# Insulin Rationing Persists Despite Policy Changes: Repeated Cross-Sectional Studies, 2017 vs 2024

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## ABSTRACT

***BACKGROUND:*** Insulin is a life-saving medication for people with diabetes, but access barriers, such as high costs, can result in rationing. Multiple policies have been introduced to limit insulin out-of-pocket costs over the past 5 years.

***OBJECTIVE:*** To compare rates of cost-related insulin rationing among patients prescribed insulin in 2024 vs. 2017, and to examine broader insulin rationing due to cost-related barriers, insurance delays, or pharmacy shortage

***DESIGN:*** A 22-item cross-sectional survey conducted from April to July 2024 compared with a survey conducted from June to August 2017.

***SETTING:*** Yale Diabetes Center

***PARTICIPANTS:*** Adults with type 1 or type 2 diabetes prescribed insulin, with 199 (60.1%) completing the survey in 2024 and 199 (56.2%) in 2017.

***MAIN MEASURES:*** Rates of cost-related insulin rationing and broader rationing due to access barriers, including cost, insurance delays, and pharmacy shortages.

***KEY RESULTS:*** In 2024, among 199 respondents (mean age of 52.4 years, 47.7% female, 58.3% white, and 47.2% type 1 diabetes), 48 (24.1%) reported cost-related insulin rationing compared to 51 (25.5%) of 199 respondents in 2017 ($p=0.41$). Characteristics of participants who reported cost-related insulin rationing were similar between 2024 and 2017, but with a higher proportion of adults with type 1 diabetes in 2024 (63.0%) compared to 2017 (43.1%, $p=0.05$). In 2024, 75 participants (37.7%) reported insulin rationing due to cost, insurance delays, or pharmacy shortages. In a multivariable model, age, sex, race, ethnicity, income, and insurance coverage were not significantly associated with rationing, but patients with type 2 diabetes had lower odds (OR 0.34, 95%CI 0.13–0.87) compared with type 1 diabetes patients.

***CONCLUSIONS:*** Despite new policies addressing insulin costs since 2017, one in four patients at Yale Diabetes Center rationed insulin due to cost in 2024, unchanged from 2017. Over one-third reported rationing due to broader access barriers. These findings highlight the ongoing need to comprehensively address insulin affordability and access.

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## INTRODUCTION

Insulin is an essential medication for individuals living with type 1 and type 2 diabetes to maintain target glucose levels and reduce the risk of health complications. For individuals with type 1 diabetes, insulin is indispensable for survival. Recognized on the Model List of Essential Medicines created by the World Health Organization, this medication should be readily available, accessible, and affordable to those with diabetes.[1] The American Diabetes Association Standards of Care emphasize insulin as an "essential treatment" for patients with type 1 diabetes and recognize that insulin becomes necessary for many patients with type 2 diabetes over time.[2] However, in the USA, several barriers affect access to insulin, including high prices of insulin and associated out-of-pocket payments, delays or difficulties obtaining insurance coverage for insulin, and shortages of insulin at the pharmacy counter.[3–7]

Several prior studies have described rates of cost-related insulin rationing.[8–10] In our prior study conducted at the Yale Diabetes Center in 2017, one in four patients prescribed insulin reported rationing insulin due to cost over the previous year.[8] Since then, multiple policies have been passed to reduce challenges associated with cost-related barriers to insulin use in Connecticut and more broadly across the USA. Specifically, a 2020 Connecticut bill capping out-of-pocket copayments for a 30-day supply of insulin to no more than $25 for those with state-regulated insurance plans went into effect on January 1, 2021,[11] and the Inflation Reduction Act, which capped out-of-pocket copayments for insulin to no more than $35 per monthly prescription for all Medicare Part D enrollees, began on January 1, 2023.[12] Even more recently, in March 2023, all three insulin manufacturers announced voluntary price reductions on some of their products.[13–15] Based on these changes, it is reasonable to expect that rates of cost-related insulin rationing have decreased since then.

At the same time, challenges to insulin access beyond cost have become more acute. Insulin shortages due to manufacturing delays or discontinuation of certain insulin products (e.g., Levemir or Novo Nordisk's human insulin pens) have challenged consistent availability of insulin at US pharmacies.[16–18] Moreover, prior authorization requirements delay insurance approvals, preventing patients from obtaining insulin in a timely manner.[19]

Accordingly, we conducted a survey study at the Yale Diabetes Center with two main objectives. First, we set out to assess the percentage of patients with diabetes who rationed insulin due to cost among patients prescribed insulin. Using the same survey questions in 2017 and in this study allowed us to examine whether there have been changes in rates of cost-related insulin rationing. Second, we aimed to examine reasons for insulin rationing more broadly, including cost-related barriers, insurance delays, or pharmacy shortages given that access can be limited for other reasons, aside from cost alone.

