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**To cite this article:** John D Piette, Ashley Beard, Ann Marie Rosland & Colleen A McHorney (2011) Beliefs that influence cost-related medication non-adherence among the “haves” and “have nots” with chronic diseases, Patient Preference and Adherence, , 389-396, DOI: [10.2147/PPA.S23111](https://doi.org/10.2147/PPA.S23111)

**To link to this article:** <https://doi.org/10.2147/PPA.S23111>



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Published online: 03 Aug 2011.



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# Beliefs that influence cost-related medication non-adherence among the “haves” and “have nots” with chronic diseases

John D Piette<sup>1</sup>

Ashley Beard<sup>1</sup>

Ann Marie Rosland<sup>1</sup>

Colleen A McHorney<sup>2</sup>

<sup>1</sup>Ann Arbor VA Healthcare System, Ann Arbor, MI, USA and the University of Michigan Medical School, Department of Internal Medicine, Ann Arbor, MI, USA; <sup>2</sup>US Outcomes Research, Merck and Co, Inc, North Wales, PA, USA

**Background and objective:** Some patients continue taking their medication as prescribed despite serious financial pressures, while others with the ability to pay forego treatment due to cost concerns. The primary goal of this study was to explore how patients' beliefs about the necessity of treatment and treatment side effects, influence cost-related non-adherence (CRN).

**Methods:** 27,302 participants in the Harris Interactive Chronic Illness Panel completed an internet survey. The current study focused on two subsamples representing: (a) the most economically-vulnerable survey respondents (ie, individuals with household incomes of US\$25,000 per year or less and monthly out-of-pocket medication costs of at least US\$60, n = 1321); and (b) respondents who were the most likely to have the financial resources to pay for medications (ie, those with incomes of US\$125,000 or more and monthly medication costs of less than US\$60.00, n = 1195). Multivariate models were constructed for each group to determine the independent impact on CRN of perceived need for medications and side-effect concerns. Increased risk for CRN associated with depression and asthma diagnoses also was examined.

**Results:** Twenty-one percent of economically vulnerable respondents reported continuing to take their medication as prescribed despite serious cost pressures, while 14% of high-income respondents reported CRN despite apparently manageable out-of-pocket costs. Both low perceived need for medications and concerns about side-effects affected CRN risk in low-income and high-income groups. Within groups of both low-income and high-income respondents, depression and asthma significantly increased patients' odds of reporting CRN.

**Conclusion:** Beyond objective financial measures, CRN is influenced by patient beliefs, which can influence the perceived value of prescription drugs. Addressing these beliefs, as well as the unique adherence concerns of patients with depression and asthma, could decrease CRN rates even if cost pressures themselves cannot be reduced.

**Keywords:** medication adherence, cost-of-care, access to care, chronic disease

## Introduction

Objective financial measures, such as income or out-of-pocket (OOP) copayment costs, explain only a minority of the variance in cost-related non-adherence (CRN) behavior. Some patients are sensitive to OOP medication cost changes even when those changes are modest, while many patients continue to report that they do not reduce their medication due to cost concerns, even when they have a limited ability to pay for treatment.<sup>1-3</sup>

Possible modifiers of patients' risk for CRN include diagnoses, medication-related beliefs, and communication patterns with clinicians about medications.<sup>4</sup>

Correspondence: John D Piette  
Department of Internal Medicine,  
University of Michigan, 300 N.  
Ingalls Bldg, Rm 7E10 Ann Arbor,  
MI 48109-5429, USA  
Tel +1 734 9364787  
Fax +1 734 936-8944  
Email [jpiette@umich.edu](mailto:jpiette@umich.edu)

