







# Access and Cost-Related Nonadherence to Prescription Medications Among Lupus Patients and Controls: The Michigan Lupus Epidemiology and Surveillance Program

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**Objective.** Medication access and adherence are important determinants of health outcomes. We investigated factors associated with access and cost-related nonadherence to prescriptions in a population-based cohort of systemic lupus erythematosus (SLE) patients and controls.

**Methods.** Detailed sociodemographic and prescription data were collected by structured interview in 2014–2015 from participants in the Michigan Lupus Epidemiology and Surveillance (MILES) cohort. We compared access between cases and frequency-matched controls and examined associated factors in separate multivariable logistic regression models.

**Results.** A total of 654 participants (462 SLE patients, 192 controls) completed the baseline visit; 584 (89%) were female, 285 (44%) were Black, and the mean age was 53 years. SLE patients and controls reported similar frequencies of being unable to access prescribed medications (12.1% versus 9.4%, respectively;  $P$  was not significant). SLE patients were twice as likely as controls to report cost-related prescription nonadherence in the preceding 12 months to save money (21.7% versus 10.4%;  $P = 0.001$ ) but were also more likely to ask their doctor for lower cost alternatives (23.8% versus 15.6%;  $P = 0.02$ ). Disparities were found in association with income, race, and health insurance status, but the main findings persisted after adjusting for these and other variables in multivariable models.

**Conclusion.** SLE patients were more likely than controls from the general population to report cost-related prescription nonadherence, including skipping doses, taking less medicine, and delaying filling prescriptions; yet, <1 in 4 patients asked providers for lower cost medications. Consideration of medication costs in patient decision-making could provide a meaningful avenue for improving access and adherence to medications.

## INTRODUCTION

Systemic lupus erythematosus (SLE), or lupus, is a chronic autoimmune disease that disproportionately affects women and minorities (1). SLE disease manifestations are heterogeneous and can affect many organ systems, resulting in one of the highest mortality rates among the rheumatic diseases (2). Medical treatments for SLE place significant financial burden on

patients and the health care system. The mean annual direct costs per patient are estimated to range from \$2,214 to \$16,875, with mean annual pharmacy costs ranging between \$1,572 and \$13,138 and accounting for 19–23% of total direct costs (3,4). The mean annual indirect costs (e.g., sick leave, unemployment, housework) are estimated from \$2,239 to \$35,540 (year 2010 values), with increased costs associated with accumulated lupus damage (5).

The findings and conclusions herein are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention, the National Institutes of Health, or the Department of Health and Human Services.

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### SIGNIFICANCE & INNOVATIONS

- Inability to access prescriptions that a doctor felt necessary was reported in ~10% of systemic lupus erythematosus (SLE) cases and controls.
- Cost-related nonadherence to prescriptions is significantly higher in SLE patients compared with frequency-matched controls from the general population, with more than one-fifth of SLE patients deviating from taking medication as prescribed for cost reasons.
- Although SLE patients were more likely than controls to ask providers for lower cost medications, inquiries about lower cost medications were infrequent in both groups.
- Consideration of medication costs as part of shared decision-making between patients and providers is a potential avenue for intervention.

Poor outcomes such as increased flares, emergency department visits, hospitalizations, and renal disease have been noted in association with nonadherence in SLE, making it essential to improve understanding of factors that compromise adherence (6–11). Several studies have documented nonadherence in SLE, and a review by Costedoat-Chalumeau et al found that the most common cause of nonadherence was fear of side effects (12). However, cost-related aspects of nonadherence have not been a central focus in the existing studies.

We utilized the Michigan Lupus Epidemiology and Surveillance (MILES) cohort to characterize access and cost-related nonadherence to prescription medications and associated disparities in SLE cases and frequency-matched controls from the general population.

### SUBJECTS AND METHODS

The MILES cohort is a population-based cohort of SLE patients and controls from southeastern Michigan that was created in 2014–2015. The precursor to the MILES cohort was the MILES Surveillance Registry, one of the national US lupus registries supported by the Centers for Disease Control and Prevention, described elsewhere (1,13). Briefly, the MILES registry included residents of Wayne or Washtenaw Counties in Michigan during 2002–2005 with a new or existing diagnosis of SLE during this calendar period. The 2 counties comprising the source population for the registry encompass the cities of Detroit and Ann Arbor and a population of ~2.4 million persons (~25% of the Michigan population). Population-based controls for the MILES cohort were recruited from a random sample of households in the same source population and were frequency-matched based on sex, race, age, and geography. Due to the rarity of SLE in male patients, an equivalent number of male controls to male SLE patients were recruited. Prospective controls were excluded if they had a history of lupus or a lupus-like condition.