## METHODS

### Data Sources

A 22-item cross-sectional survey included questions addressing demographic characteristics, insulin and health habits, prescription drug insurance coverage, and financial barriers. Survey questions were based on the initial 2017 published study, conducted from June to August 2017, with identical questions used to examine cost-related insulin rationing in 2017 and 2024.[8] Two new questions on insulin rationing due to delays in insurance approval or due to insulin not being available at the pharmacy were added to the 2024 survey. While cognitive interviewing was not completed on these two new questions, they were modeled after the National Health Interview Survey and the 2017 study.[10,13] Survey questions are available in the Supplement (Supplemental Fig. 1).

The study is approved by the Yale University Human Investigations Committee who determined that written informed consent could be waived.

### Study Participants

Eligible participants were approached in the waiting room to fill out a paper survey at the Yale Diabetes Center from April to July 2024. The inclusion criteria for the study required the following: age greater than or equal to 18 years at the time of visit, a diagnosis of diabetes (type 1 or type 2), a prescription for insulin within the last 12 months, an in-person visit at the Yale Diabetes Clinic (since patients were surveyed in clinic), and English listed in the electronic medical record as the preferred language since the survey was only available in English. While all patients were approached to fill out the survey during the times the research team was at the clinic, only those identified by Yale's Joint Data Analytics Team (JDAT) based on the above eligibility criteria were invited to complete the survey. Patients were not compensated for their participation in the survey, and completion was entirely voluntary. Some overlap between participants in the 2024 survey and the 2017 survey is possible, but this was not tracked.

### Study Outcomes

For the first analysis, the primary outcome was the percentage of patients who endorsed cost-related insulin rationing defined by a positive response to *any* of the following six questions: did you…(1) use less insulin than prescribed, (2) try to stretch out your insulin, (3) take smaller doses of insulin than prescribed, (4) stop using insulin, (5) not fill an insulin prescription, or (6) not start insulin in the past 12 months…because of cost? The same questions were used in 2024 and 2017.

For the second analysis, the primary outcome was the percentage of patients who reported insulin rationing due to access barriers defined more broadly. Specifically, the outcome included cost-related insulin rationing (as defined above), or insulin rationing due to insurance delays, or insulin shortages at pharmacies. The questions about insurance delays and pharmacy shortages defined insulin rationing based on a positive response to *any* of the following: (1) took less insulin than needed, (2) skipped insulin doses, or (3) delayed buying insulin in the past 12 months… because of insurance delays or pharmacy shortages.

### Statistical Analyses

To facilitate the analysis, some survey responses were grouped into larger categories. For prescription insurance coverage, patients who selected both Medicaid and Medicare were classified under Medicaid since insulin is covered by Medicaid for dual eligible patients. Individuals who selected Tricare and another plan such as employer-sponsored or Medicare were classified under "VA plus." Patients who selected multiple plans or listed health savings accounts or state exchange plans were categorized as having "other insurance." Data on race and ethnicity were collected differently in 2017 and 2024; race and ethnicity were reported separately to facilitate comparisons.

Characteristics of respondents and non-respondents to the current survey were compared using chi-square analysis. Similarly, characteristics of respondents to the 2024 survey were compared to those to the 2017 survey using chi-square tests. The percentage of patients who reported cost-related insulin rationing on the 2024 survey was compared to the expected percentage of patients from the 2017 survey using $z$-statistics with a two-sided alpha of 0.05. A multivariable logistic regression was used to examine factors independently associated with insulin rationing due to access barriers. All statistical analyses were conducted using SAS version 9.4 and R Studio 2023 version.

## RESULTS

### Characteristics of 2024 Survey Respondents

Of 331 patients eligible for the survey, 199 completed the survey, corresponding to a response rate of 60.1%. Differences between respondents and non-respondents were notable for age and ethnicity categories. Respondents tended to be younger and of non-Hispanic ethnicity. Response status did not differ significantly based on sex or race (Supplemental Table 1).

Survey respondents in 2024 had a mean age of 52.4 years (SD 17.2), 47.7% were female, 58.3% were white, and 47.2% had type 1 diabetes (Supplemental Table 2). The most common forms of prescription drug insurance included private plans (40.7%), Medicaid (32.3%), and Medicare Part D (20.1%).

### Characteristics of 2024 Compared to 2017 Survey Respondents

The characteristics of study respondents in 2024 were compared to those in 2017 (Supplemental Table 2). The only significant difference between the respondents in 2024 versus 2017 surveys was annual household income. The 2024 sample comprised a greater proportion of participants with family income levels over $100,000 (25.8% vs. 13.6%), whereas the 2017 sample had more participants in lower-income brackets (< $10,000: 20.5% vs. 11.3%).

