

# Nonadherence Labeling in Primary Care: Bias by Race and Insurance Type for Adults With Type 2 Diabetes



Sourik Beltrán, BA,<sup>1,2</sup> Lanair A. Lett, MBIostat,<sup>1,3,4</sup> Peter F. Cronholm, MD, MSCE<sup>4,5,6</sup>

**Introduction:** Little is known about how provider bias can influence nonadherence labeling. Therefore, a retrospective cohort analysis was conducted to assess the risk of patients with Type 2 diabetes being labeled nonadherent by sociodemographic factors.

**Methods:** Patients with Type 2 diabetes were identified from 4 primary care sites of the University of Pennsylvania Health System. Demographics, HbA1c, and ICD-10 codes for Type 2 diabetes and nonadherence were extracted from the electronic health record and analyzed in October 2017. Log-binomial regression models were used to estimate patients' risk of nonadherence labeling by race, age, sex, BMI, and insurance payer while controlling for HbA1c as a proxy for medication use.

**Results:** This study included 3,768 adults aged 18–70 years with Type 2 diabetes who received care from 1 of 4 primary care sites at University of Pennsylvania from 2014 to 2017. An increased risk was found for black patients relative to white patients (RR=2.86, 95% CI=1.91, 4.27) and Medicaid (RR=1.8, 95% CI=1.45, 2.22) or Medicare (RR=1.69, 95% CI=1.36, 2.1) relative to private insurance to be labeled as nonadherent while adjusting for HbA1c. Though statistically insignificant, Hispanic patients also showed increased risk of nonadherence labeling. BMI, age, and sex showed no association.

**Conclusions:** Black race and nonprivate insurance status were shown to be associated with increased risk of nonadherence labeling. The findings may indicate a concerning bias among providers in their perception of patient behavior by race and insurance.

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## INTRODUCTION

Nonadherence is a common clinical term often used to describe patient behavior that is perceived by healthcare providers as poor self-management. Whether related to medication use or lifestyle factors, patients' lack of engagement in care for their chronic disease has major implications, responsible for an estimated \$100 billion annually in healthcare costs and linked to 33%–69% of all medication-related hospitalizations.<sup>1,2</sup> In those with Type 2 diabetes mellitus (T2DM), low engagement in care has been associated with greater all-cause mortality, more frequent complications, and annual costs of up to \$24.6 billion.<sup>3–6</sup> The causes and correlates of patient disengagement from diabetes care have been extensively documented. However, though much of

the literature has focused on medication taking and patient lifestyle, a number of recent works have elucidated how the language used to describe patient behavior can

From the <sup>1</sup>Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania; <sup>2</sup>Department of Medical Ethics and Health Policy, University of Pennsylvania, Philadelphia, Pennsylvania; <sup>3</sup>Department of Biostatistics, Epidemiology, and Informatics, University of Pennsylvania, Philadelphia, Pennsylvania; <sup>4</sup>Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia, Pennsylvania; <sup>5</sup>Center for Public Health Initiatives, University of Pennsylvania, Philadelphia, Pennsylvania; and <sup>6</sup>Department of Family Medicine and Community Health, University of Pennsylvania, Philadelphia, Pennsylvania

Address correspondence to: Sourik Beltrán, BA, University of Pennsylvania, Jordan Medical Education Center, 6th floor, 3400 Civic Center Blvd, Philadelphia PA 19104. E-mail: [sourik.beltran@penmedicine.upenn.edu](mailto:sourik.beltran@penmedicine.upenn.edu)  
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also affect chronic disease management. For example, physician labeling of patients as nonadherent has been shown to delay necessary increases in therapeutic intensity in both HIV/AIDS and T2DM care.<sup>7,8</sup> Additionally, such perceptions can lead to paternalistic attitudes as well as overall worse care.<sup>9,10</sup>

Although several clinical tools have been developed to quantify patients' level of engagement with chronic disease management, healthcare providers tend to rely on their subjective inferences to assess patient behavior.<sup>11,12</sup> Providers' attitudes about patients can be influenced by sociodemographic factors, potentially leading to bias related to race, class, gender, or weight.<sup>13–16</sup> Similar trends have been suggested regarding perceptions of patient self-management. Lutfey et al.<sup>17</sup> demonstrated that, though patient self-assessment of medication use did not differ by sex, race, or age, provider perception of patients' medication taking varied widely along the same characteristics. Similarly, the work of Bogart and colleagues<sup>18</sup> showed that, even when controlling for other demographic and clinical factors, physicians were more likely to describe black men as nonadherent to antiretroviral therapy than their white peers. Huizinga et al.<sup>19</sup> demonstrated a parallel disparity for obese patients and antihypertensive medications.