The Institutional Review Boards of the University of Michigan and Michigan Department of Health and Human Services Ethics provided ethics approval; cohort participants signed written, informed consent. This study utilizes baseline data from the cohort, and these visits were conducted between February 2014 and September 2015.

**Data collection.** Detailed clinical, sociodemographic, and health care access and utilization data were collected through structured interviews at the MILES baseline visit. This included questions related to prescription medication access and adherence in the preceding 12 months, modeled after a subset of questions from the 2015 US National Health Interview Survey (NHIS) for adults (14) (see Supplementary Appendix A, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.24397/abstract>). To assess prescription access, participants were asked whether they had been unable to obtain prescription medicines that they or a doctor believed necessary in the preceding 12 months, and if affirmative, the main reason why. Cost-related prescription nonadherence was a composite measure based on participant report of at least 1 of the following: skipping medication doses, taking less medicine, or delay in filling a prescription.

Race and ethnicity were based on self-report. Income was based on household pretax income in the previous calendar year. Health insurance coverage in the past 12 months was based on participant response with the following categories as options: private insurance, Medicare, Medigap (supplemental Medicare coverage), Medicaid, military, Indian Health Service, a state-sponsored health plan, other government program, or none. Persons with both private and public (e.g., Medicaid) coverage were classified as having private coverage. Patient-reported outcome measures for health-related quality of life and coexisting symptom complexes included the RAND Medical Outcomes Study Short Form 36 (SF-36) health survey (15), the Patient-Reported Outcomes Measurement Information System (PROMIS) depression short form, version 1.0 (16), and the Survey Criteria for Fibromyalgia (17).

**Statistical analysis.** Chi-square tests of independence were used to test whether there were differences in proportions between cases and controls by study characteristics. Logistic regression was used to model the association between the variables and outcomes of interest. Separate logistic regression models were used for each of the outcomes. Multivariable models were used to adjust for covariates that were determined to be potential confounders a priori. Data management was performed using REDCap electronic data capture tools hosted at the University of Michigan (18). Statistical analyses were performed using Stata and R (R Foundation) software packages.

## RESULTS

A total of 654 participants (462 SLE patients, 192 controls) completed the study visit. The mean  $\pm$  SD age of the cohort was  $53.4 \pm 12.8$  years; 584 (89.3%) of participants were female, and 285 (44%) self-reported as Black race. Baseline characteristics for the cases and controls are presented in Table 1.

**Prescription access.** A similar proportion of SLE patients and controls reported that in the last 12 months they were unable to get prescription medicines that they or a doctor believed necessary: 56 (12.1%) of SLE patients, and 18 (9.4%) of controls ( $P = 0.3$ ). The main reasons reported for being unable to get such prescriptions were similar among both patients and controls, including "Insurance company wouldn't approve, cover or pay for medicine" (34.8%) and "Couldn't afford medicine" (34.8%).

**Table 1.** Baseline characteristics of systemic lupus erythematosus (SLE) patients and frequency-matched controls, 2014–2015\*

Characteristic	SLE cases (n = 462)	Controls (n = 192)	P
Age, mean $\pm$ SD years	53.3 $\pm$ 12.3	53.6 $\pm$ 14.0	NS
Sex†			<0.001
Female	430 (93.1)	154 (80.2)	
Male	32 (6.9)	38 (19.8)	
Race			NS
White	233 (50.4)	107 (55.7)	
Black	208 (45)	77 (40.1)	
Other/unspecified‡	21 (4.5)	8 (4.2)	
Median income			NS
Below US median	198 (45.5)	70 (38.0)	
Above US median	237 (54.5)	114 (62.0)	
Poverty	87 (18.8)	45 (23.4)	NS
Insurance			NS
None	10 (2.2)	7 (3.6)	
Medicaid§	112 (24.2)	47 (24.5)	
Medicare/age <65 years	68 (14.7)	13 (6.8)	
Medicare/age $\geq$ 65 years	66 (14.3)	29 (15.1)	
Private	198 (42.9)	90 (46.9)	
Other	8 (1.7)	6 (3.1)	
No. of prescriptions at time of visit, median (IQR)¶			
Prescription medications	7 (3–11)	2 (0–5)	<0.001
Chronic prescription medications#	5 (2–9)	1 (0–4)	<0.001

\* Values are the frequency (%) unless indicated otherwise. Frequency-matched by sex, race, age, and geography. IQR = interquartile range; NS = not significant (at 0.05 level).