### Cost-Related Insulin Rationing

In 2024, 48 of 199 (24.1%) individuals reported cost-related insulin rationing (Table 1). This was not statistically different

**Table 1 Characteristics of Adults with Diabetes Who Reported Cost-related Insulin Rationing on the 2024 Survey vs. 2017 Survey**

| | **2024 survey ($N = 48$)** | **2017 survey ($N = 51$)** | ***p*-value (Chi-Sq Test)** |
|---|---|---|---|
| **Age categories**, *n* (%) | | | 0.93 |
| 18–44 | 18 (38.3%) | 20 (39.2%) | |
| 44–64 | 20 (42.6%) | 20 (39.2%) | |
| 65 + | 9 (19.1%) | 11 (21.6%) | |
| Missing | 1 | 0 | |
| **Sex**, *n* (%) | | | 0.49 |
| Female | 23 (47.9%) | 28 (54.9%) | |
| Male | 25 (52.1%) | 23 (45.1%) | |
| **Race**, *n* (%) | | | 0.35 |
| Black/African American | 11 (22.9%) | 16 (31.4%) | |
| White | 23 (47.9%) | 26 (51.0%) | |
| Other/did not report | 14 (29.2%) | 9 (17.6%) | |
| **Ethnicity**, *n* (%) | | | 0.18 |
| Latino/Hispanic | 8 (6.7%) | 4 (7.8%) | |
| Not Latino/Hispanic | 40 (83.3%) | 47 (92.2%) | |
| **Diabetes type**, *n* (%) | | | 0.05 |
| Type 1 | 29 (63.0%) | 22 (43.1%) | |
| Type 2 | 17 (37.0%) | 29 (56.9%) | |
| Missing | 2 | | |
| **Drug prescription coverage**, *n* (%) | | | 0.68 |
| Private | 19 (42.2%) | 21 (41.2%) | |
| Medicaid | 13 (28.9%) | 19 (37.2%) | |
| Medicare Part D | 10 (22.2%) | 7 (13.7%) | |
| None/other/unknown | 3 (6.7%) | 4 (7.8%) | |
| Missing | 3 | 0 | |
| **Annual combined household income**, *n* (%) | | | 0.06 |
| Less than $10,0000 | 3 (8.1%) | 7 (13.7%) | |
| $10,0000 to $24,999 | 7 (18.9%) | 13 (25.5%) | |
| $25,000 to $49,9999 | 8 (21.6%) | 14 (27.5%) | |
| $50,0000 to $99,999 | 12 (32.4%) | 10 (19.6%) | |
| $100,000 and greater | 7 (18.9%) | 1 (2.0%) | |
| Missing | 11 | 6 | |
| **Difficulty buying diabetes medical equipment** | | | 0.45 |
| No | 22 (47.8%) | 21 (41.2%) | |
| Yes | 23 (50.0%) | 30 (58.8%) | |
| I do not use strips or syringes, etc | 1 (2.2%) | 0 | |
| Missing | 2 | 0 | |

compared to the rate of rationing in the 2017 study, in which 51 of 199 (25.5%) reported insulin rationing ($p = 0.41$).

The characteristics of participants who reported cost-related insulin rationing in 2024 and 2017 were largely similar (Table 1), including prescription insurance coverage and family income categories. However, of those who reported cost-related insulin rationing, a larger percentage had type 1 diabetes in 2024 when compared with 2017 (63.0% vs. 43.1%, $p = 0.05$). Furthermore, most patients who reported cost-related insulin rationing did not discuss this issue with their clinician in either year (80.8% in 2024 vs. 60.8% in 2017).

## Insulin Rationing due to Access Barriers

Insulin rationing due to cost was reported by 48 participants (24.1%), insurance delays by 34 (17.1%), and pharmacy shortages by 37 (18.6%), with 75 participants (37.7%) reporting insulin rationing due to any one of these causes (Fig. 1). A higher proportion of participants with type 1 diabetes reported insulin rationing due to one of the access barriers compared to those with type 2 diabetes (59.7% vs 40.3%, $p < 0.01$, see Table 2).

In the multivariable model (which had a C-statistic of 0.72 consistent with good fit), the only factor that was significantly associated with insulin rationing was type of diabetes ($p = 0.03$, see Fig. 2). Compared to patients with type 1 diabetes, those with type 2 diabetes had lower odds of rationing (OR 0.34, 95%CI 0.13–0.87). Participants who rationed insulin were also more likely to report being unable to buy diabetes-related medical equipment compared to those who did not ration (42.5% vs 7.6%, $p < 0.01$).

## DISCUSSION

In this cross-sectional survey study conducted at the Yale Diabetes Center in 2024, one in four patients (24.1%) prescribed insulin reported cost-related insulin rationing over the past year. Despite multiple legislative changes implemented between 2017 and 2024, the proportion of patients reporting insulin rationing due to cost did not change when compared to the prior study conducted at the Yale Diabetes Center in 2017. When broader reasons for access barriers to insulin were considered, including cost, pharmacy insurance approval delays, or pharmacy shortages, more than one in three participants (37.7%) reported insulin rationing. These findings underscore not only the persistent need to address insulin affordability but also the pressing necessity to tackle broader access barriers to insulin.