Concerns about medication side-effects have been cited as a cause of intentional non-adherence,<sup>5-7</sup> and low-income patients often express concerns about the perceived need for their medication as well as potential adverse effects.<sup>8</sup> Other studies confirm that both perceived need and side-effect concerns may affect overall medication adherence.<sup>9-13</sup> Few prior studies have directly looked at the relationship between perceived risks and benefits of therapy as determinants of CRN.<sup>14</sup> Studies addressing this association suggest that factors such as patient-clinician communication patterns<sup>15-17</sup> and an overall depressive mood<sup>18</sup> can influence adherence when patients are facing financial pressures. Most prior studies examining the influence of these beliefs on CRN have averaged effects across a broad spectrum of patients with diverse financial resources. Such studies leave questions unanswered about the ways in which mutable cofactors (such as patient health beliefs) influence CRN behaviors differently among patients with low incomes, compared with those who have the resources to pay for their prescription drugs.

Understanding modifiable co-factors for CRN among low-income and high-income individuals with chronic diseases is important for several reasons. If beliefs affecting patients' valuation of their treatments play an important role for low-income patients, it may be possible to reduce CRN behavior even if patients' ability to pay cannot be improved. Moreover, by estimating the proportion of higher-income patients reporting CRN and the non-cost factors determining that behavior, we can begin to estimate the proportion of the CRN among low-income patients that would remain if incomes were raised or medication benefit programs expanded. Finally, both low-income and high-income patients who report non-adherence due to "cost" may be expressing more general concerns about their treatment that could be addressed through improved patient education and open discussion about their medication's necessity or risk of side-effects.

The purpose of the current study was to understand the health beliefs that modify patients' risk for CRN using a large national survey of patients with serious chronic health problems. We focused on influences of patients' CRN within two subgroups representing the greatest and least OOP medication cost pressures: individuals with low incomes and relatively high OOP costs, and individuals with high incomes and relatively low OOP costs. Within each group, we examined patients' perceived need for medication as well as their concerns about side effects as two possible influences on their likelihood of forgoing treatment due to cost concerns. We also examined the independent contribution to CRN

of two chronic diseases with symptom-based treatments (depression and asthma) which have been associated with higher CRN risk in prior studies.<sup>19,20</sup> Our hypothesis was that – even in groups at the extremes of the distribution in terms of medication cost pressures – medication beliefs and symptom-based treatment issues play important and roughly consistent roles in patients' CRN.

## Methods

### Study population

The study was approved by the George Mason University Institutional Review Board. Study participants were part of the Harris Interactive Chronic Illness Panel (CIP), which is a national, internet-based panel of adults with chronic diseases. CIP participants are recruited through postal mail invitations, TV advertisements, telephone recruitment for under-represented populations, email, and websites, eg, social media sites, news sites, search engine sites, and community portals. Panel recruitment efforts are focused on maintaining a representative sample of the general population as well as identifying and reaching under-represented groups.

In February and March of 2009, randomly selected members of the CIP were sent an e-mail invitation to participate in the survey. Panel members were eligible for participation if they were aged 40 and older, resided in the US, and reported one of six chronic diseases prevalent among US adults: hypertension, hyperlipidemia, diabetes, asthma, osteoporosis, and depression. Of the 51,774 CIP panel members who were US residents aged 40 or older and who completed the chronic-disease screener, 27,302 persons with chronic diseases (53%) completed the survey. CIP members who were successfully contacted were more likely than members who were not reached, to be aged 50 or older, male, white, college educated, and of higher income (all  $P < 0.0001$ ).

We used self-reported income and OOP medication cost data to identify two contrasting groups with respect to their potential ability to pay for prescription medication. The first group represented the most economically-vulnerable respondents, ie, those reporting annual household incomes of US\$25,000 or less and monthly OOP medication costs of US\$60.00 or higher. OOP payments were used as the measure of cost pressures rather than information about patients' drug coverage because: (1) details about individual benefit packages in this national survey were not available; (2) OOP payments represent the net impact of any pharmacy benefit respondents may have had; (3) OOP payments are a more direct determinant of individuals' CRN. The second subgroup represented economically-advantaged individuals, ie, those

who reported an annual household income of US\$125,000 or more and relatively low OOP medication costs of US\$60.00 per month or less. The US\$60.00 cut-off was chosen because it approximated the median of the OOP medication cost distribution. The findings presented here were not sensitive to other cut-offs for OOP medication costs (see auxiliary analyses presented below).