† Given the rarity of SLE in male patients, an equivalent number of male controls to cases was recruited; thus, the female to male ratio within controls differs compared to cases.

‡ Other/unspecified races include American Indian and Alaska Native (n = 8), Asian (n = 6), and other/unknown (n = 15).

§ Participants with dual Medicaid/Medicare coverage (73 SLE and 16 controls) were included in the Medicaid category.

¶ Number of prescribed medications reported by participant as "currently taking" at the time of study visit.

# Chronic medication use defined as  $\geq$ 3 months.

Among SLE cases, after adjusting for potential confounders in multivariable models, patients with Medicaid or no insurance were 3 to 7 times more likely than those with private insurance to report being unable to obtain medications (for Medicaid, odds ratio [OR] 3.6 [95% confidence interval (95% CI) 1.5–8.6],  $P = 0.005$ ; for no insurance, OR 7.2 [95% CI 1.6–33.2],  $P = 0.011$ ).

**Cost-related prescription nonadherence.** SLE cases were significantly more likely than controls to report the following in the preceding 12 months to save money: skipping doses, taking less medicine, delaying filling prescriptions, and asking their doctor for a lower cost medication (Table 2). Among the SLE cases, there were pronounced differences in cost-related prescription nonadherence across types of health insurance coverage: ~60% of individuals with no insurance deviated from taking medication as prescribed, compared to ~25% of individuals with Medicaid or Medicare and 16% of individuals with private or another type of insurance ( $P = 0.002$ ). Strategies used by participants to reduce costs according to health insurance type are presented in Figure 1.

Based on multivariable models (Figure 2), the odds of cost-related prescription nonadherence were nearly 3 times higher among cases versus controls after adjusting for sex, race, age, insurance status, and household income (OR 2.9 [95% CI 1.6–5.1],  $P = 0.000$ ). The odds of cost-related nonadherence remained significantly higher among cases when models were further adjusted for 6 of the 8 SF-36 health survey domains, PROMIS depression score, or fibromyalgia (OR range 1.9–2.5). SLE patients were 2–3 times as likely as controls to report the following forms of nonadherence to save money after adjusting for potential confounders: skipping medications (OR 2.9 [95% CI 1.4–6.0],  $P = 0.004$ ), taking less medicine (OR 3.7 [95% CI 1.7–7.8],  $P = 0.001$ ), and delaying filling a prescription (OR 2.1 [95% CI 1.1–4.0],  $P = 0.017$ ) (see Supplementary Figure 1, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.24397/abstract>). Among SLE patients, increasing age was significantly associated with lower odds of skipping medications (OR 0.97 [95% CI 0.95–1.0],  $P = 0.022$ ), taking less medication (OR 0.98 [95% CI 0.96–1.0],  $P = 0.048$ ), and delaying medication (OR 0.96 [95% CI 0.94–0.98],  $P = 0.000$ ) after adjusting for all covariates, whereas no association with age was found among controls.

Among SLE patients, those identifying as Black were half as likely as White participants to ask for cheaper medications (OR 0.5 [95% CI 0.3–0.8],  $P = 0.008$ ), while those of "other" (non-Black, non-White) or unknown race were 3 times more likely than White participants to delay medication (OR 3.1 [95% CI 1.1–9.0],  $P = 0.036$ ) and >6 times as likely to use alternative therapies (OR 6.5 [95% CI 2.0–21.0],  $P = 0.002$ ), accounting for covariates. SLE patients reporting household income below the US median were significantly more likely to deviate from taking medication as prescribed for all 3 approaches compared to those with household income above the US median, as follows: skip medications (OR 3.3 [95% CI 1.5–7.1],  $P = 0.002$ ); take less medication to