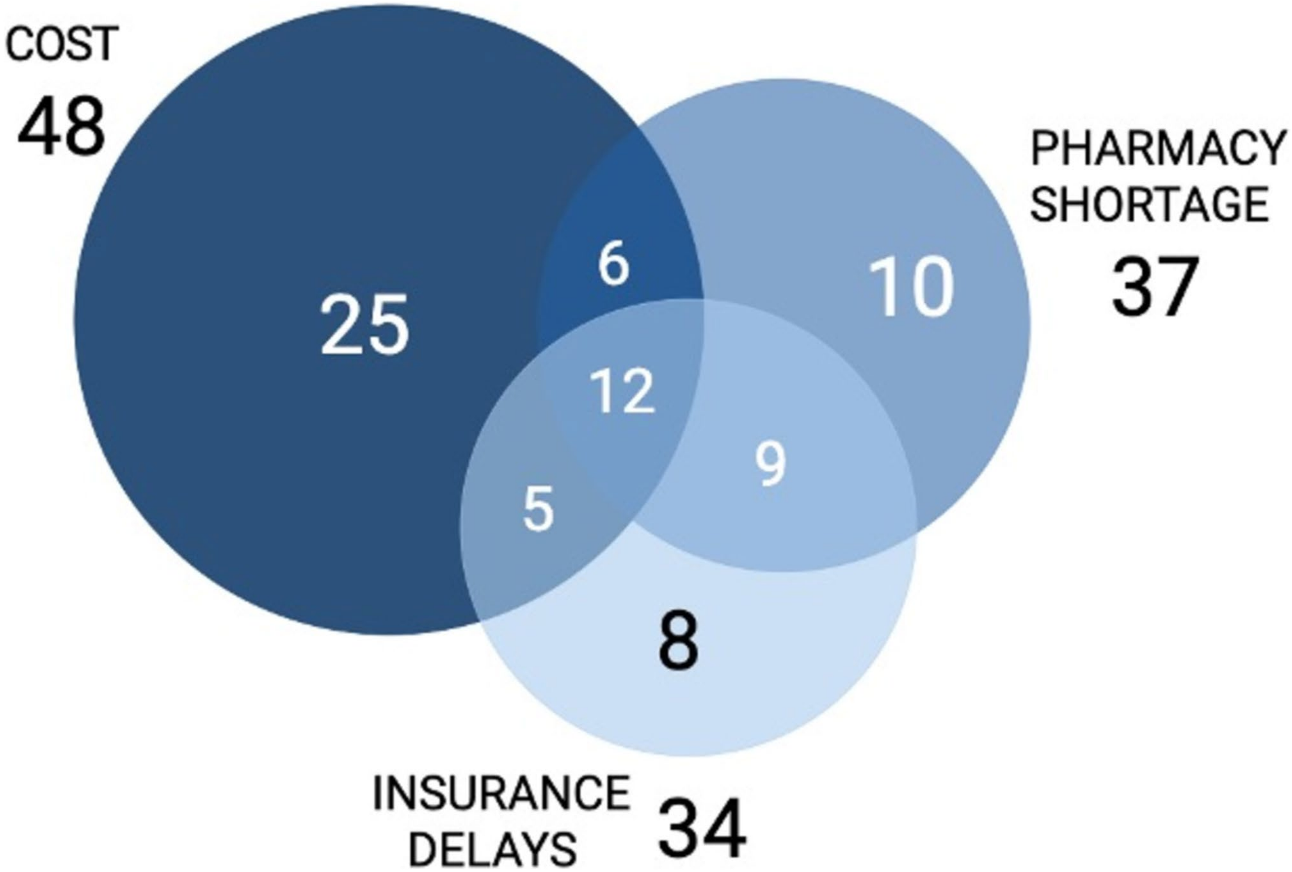


**Figure 1** **Number of participants reporting insulin rationing due to cost, pharmacy shortages, or insurance delays on the 2024 survey (total of 199 respondents).**

**Table 2 Characteristics of 2024 Respondents Who Did vs. Did Not Report Insulin Rationing due to Access Barriers (Including Cost, Pharmacy Shortages, and Insurance Delays) Using Bivariate Analysis**