## Measures

Data about participants' sociodemographic characteristics (age, gender, educational attainment, and race/ethnicity) were available from information they provided when enrolling in the CIP. Participants responded to a series of CRN questions regarding strategies adults use to reduce medication use in order to minimize out-of-pocket costs. Items were adapted based on measures in prior surveys conducted by the Medicare Current Beneficiary Survey, the AARP (formally known as the American Association of Retired Persons), the Kaiser Family Foundation, and other groups.<sup>12,16,21–29</sup> The role of cost in patients' adherence behavior was emphasized using the question stem: "In 2008, because of the cost of all of [your] prescription medications..." Questions asked respondents about the frequency with which they engaged in six cost-reducing strategies including: "I delayed a new prescription fill because I couldn't afford it," "I took fewer pills than prescribed or skipped doses in order to make the prescription last longer," and "I stopped taking one or more of my prescription drugs altogether because I could not afford them." The frequency of each cost-reducing strategy was measured using a five-point scale ranging from "Yes, very often" to "No, never." For analyses presented here, we created a binary measure for any reported CRN across the 6 behaviors. We also created separate measures representing: (a) CRN behavior that involved decreasing the frequency of adherence, ie, "took fewer pills or skipped doses," "delayed filling a new/existing prescription" and "split pills in half to make them last longer"; and (b) not taking a medication at all, ie, "stopped taking a prescription altogether" or "did not fill a new prescription because I could not afford it."

Patients' beliefs about their medication were reported using a series of questions asking about respondents': perceived need for medication (ten items), concerns about side-effects (six items), and perceived information/knowledge about their prescriptions (four items). The medication belief questions were answered specific to the condition for which the respondent was enrolled in the sample. For example, patients whose index condition was diabetes were asked about their beliefs about their "diabetes" medication.

Participants responded to belief items using a six-point Likert scale from "agree completely" to "disagree completely." We created summary measures for beliefs about medication necessity, side-effects, and perceived information by averaging item responses within that domain. Alpha reliability measures for the summary scores were each 0.90 or higher. To provide more interpretable odds ratios in the multivariate logistic models, summary scores were categorized into tertiles (eg, a low, moderate, or high-level of side-effect concern).

## Analysis

Initial analyses focused on differences between low-income/high-OOP and high-income/low-OOP groups in respondents' demographic characteristics, chronic diseases, CRN behaviors, and medication beliefs. Multivariate logistic models were fit within each group to determine the independent effect of medication beliefs, controlling for patients' age, gender, and educational attainment. Initial multivariate models included the three trichotomized measures of health beliefs (perceived need, side-effects, and knowledge). Knowledge scores had no independent effect on CRN and were dropped from subsequent analyses. Each model also included indicators for the 6 chronic diseases defining patients' eligibility for the survey. As predicted by prior research,<sup>20,30–32</sup> the two symptomatic chronic diseases, depression and asthma, were associated with substantially higher rates of CRN and were retained in the final models. Controls for confounding in each model included patients' age, gender, and educational attainment.

## Results

### Sample description and CRN behaviors

The sample was predominately white with a mean age of 60 (Table 1). Low-income respondents were more than twice as likely as high-income respondents to be female and were less than one-third as likely to have a college degree. Low-income respondents were substantially sicker on average: 64% reported fair or poor health (compared to 15% of respondents with high incomes and low costs), 40% of low-income respondents reported taking four or more prescriptions (compared to 13% of respondents with high incomes and low cost), and substantially more low-income than high-income respondents reported asthma (26% vs 11%), depression (44% vs 14%), diabetes (36% vs 18%), and osteoporosis (18% vs 7%, all  $P < 0.001$ ).