**Table 2.** Self-reported prescription access, cost-related nonadherence, and participant strategies used to reduce prescription drug costs within the preceding 12 months in patients with systemic lupus erythematosus (SLE) compared to frequency-matched controls\*

Interview item	SLE cases (n = 462)	Controls (n = 192)	P
Prescription access			
Unable to get prescriptions that doctor felt necessary	56 (12.1)	18 (9.4)	0.3
Cost-related nonadherence†			
Skipped medication doses to save money	62 (13.4)	12 (6.3)	0.008
Taken less medicine to save money	70 (15.2)	11 (5.7)	0.001
Delayed filling a prescription to save money	75 (16.2)	17 (8.9)	0.013
Other strategies to reduce prescription costs			
Asked doctor for lower cost medication to save money	110 (23.8)	30 (15.6)	0.02
Bought prescription from another country to save money	5 (1.08)	2 (1.04)	0.9
Used alternative therapies to save money	38 (8.2)	11 (5.7)	0.3

\* Values are the frequency (%) unless indicated otherwise.

† Composite measure including “skipped medication doses,” “taken less medicine,” and/or “delayed filling a prescription.” Participants could use >1 strategy to reduce prescription drug costs.

save money (OR 2.8 [95% CI 1.4–5.5], *P* = 0.003); and delay filling prescriptions to save money (OR 2.5 [95% CI 1.3–4.9], *P* = 0.009), again adjusting for covariates.

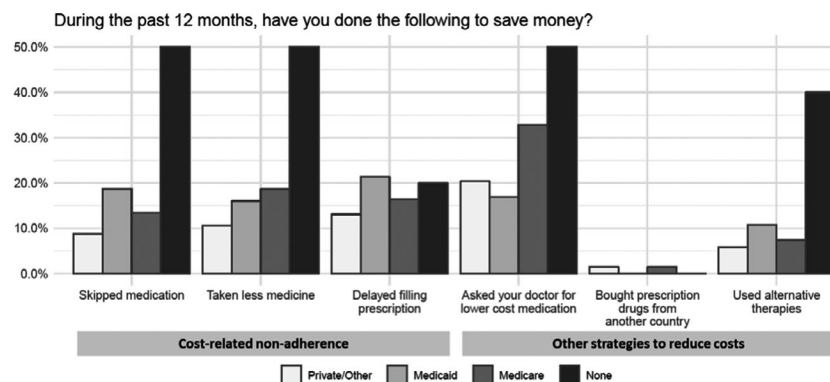
**DISCUSSION**

In this sociodemographically diverse study that included well-characterized SLE cases and frequency-matched population controls from southeastern Michigan, we found that SLE patients were more likely than controls to report cost-related prescription nonadherence as assessed by activities such as skipping medications, taking less medicine, or delaying filling a prescription. Overall, <1 in 4 participants asked their providers for lower cost medications. Disparities in cost-related adherence were found in association with household income and health insurance type.