| | **Insulin rationing due to access barriers** | | **Total (*N* = 199)** | ***p*-value** |
|---|---|---|---|---|
| | **Yes (*N* = 75)** | **No (*N* = 124)** | | |
| **Age** | | | | 0.04[1] |
| Mean (SD) | 49.1 (16.9) | 54.4 (17.1) | 52.4 (17.2) | |
| Missing | 1 | 1 | 2 | |
| **Age categories**, *n* (%)* | | | | 0.17[2] |
| 18–44 | 30 (40.5%) | 38 (30.9%) | 68 (34.5%) | |
| 44–64 | 28 (37.8%) | 44 (35.8%) | 72 (36.5%) | |
| 65 + | 16 (21.6%) | 41 (33.3%) | 57 (28.9%) | |
| Missing | 1 | 1 | 2 | |
| **Sex**, *n* (%)* | | | | 0.24[2] |
| Female | 40 (53.3%) | 54 (44.3%) | 94 (47.7%) | |
| Male | 35 (46.7%) | 68 (55.7%) | 103 (52.3%) | |
| Missing | 0 | 2 | 2 | |
| **Race**, *n* (%)* | | | | 0.76[2] |
| Asian | 2 (3.1%) | 3 (2.6%) | 5 (2.8%) | |
| Black | 18 (27.7%) | 29 (25.0%) | 47 (26.0%) | |
| Other/multiple | 6 (9.2%) | 7 (6.0%) | 13 (7.2%) | |
| White | 39 (60.0%) | 77 (66.4%) | 116 (64.1%) | |
| Missing | 10 | 8 | 18 | |
| **Ethnicity**, *n* (%)* | | | | 0.70[2] |
| Hispanic/Latino | 3 (4.6%) | 4 (3.4%) | 7 (3.9%) | |
| Not Hispanic/Latino | 62 (95.4%) | 112 (96.6%) | 174 (96.1%) | |
| Missing | 10 | 8 | 18 | |
| **Diabetes type**, *n* (%)* | | | | < 0.01[2] |
| Type 1 | 43 (59.7%) | 48 (39.7%) | 91 (47.2%) | |
| Type 2 | 29 (40.3%) | 73 (60.3%) | 102 (52.8%) | |
| Missing | 3 | 3 | 6 | |
| **Education**, *n* (%)* | | | | 0.74[2] |
| High school or less | 21 (28.4%) | 32 (26.0%) | 53 (26.9%) | |
| Some college or more | 53 (71.6%) | 91 (74.0%) | 144 (73.1%) | |
| Missing | 1 | 1 | 2 | |
| **Drug prescription coverage**, *n* (%)* | | | | 0.91[2] |
| Private | 28 (38.9%) | 49 (41.9%) | 77 (40.7%) | |
| Medicaid | 25 (34.7%) | 36 (30.8%) | 61 (32.3%) | |
| Medicare Part D | 15 (20.8%) | 23 (19.7%) | 38 (20.1%) | |
| VA | 0 (0.0%) | 2 (1.7%) | 2 (1.1%) | |
| VA Plus | 1 (1.4%) | 1 (0.9%) | 2 (1.1%) | |
| Self-pay | 0 (0.0%) | 2 (1.7%) | 2 (1.1%) | |
| Other | 3 (4.2%) | 4 (3.4%) | 7 (3.7%) | |
| Missing | 3 | 7 | 10 | |
| **In the past 12 months, have you received any coupons, vouchers, co-pay discount cards or instant savings cards to help cover the cost of your insulin prescription?**, *n* (%)* | | | | 0.34[2] |
| No | 65 (91.5%) | 113 (95.8%) | 178 (94.2%) | |
| Yes | 6 (8.5%) | 5 (4.2%) | 11 (5.8%) | |
| Missing | 4 | 6 | 10 | |
| **Annual combined household income**, *n* (%)* | | | | 0.78[2] |
| Less than $10,0000 | 5 (8.2%) | 12 (13.3%) | 18 (11.3%) | |
| $10,0000 to $24,999 | 14 (23.0%) | 18 (18.4%) | 32 (20.1%) | |
| $25,000 to $49,9999 | 11 (18.0%) | 17 (17.3%) | 28 (17.6%) | |
| $50,0000 to $99,999 | 17 (27.9%) | 23 (23.5%) | 40 (25.2%) | |
| $100,0000 and greater | 14 (23.0%) | 27 (27.6%) | 41 (25.8%) | |
| Missing | 14 | 26 | 40 | |
| **In the past year, how often did it happen that you did not have enough money to buy food, clothes, or other things you needed?**, *n* (%)* | | | | 0.14[2] |
| Very often | 8 (11.4%) | 10 (8.6%) | 18 (9.7%) | |
| Fairly often | 13 (18.6%) | 11 (9.5%) | 24 (12.9%) | |
| Not very often | 20 (28.6%) | 29 (25.0%) | 49 (26.3%) | |
| Never | 29 (41.4%) | 66 (56.9%) | 95 (51.1%) | |
| Missing | 5 | 8 | 13 | |
| **Count of prescriptions currently taking**, *n* (%)* | | | | 0.47[2] |
| Less than 5 | 26 (36.1%) | 35 (28.5%) | 61 (31.3%) | |
| 5–9 | 32 (44.4%) | 65 (52.8%) | 97 (49.7%) | |
| 10 or more | 14 (19.4%) | 23 (18.7%) | 37 (19.0%) | |
| Missing | 3 | 1 | 4 | |
| **Type of insulin**, *n* (%)* | | | | 0.09[3] |