Studies exploring healthcare providers' perceptions of patient engagement with chronic disease care have focused largely on physician accounts of patient behavior rather than how such attitudes may manifest specifically in the inclusion of nonadherence language in patients' medical records. Furthermore, few studies have explored provider perceptions of patient behavior in terms of potential bias in the context of T2DM. Therefore, a multisite, retrospective cohort analysis was performed to identify the risk of adult patients with T2DM being labeled as nonadherent by race, sex, age, BMI, and insurance status while controlling for HbA1c as a proxy for medication use.

## METHODS

### Study Population

The study sample was defined as the population of T2DM patients, aged 18–70 years, who received care between 2014 and 2017 at any of 4 primary care practices within the University of Pennsylvania Health System. Patients with ICD-10 code E11 (T2DM), in either their active problem list or past medical history electronic health record (EHR) fields, were treated as having T2DM. Additional attributes extracted from the EHR included demographics (i.e., age, sex, race, BMI, height, weight, and insurance provider), HbA1c, and ICD-10 codes for nonadherence labeling. All data were extracted from the EHR and analyzed in October 2017 following IRB approval for this study obtained on October 17, 2017 from the University of Pennsylvania.

### Measures

The primary outcome, nonadherence labeling, was assigned to any patient with an ICD-10 code within 2 general ICD-10 nonadherence diagnoses: ICDZ91.1 (“patient’s noncompliance with medical treatment and regimen”) or ICDZ53.2 (“procedure and treatment not carried out because of patient’s decision for other and unspecified reasons”) in their active problem list or past medical history. The use of these codes is up to individual clinicians who may decide to add a diagnosis of nonadherence to patients’ charts for a variety of reasons. ICD-10 subcodes noting specific reasons for the use of the label were not differentiated and were instead pooled within the 2 aforementioned ICD-10 codes. Race was characterized as black or white, with other racial groups being excluded. Ethnicity characterized patients as Hispanic or non-Hispanic. Patients were categorized by BMI as normal ( $\geq 18.5$  and  $< 25$ ), overweight ( $\geq 25$  and  $< 30$ ), or obese ( $\text{BMI} > 30$ ). HbA1c was dichotomized to differentiate patients with  $\text{HbA1c} \leq 7\%$  and patients with  $\text{HbA1c} > 7\%$  for stratified analysis. Insurance status was categorized as private, Medicare, or Medicaid.

### Statistical Analysis

Sample characteristics were summarized with medians and IQRs for continuous predictors and counts and percentages for categorical predictors. Difference between strata was tested with the Wilcoxon rank-sum test for continuous predictors and chi-square test for independence for categorical predictors at the Type I error rate ( $\alpha$ ) of 0.05. To determine the association between risk of nonadherence labeling and patient characteristics, univariable log-binomial regression models were used to estimate crude RRs to avoid overestimating risk given the prevalence of nonadherence labeling ( $> 10\%$ ) in the cohort.<sup>20</sup> For the primary aim, the overall cohort and HbA1c-stratified categories were analyzed to determine if there was association modification between populations of patients who had  $\text{HbA1c} > 7\%$  or  $< 7\%$ . Patients were stratified by HbA1c to examine association modification rather than including product terms given concerns of being underpowered for second-order regression terms and failing to identify meaningful modification based on statistical significance alone.<sup>21</sup> HbA1c was included as a continuous predictor to assess associations between HbA1c and nonadherence labeling directly, overall, and within strata. Age, BMI, sex, race, ethnicity, insurance status, and HbA1c were included in adjusted models.

