden and willingness to sacrifice for the caregivee; caregivers who managed incrementally more prescriptions for their caregivees were increasingly likely to report that they sacrificed their own health care needs in favor of those of the person for whom they cared.

Younger caregivers and caregivers who cared for children at home were most likely to report that they sacrificed their health care needs for their family. These patients may have the least experience with the health care system and may feel that their caregivees were most dependent on their care, and caring for children may be associated with different types of burden compared with caring for adults.

Previous studies have reported inconsistent results about the frequency with which caregivers engage in healthy behaviors or preventive screening,[17–19] and respondents to our survey were no more likely to forgo screening procedures and other healthy activities than noncaregivers. However, we are aware of only one previous study that explored caregiver medication use, albeit not as a central focus of study.[13] Similar to Burton et al.,[13] we found that medication adherence was significantly worse in caregivers. However, our study delved further into the reasons for medication nonadherence and the predictors of use, offering additional guidance to inform approaches to support caregivers.

Our results highlight an important opportunity to identify a population at particularly high risk for medication nonadherence. Unfortunately, no simple solution exists for reducing the burden that caregivers experience, and numerous studies have demonstrated the difficulty of providing assistance to caregivers.[18,20] However, caregivers frequently engage the health care system, and interventions to improve their medication use may be more fruitful. Physicians may consider a simple screening question to assess whether a patient is providing caregiving services to a family member or friend. If so, physicians should explicitly discuss the patient's medication use and consider potential barriers to medication adherence such as regimen complexity and cost. However, physicians have not been shown to be as effective as other health professionals, such as pharmacists, in delivering adherence-improving interventions.[21]

Pharmacists may play a more important role in supporting appropriate medication use because the caregiver likely interacts with the same pharmacist for their own care and that of their caregivee. As a result, the pharmacist may be most aware of the caregiver's burden and may be optimally positioned to intervene and support appropriate medication use. Pharmacists may be most aware of changes in the health of the caregivee that may increase caregiver vulnerability to changes in routines and, hence, medication nonadherence. Pharmacists must interact with caregivers in their role as caregivers on a regular basis and may be in the best position to provide additional support and counseling to these patients.

Limitations

Our study is limited by the sample we surveyed. Our response rate was suboptimal; therefore, our results should be considered exploratory and not representative of the entire population. The proportion of respondents describing themselves as caregivers in our study was higher than national estimates (38% vs. 28.5%). This difference likely is a result of the fact that patients were only eligible if they purchased a prescrip-

tion medication at a community pharmacy in the previous year, enriching our sample with caregivers. In addition, we did not exclude parents who care for healthy children at home as caregivers, as was done in other national surveys, because we were interested in how such caregiving influenced medication use as well.

We recruited respondents using an Internet survey, and patients who use the Internet and participate in such surveys may differ in important characteristics from patients who do not engage in these activities. Similarly, by requiring patients to have purchased medications from a community pharmacy, we may underrepresent patients who use mail service pharmacies exclusively. We must not use these results to attribute causality to the effect of caregiver status on medication adherence, as caregivers may differ from noncaregivers in other important ways that predict medication use. Social desirability also may have created some bias; patients may choose to report adherence that is superior to their actual behavior. However, caregivers may feel underappreciated for the services they provide, and survey responses may overestimate their frustrations.

Conclusion

We have found a compelling relationship between caregiving and medication adherence. Caregiving is very common in the United States, and if this population is disproportionately failing to appropriately manage their chronic diseases, interventions are needed to provide them with additional support. As we seek strategies to reduce health care spending and to care for patients at home, caregiving may become even more common, and the health burden of nonadherence to essential medications may increase. Our findings indicate that caregiving status may be an important characteristic for providers to identify and that caregivers may represent a fertile target for adherence interventions to improve chronic disease management and prevent chronic disease. Further research to assess how to screen for caregiving status and adherence problems among caregivers will be essential to developing and implementing interventions to improve medication use. Physicians and pharmacists may play an important role in providing education and assistance to caregivers to ensure that their health does not suffer as a consequence of their service to others.

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