Overall 79% of low-income respondents with high OOP medication costs reported some CRN, while the

**Table 1** Patient characteristics

	Low income high OOP	High income low OOP	P-value
N	1,321	1,195	
Age (mean, SD)	60.5, 9.6	59.5, 8.8	0.007
Female (%)	67.3	33.8	<0.001
White (%)	93.4	93.7	0.77
College degree (%)	23.4	74.7	<0.001
Employment status (%)			<0.001
Employed	21.8	59.2	
Retired	35.8	26.4	
Unemployed	42.3	14.4	
Fair/poor health (%)	64.4	15.3	<0.001
Number of Rx (%)			<0.001
1	22.2	39.8	
2	20.8	30.4	
3	17.5	16.6	
4+	39.5	13.2	
Chronic diseases (%)			
Asthma	26.4	10.5	<0.001
Hypertension	63.6	67.1	0.07
Depression	44.3	14.1	<0.001
Diabetes	36.2	18.4	<0.001
Hyperlipidemia	44.9	38.8	0.002
Osteoporosis	18.3	7.3	<0.001

**Note:** Percents are column percents.

**Abbreviations:** OOP, out-of-pocket medication costs; Rx, prescriptions.

remaining 21% did not report modifying their adherence despite their limited ability to pay (Table 2). As expected, significantly fewer high-income respondents with low OOP costs reported CRN, although 14% still reported cutting-back on their medication due to cost concerns. Low-income respondents reported a variety of strategies to avoid medication costs including delaying a prescription fill (72%), stopping a prescription all-together (48%), and not filling a new prescription at all (59%). The most common CRN behavior among high-income respondents was

**Table 2** Cost-related non-adherence (CRN) behaviors

	Low income high OOP	High income low OOP	P-value
Any CRN (%)	79.0	14.4	<0.001
<b>Delaying</b>			
Delayed filling a prescription (%)	72.0	6.5	<0.001
Split pills/take fewer doses (%)	64.1	11.0	<0.001
<b>Stopping</b>			
Stopped taking Rx altogether (%)	47.9	2.5	<0.001
Did not fill a prescription at all (%)	59.3	3.5	<0.001

**Note:** Percents are column percents.

**Abbreviations:** OOP, out-of-pocket medication costs; Rx, prescriptions.

splitting pills or taking fewer doses to make a prescription last longer (11%).

## Differences across income groups in beliefs about medications

A substantial number of all respondents either “agreed” or “strongly agreed” with beliefs about the prescription medication prescribed for their index condition that could affect their risk for CRN. Low-income respondents were less likely than high-income respondents to agree that they needed their medication, with fewer agreeing that the medication would improve their condition (64% vs 75%,  $P < 0.001$ ) or that the benefits of the medication outweighed the risks (62% vs 73%,  $P < 0.001$ ). Despite using more medications, low-income respondents were somewhat less likely than high-income respondents to report that they were well informed about the prescription medication related to their index disease (69% vs 74%,  $P < 0.001$ ). Substantially more low-income than high-income respondents reported that they worried about the side-effects of their prescriptions (20% vs 10%,  $P < 0.001$ ), and more than three times as many low-income respondents agreed that they are likely to experience negative side effects from their medications (17% vs 5%,  $P < 0.001$ ). With respect to summary scores, high-income patients on average reported higher medication need, greater knowledge about their treatments, and fewer concerns about medication side-effects (each  $P < 0.05$ ).