**Table 2** (continued)

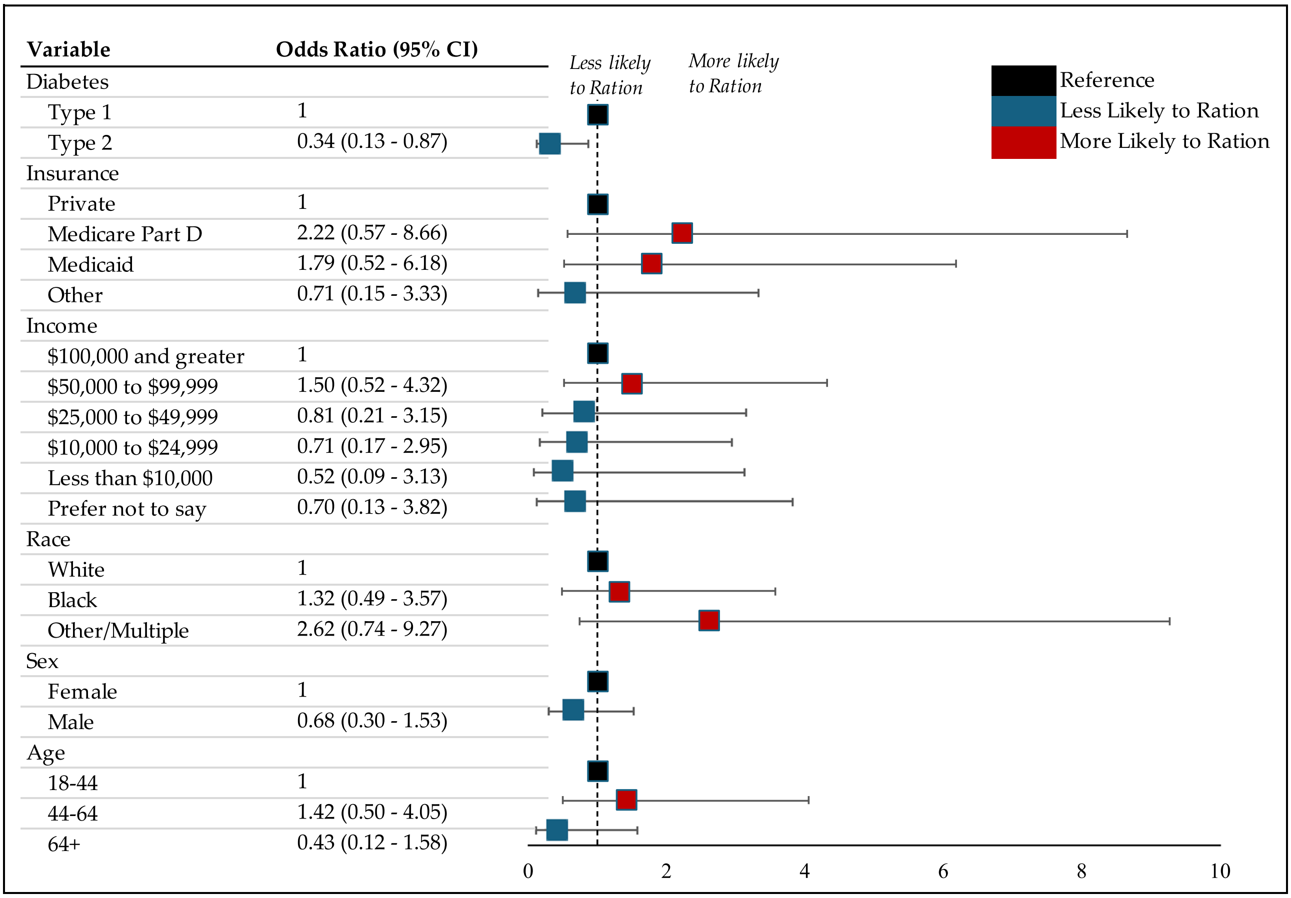
| | **Insulin rationing due to access barriers** | | **Total ($N = 199$)** | ***p*-value** |
|---|---|---|---|---|
| | **Yes ($N = 75$)** | **No ($N = 124$)** | | |
| Short acting | 30 (40.5%) | 35 (29.2%) | 65 (33.5%) | |
| Long acting | 9 (12.2%) | 26 (21.7%) | 35 (18.0%) | |
| Pre-mixed | 0 (0.0%) | 4 (3.3%) | 4 (2.1%) | |
| Short and long acting | 35 (47.3%) | 55 (45.8%) | 90 (46.4%) | |
| Missing | 1 | 14 | 5 | |
| **In the past 12 months, have you discussed the cost of insulin with your primary care provider or diabetes specialist?**, *n* (%)* | | | | $< 0.01^3$ |
| No | 54 (72.0%) | 113 (92.6%) | 167 (84.8%) | |
| Yes | 21 (28.0%) | 9 (7.4%) | 30 (15.2%) | |
| Missing | 2 | 0 | 2 | |
| **In the past 12 months, did you ever have a time when you could not buy diabetes medical equipment?**, *n* (%)* | | | | $< 0.01^3$ |
| Yes | 31 (42.5%) | 9 (7.6%) | 40 (20.8%) | |
| No | 41 (56.2%) | 107 (89.9%) | 148 (77.1%) | |
| I do not use strips or syringes, etc. | 1 (1.4%) | 3 (2.5%) | 4 (2.1%) | |
| Missing | 2 | 5 | 7 | |