The following sensitivity analyses were also performed:

1. Separate and adjusted models for each of the ICD-10 codes used as markers of nonadherence labeling to determine if they have comparable relationships with predictors; and
2. Adjusted models that included an indicator variable for treatment site to explore site-specific variation.

For all models, estimated RRs and 95% CIs are reported. CIs that do not span 1 indicate statistical significance at a Type I error rate ( $\alpha$ ) of 0.05. All statistical analyses were conducted in R, version 3.5.3.

## RESULTS

A total of 4,167 patients with T2DM, aged 18–70 years, were treated at 3 Internal Medicine sites ( $n=1,509$ ,  $n=892$ ,

and  $n=780$ ) and one Family Medicine site ( $n=986$ ) within the University of Pennsylvania Health System. For race, American Indian ( $n=8$ ) and Pacific Islander ( $n=2$ ) were excluded owing to small counts. The “other” ( $n=101$ ) category was also excluded because of the inherent heterogeneity of the group, comprising individuals from an unknown number of racial backgrounds. Asian ( $n=102$ ) and East Indian ( $n=24$ ) patients were excluded from the study as none were labeled as noncompliant, making it impossible to model the outcome. BMIs not directly recorded in the EHR ( $n=251$ ) were calculated based on extracted weight and height if both were available ( $n=194$ ). The 13 patients noted to be underweight ( $\text{BMI}<18.5$ ) were also excluded owing to small counts. Where available ( $n=45$ ), the most recent HbA1c was used as the average for patients where no average HbA1c was available ( $n=58$ ). The final analytic cohort with complete values for all variables of interest included 3,876 patients. Within the sample, 450 (11.6%) patients were labeled nonadherent by either ICDZ91.1 ( $n=308$ ), ICDZ53.2 ( $n=103$ ), or both ( $n=34$ ). Strata for patients with HbA1c  $<7\%$  or  $>7\%$  included 1,455 (38.6%) and 2,313 (61.4%) patients, respectively. In the overall cohort, there were more male (59.3%), more black (85.2%), and few Hispanic (2.0%) patients. Most patients in the cohort were obese (68.9%), and few had normal BMIs (8.2%). Approximately half the cohort (52.5%) had private insurance and the remaining were divided between Medicare (25.5%) and Medicaid (22.0%). Between strata, there

were small but statistically significant differences by age, sex, and insurance, and no difference between strata for ethnicity and BMI. Table 1 summarizes characteristics in the overall cohort and within strata.

Regression models adjusted for ethnicity, age, sex, BMI, and HbA1c indicated a relationship between nonadherence labeling and both race and insurance status. Black patients were significantly more likely to be labeled nonadherent, compared with white patients in the overall cohort and across strata (overall:  $\text{RR}=2.85$ , 95%  $\text{CI}=1.91, 4.26$ ; HbA1c  $\leq 7\%$ :  $\text{RR}=3.14$ , 95%  $\text{CI}=1.47, 6.70$ ; HbA1c  $>7\%$ :  $\text{RR}=2.64$ , 95%  $\text{CI}=1.65, 4.24$ ; Table 2). Hispanic patients in the overall cohort and within strata were more likely to be labeled nonadherent (overall:  $\text{RR}=1.61$ , 95%  $\text{CI}=0.89, 2.92$ ; HbA1c  $\leq 7\%$ :  $\text{RR}=1.35$ , 95%  $\text{CI}=0.35, 5.25$ ; HbA1c  $>7\%$ :  $\text{RR}=1.54$ , 95%  $\text{CI}=0.8, 2.98$ ; Table 2). In the overall cohort, individuals with Medicaid or Medicare had a significantly increased risk of nonadherence labeling compared with patients with private insurance (Medicaid:  $\text{RR}=1.76$ , 95%  $\text{CI}=1.43, 2.18$ ; Medicare:  $\text{RR}=1.67$ , 95%  $\text{CI}=1.34, 2.08$ ; Table 2), which was similar within patients with HbA1c  $<7\%$  and  $>7\%$ . HbA1c was significantly associated with nonadherence labeling in the overall cohort, with a 1% increase in HbA1c associated with 2% increased risk of nonadherence labeling. BMI, age, and sex were not associated with nonadherence labeling.