## Impact of health beliefs on CRN behaviors

In multivariate models among respondents with low incomes and high OOP costs, respondents with the lowest perceived need for their medication had 50% greater odds of CRN than patients with the greatest perceived need (Table 3, adjusted odds ratio [AOR]: 1.5, 95% CI: 1.2–1.8). Independent of perceived need and other covariates, low-income respondents with high OOP costs had 80% greater odds of CRN if they had a high level of side-effect concerns (AOR: 1.8, 95% CI: 1.2–2.8). Perceived need played an even larger role in the CRN behaviors of respondents with higher incomes and relatively manageable OOP medication costs. In this group, respondents reporting low perceived need for their medication were 2.1 times as likely to report CRN as those with high perceived need (95% CI: 1.3–3.4). Among high-income/low-OOP respondents, those reporting a high level of side-effect concerns had 2.3 times odds of CRN as those with low concerns (95% CI: 1.4–3.7). Depression and asthma influenced CRN decisions for both



**Table 3** Adjusted odds ratios predicting overall cost-related non-adherence

	Low income high OOP	High income low OOP
<b>Medication beliefs</b>		
Need (moderate)	1.1 (0.8, 1.7)	1.9** (1.2, 3.0)
Need (low)	1.5** (1.2, 1.8)	2.1** (1.3, 3.4)
Side effects (moderate)	1.4* (1.0, 2.1)	1.3 (0.9, 1.9)
Side effects (high)	1.8** (1.2, 2.8)	2.3** (1.4, 3.7)
<b>Diagnoses</b>		
Depression	1.8** (1.3, 2.5)	2.0** (1.3, 2.9)
Asthma	1.6** (1.1, 2.3)	2.0** (1.3, 3.2)
Pseudo R-square	0.10	0.12

**Note:** Models controlled for patients' age, gender, and educational attainment.  
\* $P < 0.05$ ; \*\* $P < 0.01$ .

**Abbreviations:** OOP, out-of-pocket medication costs; Rx, prescriptions.

low-income/high-OOP respondents and those with high incomes/low OOP.

The overall pattern shown in Table 3 was observed both for CRN behaviors involving taking less medication as well as those involving either stopping a medication altogether or failing to fill a prescription at all (Table 4). In general, perceived need and side effect concerns influenced

**Table 4** Adjusted odds ratios predicting cost-related non-adherence by subtype

	Slow		Stop	
	Low income high OOP	High income low OOP	Low income high OOP	High income low OOP
<b>Medication beliefs</b>				
Need (moderate)	1.3 (0.9, 1.9)	2.0** (1.3, 3.3)	1.1 (0.8, 1.6)	1.6 (0.7, 3.8)
Need (low)	1.5** (1.2, 1.9)	2.2** (1.3, 3.6)	1.4* (1.0, 2.0)	2.5* (1.1, 5.8)
Side effects (moderate)	1.4* (1.0, 2.0)	1.3 (0.9, 1.9)	1.1 (0.8, 1.5)	1.0 (0.5, 2.0)
Side effects (high)	1.7** (1.1, 2.5)	2.4** (1.5, 3.8)	1.8** (1.3, 2.6)	2.0* (1.0, 4.4)
<b>Diagnoses</b>				
Depression	1.8** (1.3, 2.4)	1.9** (1.3, 2.9)	1.4** (1.1, 1.9)	2.2* (1.1, 4.1)
Asthma	1.5* (1.0, 2.2)	2.0** (1.3, 3.1)	1.5** (1.1, 2.0)	2.1** (1.1, 4.1)
Pseudo R-square	0.10	0.12	0.12	0.12

**Notes:** Slow = cost-related non-adherence involving taking less of ongoing prescriptions by (eg, taking fewer pills or delaying the time until refill); Stop = not filling a prescription at all due to cost concerns or stopping medication use completely. Models controlled for patients' age, gender, and educational attainment. \* $P < 0.05$ ; \*\* $P < 0.01$ .

**Abbreviations:** OOP, out-of-pocket medication costs; Rx, prescriptions.

both types of CRN behaviors in the low-income and high-income groups. Depression was associated with a significantly increased risk of CRN among both low-income and high-income respondents. Asthma diagnosis also was associated with a substantially increased risk, particularly among participants with high incomes and relatively low OOP costs.