* All Percentages exclude missing values

[1] Equal variance two-sample *t*-test

[2] Fisher exact *p*-value

[3] Chi-square *p*-value



| **Variable** | **Odds Ratio (95% CI)** |
|---|---|
| Diabetes | |
| Type 1 | 1 |
| Type 2 | 0.34 (0.13 - 0.87) |
| Insurance | |
| Private | 1 |
| Medicare Part D | 2.22 (0.57 - 8.66) |
| Medicaid | 1.79 (0.52 - 6.18) |
| Other | 0.71 (0.15 - 3.33) |
| Income | |
| $100,000 and greater | 1 |
| $50,000 to $99,999 | 1.50 (0.52 - 4.32) |
| $25,000 to $49,999 | 0.81 (0.21 - 3.15) |
| $10,000 to $24,999 | 0.71 (0.17 - 2.95) |
| Less than $10,000 | 0.52 (0.09 - 3.13) |
| Prefer not to say | 0.70 (0.13 - 3.82) |
| Race | |
| White | 1 |
| Black | 1.32 (0.49 - 3.57) |
| Other/Multiple | 2.62 (0.74 - 9.27) |
| Sex | |
| Female | 1 |
| Male | 0.68 (0.30 - 1.53) |
| Age | |
| 18-44 | 1 |
| 44-64 | 1.42 (0.50 - 4.05) |
| 64+ | 0.43 (0.12 - 1.58) |

**Figure 2** **Multivariable logistic regression model of insulin rationing due to access barriers (costs, pharmacy shortages, or insurance delays) in 2024.**

Prior studies have examined cost-related insulin rationing in larger samples, but none compared rates of rationing over time. The National Health Interview Study (NHIS) has provided critical insights into cost-related insulin rationing among individuals with diabetes in the USA. In 2021, 16.5% of NHIS respondents with diabetes using insulin therapy reported rationing insulin due to cost,[10] which is substantially lower than the rate reported in either the 2024 or 2017 surveys conducted at the Yale Diabetes Center. This could be due to differences in the characteristics of the Yale Diabetes Center population compared to the national sample. Additionally, Gaffney et al. employed a more limited definition for insulin rationing, which included three types of rationing behaviors due to cost (skipping doses, taking less insulin than prescribed, or delaying buying insulin), whereas our study's broader definition also included stretching out insulin over time, taking smaller doses, stopping insulin altogether, or delaying starting insulin.

What explains the lack of improvement in rates of cost-related insulin rationing over time? Despite legislative changes, there are several factors that may have led to stagnation in progress. First, increased restrictions imposed by pharmaceutical companies on the availability of discounted insulin at community pharmacies through the 340B Drug Pricing Program may have resulted in reduced access to affordable insulin for many vulnerable populations.[20] Additionally, the limited applicability of the Inflation Reduction Act (IRA), which primarily benefits individuals covered by Medicare, creates a significant equity gap for those under the age of 65 who lack similar protections. Based on 2021 NHIS data, 71% of all adults who reported rationing due to cost were younger than 65 years old[21] and therefore would not be eligible for the out-of-pocket limits set by this policy. Additionally, the $35 co-pay cap applies to a month's supply of each insulin product; therefore, those who require multiple insulin products (e.g., basal and bolus insulin) incur a higher co-pay. Finally, the 2020 co-pay cap in Connecticut only applies to state-regulated health plans, thereby excluding many individuals who are uninsured, or enrolled in self-insured or out-of-state plans.

Individuals with type 1 diabetes were more likely to report rationing due to any access barrier compared to those with type 2 diabetes, and the proportion of participants with type 1 diabetes who reported cost-related insulin rationing was significantly higher in 2024 compared to 2017. There are several potential reasons for these findings. The total and out-of-pocket healthcare costs for managing type 1 diabetes are significantly higher than for type 2 diabetes.[22] This is because individuals with type 1 diabetes need insulin replacement lifelong to meet both prandial and basal needs. In contrast, those with type 2 diabetes may require less frequent insulin administration or lower doses of insulin when treated with other glucose-lowering agents. Greater dependence on insulin in type 1 diabetes often comes with increased complexity of management and reliance on diabetes technology such as insulin pumps and continuous glucose monitors, which can further contribute to financial burden. Notably, existing policy interventions have not specifically addressed the unique needs of individuals with type 1 diabetes, leaving gaps in affordability and access for this population. The legislative insulin cost caps limited to state-regulated health plans or Medicare exclude a substantial portion of younger adults with type 1 diabetes who are uninsured or who use self-insured health plans.[21]

While discussions about insulin costs with clinicians were more commonly reported by patients who rationed insulin (28%) than those who did not (7.4%), a significant percentage of those who rationed (72%) did not discuss the cost of insulin with their clinician. By contrast, 60.8% of participants who reported cost-related insulin rationing in 2017 discussed insulin costs with their clinician.[8] We speculate several potential reasons for this decline. First, patients may perceive that insulin costs are fixed and that their clinicians have limited influence over insulin pricing or addressing out-of-pocket costs, especially after years of public discourse on this issue. Second, clinicians may be less likely to raise insulin costs with patients, assuming that recent policy changes have resolved affordability concerns. Moreover, increasing visit complexity[23] and physician workload[24] may all contribute to the decline in these conversations. These findings underscore a critical gap and opportunity to initiate conversations surrounding insulin access and affordability in the clinic through means such as standardizing screenings for cost-related issues. As an example, the Comprehensive Score for Financial Toxicity-Functional Assessment of Chronic Illness Therapy (COST-FACIT) has recently been studied as a validated tool to identify patients experiencing financial stress due to diabetes care;[25] however, the use of these tools is not widespread in clinical settings at this time.