**Table 1.** Sample Characteristics

Characteristics	Overall ( $n=3,768$ )	HbA1c $\leq 7\%$ ( $n=1,455$ )	HbA1c $> 7\%$ ( $n=2,313$ )	<i>p</i> -value <sup>a</sup>
Age, years, median (IQR)	57 (50–63)	58 (51–64)	56 (49–62)	<b>&lt;0.001</b>
Biologic sex, <i>n</i> (%)				<b>0.004</b>
Male	2,234 (59.29)	905 (62.2)	1,329 (57.46)	
Female	1,534 (40.71)	550 (37.8)	984 (42.54)	
Race, <i>n</i> (%)				<b>0.017</b>
White	557 (14.78)	241 (16.56)	316 (13.66)	
Black	3,211 (85.22)	1,214 (83.44)	1,997 (86.34)	
Ethnicity, <i>n</i> (%)				0.191
Non-Hispanic	3,693 (98.01)	1,432 (98.42)	2,261 (97.75)	
Hispanic	75 (1.99)	23 (1.58)	52 (2.25)	
BMI, <i>n</i> (%)				0.137
Normal ( $\geq 18.5$ – $<25$ )	313 (8.31)	134 (9.21)	179 (7.74)	
Overweight ( $\geq 25$ – $<30$ )	860 (22.82)	314 (21.58)	546 (23.61)	
Obese ( $\geq 30$ )	2,595 (68.87)	1,007 (69.21)	1,588 (68.66)	
HbA1c, median (IQR)	8.16 (6.6–9.2)	6.31 (6–6.7)	9.32 (7.8–10.2)	<b>&lt;0.001</b>
Insurance status, <i>n</i> (%)				<b>&lt;0.001</b>
Private	1,978 (52.49)	706 (48.52)	1,272 (54.99)	
Medicaid	829 (22)	301 (20.69)	528 (22.83)	
Medicare	961 (25.5)	448 (30.79)	513 (22.18)	

Note: Boldface indicates statistical significance ( $p<0.05$ ).

<sup>a</sup>*p*-value for Wilcoxon rank-sum test (age, HbA1c), or chi-square test for independence (biological sex, race, ethnicity, BMI, HbA1c, insurance status).

**Table 2.** Adjusted RRs and 95% CIs Showing Increased Nonadherence Labeling Among Black and Medicare/Medicaid Patients, by HbA1c and ICD-10 Code

Variable	Overall(n=3,768) (Labeled n=445)	HbA1c ≤7% (n=1,455) (Labeled n=119)	HbA1c >7% (n=2,313) (Labeled n=326)	ICD-Z91.1 (n=3,768) (Labeled n=342)	ICD-Z53.2 (n=3,768) (Labeled n=137)
Race					
White	ref	ref	ref	ref	ref
Black	<b>2.85 (1.91, 4.26)</b>	<b>3.14 (1.47, 6.7)</b>	<b>2.64 (1.65, 4.24)</b>	<b>3.16 (1.96, 5.08)</b>	<b>2.24 (1.11, 4.49)</b>
Ethnicity					
Non-Hispanic	ref	ref	ref	ref	ref
Hispanic	1.61 (0.89, 2.92)	1.35 (0.35, 5.25)	1.54 (0.8, 2.98)	1.5 (0.72, 3.11)	2.09 (0.77, 5.66)
Age	1 (0.99, 1.01)	1.01 (0.99, 1.03)	1.01 (0.99, 1.02)	1 (0.99, 1.02)	1 (0.98, 1.02)
Biologic sex					
Male	ref	ref	ref	ref	ref
Female	0.91 (0.76, 1.09)	0.7 (0.5, 1)	1.04 (0.84, 1.27)	0.84 (0.69, 1.04)	1.18 (0.83, 1.67)
BMI					
Normal	ref	ref	ref	ref	ref
Overweight	0.85 (0.61, 1.17)	0.7 (0.37, 1.32)	0.9 (0.62, 1.32)	0.84 (0.58, 1.22)	0.87 (0.45, 1.68)
Obese	0.84 (0.63, 1.13)	0.91 (0.53, 1.57)	0.86 (0.6, 1.21)	0.82 (0.59, 1.15)	0.96 (0.53, 1.73)
HbA1c	<b>1.02 (1.01, 1.04)</b>	0.77 (0.54, 1.1)	1.02 (1, 1.04)	<b>1.03 (1.01, 1.04)</b>	1.03 (1, 1.05)
Insurance status					
Private	ref	ref	ref	ref	ref
Medicaid	<b>1.76 (1.43, 2.18)</b>	<b>1.61 (1, 2.61)</b>	<b>1.79 (1.42, 2.26)</b>	<b>1.65 (1.29, 2.13)</b>	<b>2.2 (1.48, 3.26)</b>
Medicare	<b>1.67 (1.34, 2.08)</b>	<b>2.11 (1.39, 3.2)</b>	<b>1.52 (1.17, 1.98)</b>	<b>1.71 (1.33, 2.2)</b>	<b>1.66 (1.08, 2.55)</b>