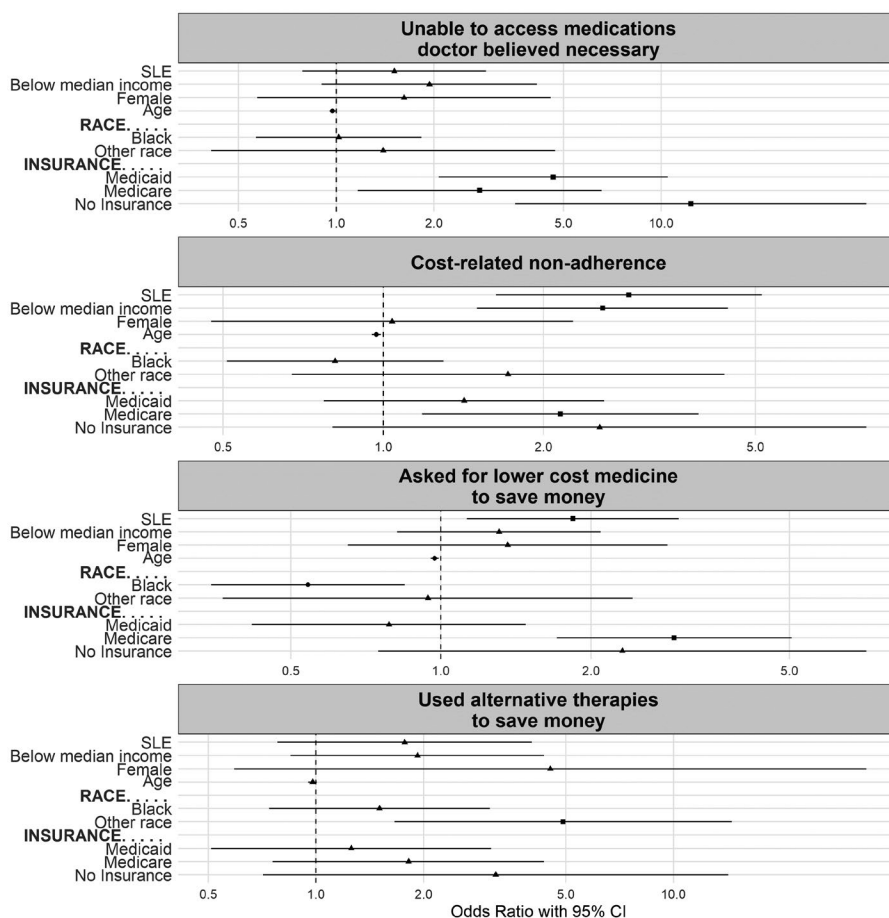
In a recent review of 11 studies, the majority reported that over one-half of SLE patients were nonadherent to therapy (19). Another review found that factors associated with nonadherence included low socioeconomic and educational status, depression, disease severity, polypharmacy, and the quality of the patient–doctor relationship (12). Our study builds on prior

work by examining cost-related aspects of nonadherence in SLE and enables comparison to population controls from the same region, as well as adults from the general US population, given that our assessment of prescription drug access included data elements in common with the NHIS (14). SLE patients in our study were more than twice as likely to deviate from taking medications as prescribed compared to the MILES controls or US adults from the NHIS over the same calendar period (20) (SLE 21.7%, MILES controls 10.4%, NHIS 8%). SLE patients more commonly reported asking a doctor for lower cost medication (23.8%) compared to our study controls (15.6%) or the NHIS adults (15.1%) (20), although only one-fourth of SLE patients do so. Black participants in our study were less likely to ask their doctor for lower cost alternatives compared to White participants. These findings, coupled with the fact that many physicians routinely overestimate costs of inexpensive medications but underestimate costs of expensive ones (21), highlight a potential opportunity not only to educate patients about medication costs but also to address a knowledge gap among rheumatologists.

Cost-related nonadherence in other patient populations has been shown to be associated with population-level prescription



**Figure 1.** Participant strategies used by patients with systemic lupus erythematosus (SLE) in the Michigan Lupus Epidemiology and Surveillance (MILES) cohort to reduce prescription drug costs according to health insurance status.



**Figure 2.** Forest plots from a series of multivariable models of factors associated with aspects of prescription medication access and adherence. The referent category for race is White, and for insurance the referent is private. Axes denoting the odds ratio (OR) are truncated from 0.35 to 10 for visualization purposes. The OR for “No Insurance” on “Unable to access medications doctors believed necessary” is ~12 and thus falls outside of this range. Additionally, the upper 95% confidence interval mark is >10 for the effect of “No Insurance” on “Unable to access medications doctors believed necessary” and for “Female,” “Other Race,” and “No Insurance” on “Used alternative therapies to save money.” Squares represent positive ORs, circles represent negative ORs, and triangles represent nonsignificant ORs; horizontal lines indicate 95% confidence intervals (95% CIs); vertical lines indicate OR = 1 (OR > 1 denotes that the event is more likely to occur, while OR < 1 denotes that the event is less likely to occur). SLE = systemic lupus erythematosus.

drug coverage, with nonadherence rates lowest in Scandinavian and western European countries and highest in the US (22). One study found cost-related nonadherence to be 43.3% for working-age adults in the US who lacked health insurance (23). A review has shown that medication costs rather than drug coverage was the more influential factor for cost-related nonadherence (24). There is a paucity of treatment options in lupus; the newest Food and Drug Administration–approved medication, belimumab, following a weight-based dosing regimen, can cost ~\$35,000 per year (25). The study findings and previous literature in other chronic diseases suggesting that cost-related nonadherence is linked to worse outcomes (26–29) support the view that medication management efforts aimed at improving adherence would benefit from including cost considerations. In diabetes mellitus, where cost-related nonadherence has been found to be 16–19% (30,31), different factors contribute based on age. A study utilizing data from the Behavioral Risk Factor Surveillance System showed

that household income and lack of health insurance were the most important factors in explaining cost-related nonadherence for diabetic patients younger than 65 years of age, while depression was the predominant factor for those older than 65 years of age (32). Such nuances will need to be evaluated further in lupus.