Beyond the price of insulin, the cost of managing diabetes includes the essential insulin-related supplies, such as syringes, pen needles, and insulin pumps, and diabetes-related supplies, such as glucometers and continuous glucose monitors. Prior studies seeking to shed light on the breakdown of expenses in diabetes management have identified that spending on insulin comprises a relatively small proportion of overall spending on diabetes care. For example, Chua et al. found that among people with type 1 diabetes, the mean out-of-pocket spending for all care was nearly $2500 in 2018, with insulin accounting for only 18% of all spending and less out-of-pocket expense than diabetes-related supplies.[7] In our study, we found that among those respondents who reported insulin rationing, 42.5% also reported challenges in purchasing diabetes-related medical equipment, compared to 7.6% among those who did not report rationing. This highlights the substantial cost burden that exists for patients with diabetes, especially when considering the additional cost of diabetes medical equipment and supplies, even if the costs of insulin were accounted for.

Access barriers due to cost are not the only reasons that lead to insulin rationing. In our study, a substantial proportion of patients reported insulin rationing due to pharmacy shortages and insurance approval delays, which were not considered in the surveys conducted by NHIS or the 2017 Yale Diabetes Center study. We found that while 48 participants reported rationing due to cost, 34 cited insurance delays, and 37 cited limited availability or shortages of insulin at the pharmacy counter. Although there is overlap in rationing due to these distinct reasons, using a broader definition that encompasses all these factors led to a significantly larger proportion of people reporting insulin rationing, at 37.7%, as opposed to 24.1% when considering cost alone.

These findings suggest a continued need to address insulin affordability and, at the same time, to tackle other access barriers, including pharmacy shortages (i.e., security of insulin supply[26]) and insurance delays. Recent insulin shortages have been, at least in part, attributed to drug manufacturers turning toward production of more profitable medications, such as glucagon-like peptide 1 receptor agonists.[17] The market dominance by three large multinational companies (Eli Lilly, Novo Nordisk, and Sanofi), which together have a 96% share of the insulin market and hold 99% of the market by value,[27] along with challenges with biosimilar options,[28] means that there are few alternative suppliers of insulin when one of the companies stops production or exits from the insulin market.[17] Interventions at the federal or state level, such as CalRx, which focuses on expanding manufacture into the public sector, may be one way to tackle these issues.[29]

Insurance approval delays, such as those encountered with prior authorization, may also contribute to insulin access barriers. The prior authorization process can be time-consuming for prescribers and challenging to navigate for patients. One recent study noted that among patients prescribed a diabetes medication which required prior authorization, over 40% did not receive either the requested medication or a new alternative.[19] Compared with patients who did receive the requested medication or a new alternative, patients in the "no medication" group were more likely to be Hispanic/Latino and had worse resultant glycemic control.

Our study has several limitations. First, the small sample size focused on a single health center may not be generalizable to other populations. Additionally, the small sample may have limited the statistical power to detect meaningful differences between subgroups. The reliance on self-reported data also introduces the potential for selection bias and misclassification, as participants may have different motivations for completing the survey. Questions about cost-related insulin rationing and broader access barriers were worded differently, potentially affecting rates of positive responses. Another potential limitation is the use of the patient's primary language as recorded in their electronic health record to screen for inclusion criteria, as this may have inadvertently excluded individuals who, while capable of understanding and speaking English, were classified under a different language in their records. Finally, our response rate of 60%, while generally considered adequate,[30] may have introduced non-response bias.

Despite these limitations, the study has several strengths. We used the same exact set of questions to capture cost-related insulin rationing in the 2024 and 2017 surveys to ensure consistency in data collection. Importantly, we maintained diligent tracking of non-respondents, which allowed for comparisons between respondents and non-respondents to assess for systematic differences.

In summary, it is evident that the prevalence of cost-related insulin rationing at the Yale Diabetes Center remains unchanged before and after legislative changes and policies surrounding co-payment caps for insulin, including the Inflation Reduction Act. Current out-of-pocket caps on insulin copayments appear to be insufficient in scope; they leave out many patients, and patients still ration insulin despite the current caps. Moreover, copayment caps do not address insurance delays or pharmacy shortages, which were reported as additional access barriers to insulin. These findings suggest that additional price reductions are needed, of not only insulin but also insulin-related and diabetes-related supplies, and, on a larger scale, governmental oversight of market dominance and major healthcare systems reforms surrounding healthcare coverage and policies, to ensure equitable access to insulin and diabetes supplies for everyone living with diabetes.

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***Author Contribution*** *SK, NR, and KL developed the concept and designed the study. SK, NR, and DW collected the data. MB and SK conducted statistical analyses. SK, NR, and KL wrote the draft of the manuscript. SK, NR, LN, DW, and MB all made critical edits to the manuscript.*

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