Note: Boldface indicates statistical significance ( $p < 0.05$ ). Estimated RR and 95% CIs from log-binomial regression models. Label  $n$  is the count of patients labeled nonadherent for either ICD-10 code (columns 2–4) or for each ICD-10 code separately (columns 5 and 6). For categorical variables, ref indicates the reference category. For categorical variables, ref indicates the reference category.

In a sensitivity analysis treating nonadherence labeling labeled by ICDZ91.1 and ICDZ53.2 separately (Table 2), black race and insurance exhibited similar associations with both status indicators in adjusted models (e.g., for black patients, ICDZ91.1: RR=3.16, 95% CI=1.96, 5.08; ICDZ53.2: RR=2.24, 95% CI=1.11, 4.49; Table 2). Although ICDZ91.1 showed a higher RR than ICDZ53.2, the CIs overlap, suggesting that the associations are similar. Also, in a sensitivity analysis adjusting for treatment site (data not shown), the effect estimates for insurance and race as well as all other covariates were similar.

## DISCUSSION

This multisite, retrospective cohort analysis of adult patients with T2DM found a statistically significant association between black race and nonprivate insurance with nonadherence labeling. The findings persisted after controlling for HbA1c as a proxy for patient behavior as well as when patients were stratified by HbA1c categories. Though not statistically significant likely owing sample size, Hispanic patients also showed an increased risk of being labeled nonadherent. Though excluded from regression analysis, it is notable that no patient

categorized as Asian received nonadherence labeling. Other measures including BMI, age, and sex, did not show an association with nonadherence labeling among adult patients with T2DM.

In addition to its use as a long-term measure of blood glucose, HbA1c is also a strong correlate of medication use in T2DM such that differences in patient behavior may account for observed gaps in average HbA1c by race.<sup>22,23</sup> Therefore, although studies have found that black patients with T2DM tend to have lower use of antidiabetic medications than white patients,<sup>23–25</sup> this is unlikely to explain the findings, because a statistically significant increased risk of nonadherence labeling for black patients was found after controlling for HbA1c. Instead, the analysis suggests that black race is independently associated with nonadherence labeling and may indicate bias among healthcare providers in their perception of black patients' behaviors. The findings are consistent with previous work showing that black patients with HIV are more likely than white patients to be viewed as nonadherent.<sup>19</sup> To the authors' knowledge, the study is the first to describe such a trend in adults with T2DM.

The association between patients' insurance and nonadherence labeling was a novel finding not yet explored

in previous studies. Although Medicaid patients may have lower overall treatment compliance than privately insured patients,<sup>26</sup> this is unlikely to explain the results because Medicaid patients showed a statistically significant increased risk for nonadherence labeling after controlling for HbA1c. One possible explanation is that, as Medicaid is a correlate of lower SES, the results may represent the effect of class bias on the part of providers, which has been shown to impact clinical judgment.<sup>14,27,28</sup> Of note, Medicare patients also showed an increased risk of nonadherence labeling, although the connection to class bias is less clear given the differences between Medicare and Medicaid populations. As poor communication has been associated with provider misperception of treatment behaviors,<sup>11</sup> the observation that patients with T2DM on Medicare tend to have worse communication with their providers<sup>29</sup> may serve as an alternative explanation.