## Auxiliary analyses

As noted in the Methods, participants reported CRN behavior with respect to all of the medication in their regimen, while medication beliefs questions focused on their main diagnosis determining eligibility for the study. In auxiliary analyses, we re-fit each model within the subset of respondents with no more than four medications, ie, those for whom a larger proportion of their regimen was targeted to their index chronic disease. Overall findings were similar to those presented here.

As noted earlier, we used US\$60.00 per month to define groups "high" vs "low" monthly medication costs. The pattern of effects presented here was not sensitive to other cut-offs in the range of US\$40 to "greater than US\$100" per month. For example, among low-income patients with monthly OOP costs in excess of US\$100 ( $n = 931$ ), patients with the greatest concerns about side-effects had twice the odds of CRN as other low-income patients (AOR: 2.0, 95% CI: 1.2–3.2), controlling for the covariates show in Table 3. In that same subsample, depression was associated with a 40% increased odds of CRN, and asthma was associated with a 60% increased odds (both  $P < 0.05$ ). We conclude that even at very high levels of cost pressures, non-cost factors continue to influence low-income patients' risk of "cost-related" medication underuse.

Although the main purpose of choosing these two subgroups was to explore the impact of health beliefs in groups with very different cost pressures, in additional analyses exploring other combinations of income and OOP costs, we observed similar findings. For example, perceived need and side-effect concerns also played a similar role as determinants of patients' risk of CRN among patients with low incomes and low OOP costs, as well as among patients with high incomes and high (>US\$100 per month) OOP costs.

## Discussion

### "Have nots" who bear medication costs and "haves" who report CRN

While most respondents with household incomes of US\$25,000 or less and relatively high OOP medication

costs reported CRN, 21% continued to take their medication as prescribed despite cost pressures. Cost pressures were significantly less for participants with incomes of US\$125,000 or more (2.5 times the national median) and lower OOP medical costs. Nevertheless, 14% of this group still reported some cost-related non-adherence.

## What factors modify patients' response to cost pressures?

Results from the current study demonstrate that factors affecting patients' valuation of their medication – particularly their beliefs about their medication's necessity as well as concerns about side effects – influenced their decisions to forgo treatment in the context of cost pressures. Among patients with low incomes and high costs, both perceived need and side-effect concerns can tip the scales toward CRN. These beliefs play similar roles in the adherence decisions of individuals with a substantially greater ability to pay for their treatment. Overall, these findings suggest that decisions about non-adherence due to cost are influenced by some of the same determinants that influence non-cost-related adherence behaviors. Factors such as the patient's perceived susceptibility to disease complications, the medication's perceived efficacy, and the perceived link between medication use and side effects all play a role in patients' choice to forgo treatment when faced with cost pressures.<sup>9</sup>

Patients' beliefs about their medications' necessity and side-effect profile can be addressed in multiple ways. Many patients with chronic illnesses are prescribed more medication than is appropriate, providing little added benefit to justify the increased OOP costs and associated risk of drug–drug interactions.<sup>33</sup> Prescribers should carefully consider patients' regimen in its entirety and ensure that all pharmacotherapy is justified both clinically and in terms of the costs that patients must bear. Patients may be more likely to question a medication's importance for their health if they lack trust in their prescriber or have poor communication with that clinician.<sup>16,17</sup> Raising issues such as potential medication benefits or side-effect concerns may improve that level of trust and consequently increase patients' willingness to take their medication as prescribed despite cost pressures.