Nonadherence in lupus has been shown to be independently associated with worse outcomes in SLE, including increased all-cause and SLE-related emergency department visits (33) and hospitalizations (7,11). Renal disease, often asymptomatic, can insidiously progress without diligent adherence to immunosuppressive and antihypertensive medications. As expected, renal disease, and particularly end-stage renal disease (ESRD), is more common in nonadherent SLE patients (6,10). While in the US, both ESRD and mortality in lupus have been associated with race and socioeconomic status (34,35). Such disparities in lupus are less prominent in other countries. In a British inception cohort with 21 years of follow-up, race was predictive of neither



lupus damage accrual nor death (36); the authors point to the equitable access within the national UK health care system as a potential explanation for the lack of association between ethnicity and damage accrual. A US-based study by Mosley-Williams et al found that barriers to medication adherence differed between Black and White women with SLE; for instance, Black women were more likely to rely on religion and reported greater concern about long-term side effects (37). Our novel finding that individuals of “other” race (mostly Asian participants in our study) were more likely to use alternative medications to save money further suggests that cultural influences may affect adherence in lupus and warrant further study. The variable “race” should be considered a contextual variable and crude proxy for a variety of social, cultural, and biologic constructs and not interpreted simply as a risk factor or intrinsic biologic factor per se (38–41). Furthermore, it is increasingly recognized that accumulated and pervasive effects of structural racism contribute to race-associated disparities in health outcomes (42,43). Vigorous investigations will be needed to unravel the complexity of race in lupus.

This study has several strengths. It is one of the largest population-based, epidemiologic studies of a well-characterized, racially diverse, control-matched lupus population in the US. The lupus cases are therefore not restricted to patients from the tertiary care setting. Further, the comparison group is also population-based and not restricted to healthy (usually employed) controls, which increases generalizability to the underlying population.

Our study also has several limitations. First, the majority of our study population self-reported race as White or Black, which reflects regional demographics but limits generalizability of our results beyond these racial groups. Only a small percentage reported Hispanic ethnicity, so that ethnicity could not be examined. Second, many of the coverage provisions of the Affordable Care Act (ACA) took effect January 1, 2014 (44), the month prior to the start of our baseline visits that formed the basis of this study. For example, lupus patients without insurance may have purchased private coverage through the newly created Health Insurance Marketplace; yet, the 12-month period addressed in the interview questions would encompass time before such insurance took effect in January 2014. The passage of the ACA is complicated by the acceleration of cost-sharing and expansion of tiered medications systems raising costs and increasing hurdles for patient medication access (45). In light of this juxtaposition, it will be important to monitor the issue of prescription drug access and adherence as the health care landscape continues to change. In our study, questions about medication access were related to prescriptions in general, not to specific medications such as immunosuppressants, antimalarials, or antihypertensives. It is unclear how much of the lack of access and nonadherence was related specifically to medications treating underlying lupus rather than other comorbid conditions. However, lupus-specific medication questions would have precluded comparisons to controls. Finally, the degree to which self-reported nonadherence reflects actual nonadherence is unclear.

Our data from this epidemiologic study reveal that SLE patients were more likely than controls from the general population to report cost-related nonadherence to prescriptions. Disparities were found in association with income and health insurance status. Racial disparities were noted in strategies to reduce costs. Overall, <1 in 4 patients asked providers for lower cost medications. These findings point to the importance of physicians trying to ascertain adherence and being aware of medication costs to individual patients when planning treatment changes and prescribing medications, which could provide a meaningful avenue for improving medication access and adherence through shared decision-making.

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## AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Somers had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study conception and design.** Minhas, Marder, Harlow, Hassett, Gordon, Barbour, Helmick, Padua, Somers.

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**Analysis and interpretation of data.** Minhas, Hassett, Zick, Gordon, Barbour, Helmick, Wang, Lee, McCune, Somers.

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