Notably, explorations of the joint association of race and insurance status with nonadherence labeling illustrated a fivefold increased risk for black patients with nonprivate insurance in being labeled as nonadherent compared with white patients with private insurance. The findings of compounded risk suggest a coaction in bias generation between the subjective effects that patients' race and insurance status may have on providers' use of nonadherence labels in patient records. Regarding BMI, it is also important to note that the results did not show an association between either overweight or obesity status and nonadherence labeling. The results contrast previous work that showed differences in providers' perception of patient behavior by obesity status.<sup>18</sup>

Finally, the sensitivity analysis revealed that the associations between black race, nonprivate insurance status, and nonadherence labeling persisted both when analyzing 2 nonadherence diagnoses separately and when adjusting for site-level variation between the 4 primary care practices included in the study. These findings may serve as evidence of a systemic issue of bias in disproportionate labeling of black patients with T2DM and those with nonprivate insurance as nonadherent regardless of HbA1c.

These results may have several implications. First, the results may call into question prior research on patient medication use that has not taken into account the influence of bias in various population-level measures that may be dependent on nonadherence labels in the EHR. For example, if racial or class bias on the part of clinicians is leading significant numbers of patients with diabetes to be labeled as nonadherent independent of their behavior, prior calculations of the economic impacts or outcomes related to patients with T2DM who are labeled nonadherent may need to be adjusted for provider biases.

Next, the results may point to a concerning mechanism by which sociodemographic bias can encode itself into patient records. As prior studies have shown, nonadherence labels can impact clinical decision making by affecting providers' subjective judgments of patient behavior. Thus, nonadherence labeling that is rooted in prejudice may ultimately transfer that bias to future clinical encounters where subsequent providers may be unaware of the label's biased origins.

Finally, the findings of this study may lead clinicians to interrogate nonadherence labels encountered in the EHR as possibly representative of provider bias rather than patient behavior alone. In practice, clinicians should approach such labels with increased caution, questioning one's own individual biases when interpreting or deciding to employ a nonadherence diagnosis. Such language rooted in an adherence versus nonadherence paradigm carries the risk of erasing the multifactorial nature of patient self-management. Therefore, the authors recommend avoiding the traditional terminology of adherence altogether and instead employing language that is neutral, nonstigmatizing, and based on patients' strengths and values rather than implied behavioral deficiencies.

### Limitations

This study has several limitations. The retrospective analysis of observational data may have failed to detect residual confounding because of predictors not accounted for in the study design. Also, as a cross-sectional study, a temporal relationship between nonadherence labeling and patients' HbA1c cannot be established. Furthermore, the findings reported here may not generalize to patients treated at nonacademic centers like private practices or community clinics. It is unclear what is driving the association between race or insurance status with nonadherence labeling, and conditions at the patient, physician, and institutional level may contribute. At the patient level, future studies should incorporate other socioeconomic measures potentially confounding the observed relationship between race and nonadherence labeling, such as individual- or neighborhood-level estimates of poverty or education. Further, owing to the limitations of the study population, several racial groups were excluded from the analysis, so understanding if there is differential risk of nonadherence labeling in these populations would require further study. At the physician level, quantitative and qualitative studies are necessary to critically evaluate what aspects of patient identity and physician–patient interaction trigger nonadherence labeling and to what degree implicit or explicit bias drives the phenomenon. Finally, at the institutional level, similar studies should be replicated to determine if differential nonadherence labeling by race and insurance is a systemic issue across healthcare systems.

## CONCLUSIONS

The results of this study add to the growing body of literature documenting the clinical significance of nonadherence language and the ways that sociodemographic bias can influence patient labeling. These findings can be viewed as evidence that bias on the part of providers may lead to the disproportionate labeling of black and nonprivately insured patients with T2DM as nonadherent, independent of their behavior. Further research is needed to understand the precise clinical implications of biased nonadherence labeling in T2DM such as the potential impact of these labels on individual patient outcomes.

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All authors are responsible for this reported research. All authors interpreted results and critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted. SB and PC were responsible for study conceptualization. LAL was responsible for data processing and statistical analysis. All authors assisted in interpreting the results. SB and LAL drafted the original manuscript and revised subsequent drafts. PC was responsible for critically revising the manuscript for publication.

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