Depression and asthma diagnoses played significant roles in determining CRN for both low-income and high-income respondents. Pessimism about the future and fatalism about one's ability to control outcomes are hallmarks of depression, and this study suggests that those cognitions may increase patients' risk of forgoing treatment due to concerns about

the value of their treatment. Primary care providers should consider targeting patients with depression for more explicit conversations about medication cost concerns. More generally, these results highlight the importance of treating patients' depression effectively through counseling, pharmacologic management, or both.<sup>34–36</sup> One study has shown that Medicare patients on inhaler medications for chronic pulmonary disease may be at higher risk of CRN than patients using other medications.<sup>37</sup> Other studies confirm that costs play a role in asthma treatment adherence, although it is likely that costs interplay with other characteristics of the regimen in influencing patients' behavior.<sup>38,39</sup> Given that patients with more severe asthma are also more likely to suffer depressive symptoms,<sup>40</sup> greater attention to the ways in which patients with these chronic illnesses make decisions about adherence when facing out-of-pocket costs should be a priority for research.

## How valid are these comparisons of CRN between the “haves” and “have nots”?

As shown in Table 1, low-income and high-income groups in the current study were very different on multiple dimensions including their sociodemographic characteristics, medication use, and diagnoses. Other factors, such as patients' health literacy levels,<sup>41</sup> undoubtedly also vary across the groups and may have a strong impact on health beliefs and CRN. In the current study, we have addressed these differences in three ways: (a) by controlling for gender, age, diagnoses, and educational attainment in multivariate models; (b) by conducting auxiliary analyses that examined the relationships of interest within the subgroup of respondents on no more than four medications; and (c) by examining the relationships of interest using other cut-offs for OOP costs and using other combinations of cost and income (eg, within the subgroup of patients with high incomes and high costs). Nevertheless, residual differences in health literacy, disease severity and other factors likely remain. Despite these measured and unmeasured differences between the income groups, both perceived need and side-effect concerns played consistent and largely similar roles in patients' CRN. We believe that this is one of the most important and striking findings from this study, and that it is one which is valid despite the study's limitations.

## Limitations and conclusions

While data were drawn from a large, national sample, individuals less likely to be represented in this Internet-based

survey (specifically lower-income patients, those with lower health literacy levels, and those more likely to be racial/ethnic minorities) may differ with respect to the influence that their health beliefs have on their risk for CRN. Beliefs questions in this study focused on the main condition for which patients were identified, while CRN questions focused more broadly on patients' overall non-adherence due to cost concerns. Initial analyses found little variation in CRN independently associated with asymptomatic chronic conditions, and controlling for depression and asthma minimized the potential confounding effect of diagnosis on the beliefs-CRN relationship. Overall, variation in patients' beliefs across different medications in their regimen would tend to lessen the magnitude of the relationships observed, suggesting that perceived medication necessity and side-effect concerns may play an even larger role in CRN than what is suggested here. Other medication beliefs besides those related to treatment necessity or side-effects may also play a role in patients' risk for CRN. For example, patients may find their medication-taking inconvenient or that their medication use draws attention to their illness in a way that adversely affects their self-image. Finally, the relationship between patients' beliefs and CRN may differ for patients with other chronic diseases not captured in the current study, such as patients with irritable bowel disease, chronic low back pain, or HIV/AIDS. Future studies, including those using qualitative methods, those with objective measures of patients' adherence behavior and prescription drug costs, and those including some of the conditions mentioned above would be useful to explore more fully the ways in which patients' beliefs impact their willingness to pay for their prescription medications.

In sum, this study suggests that even at the extremes of the continuum representing patients with a high degree and low degree of medication cost pressures, there is substantial variation in patients' adherence. CRN decisions in both of these groups are influenced by non-cost factors, including patients' concerns about the necessity of their treatment and side-effects. Depression and asthma diagnoses also influences patients' risk for CRN, independent of costs, these beliefs, and sociodemographic covariates. While efforts to increase the affordability of essential medications remains critically important, addressing these beliefs as well as the unique issues among patients with symptom-based regimens also should be the focus of efforts to prevent CRN.

## Disclosure

The authors report no conflicts of interest in this work.

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