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Cost-Related Insulin Rationing in US Adults Younger Than 65 Years With Diabetes

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This study uses 2021 National Health Interview Survey data to examine the prevalence of insulin rationing among adults younger than 65 years in the US by demographic characteristics.

On August 16, 2022, President Biden signed the Inflation Reduction Act into law, capping the out-of-pocket cost of insulin to \$35 a month for Medicare beneficiaries. However, adults with diabetes younger than 65 years were not included. Persons with diabetes who cannot afford their medication may ration its use.¹ This study characterized the prevalence of insulin rationing among adults younger than 65 years in the US by demographic characteristics.

Methods

We analyzed the 2021 National Health Interview Survey (NHIS), a nationally representative study of noninstitutionalized US adults (see eMethods in [Supplement 1](#)). Because of the COVID-19 pandemic, telephone interviews were conducted from January to April in 2021 and in-person interviews were conducted thereafter. The response rate for the 2021 NHIS was 50.9%, with detailed procedures to account for nonresponse bias (eMethods in [Supplement 1](#)).

In adults younger than 65 years who reported a diagnosis of diabetes and the current use of insulin, we estimated the percentage who reported engaging in cost-related insulin rationing. We defined this as an affirmative response to any of the following questions: “During the past 12 months, were any of the following true for you? You skipped insulin doses to save money; You took less insulin than needed to save money; You delayed buying insulin to save money.” Among all adults rationing insulin, we characterized the percentage who were younger than 65 years to assess ineligibility for the out-of-pocket cost limit. We conducted analyses by sex, nativity (birth in the US), race and ethnicity, income, insurance coverage, and diabetes type (eMethods in [Supplement 1](#)).

Analyses were conducted using Stata, version 17.0. We used recommended survey weights to account for oversampling and survey nonresponse. The National Center for Health Statistics institutional review board approved the survey protocol, and all participants provided written informed consent.

Results

In 2021, 495 (32.5% [95% CI, 29.1%-35.4%]; weighted percentage) US adults younger than 65 years with diagnosed diabetes reported using insulin (mean age, 50.7; 253 [46.8%] women). Among these individuals, 93 (20.4% [95% CI, 16.2%-25.3%]) reported rationing insulin be-

cause of cost ([Table 1](#)). Cost-related rationing was most common in non-Hispanic Black, middle-income, and underinsured or uninsured adults.

Among all adults who reported rationing insulin, 71.1% (95% CI, 62.0%-78.8%) (93/142) were younger than 65 years ([Table 2](#)). Of those rationing insulin because of cost, the percentage younger than 65 years was highest among Hispanic adults (87.4%) and those with type 1 diabetes (98.5%).

Discussion

Among US adults younger than 65 years with diabetes using insulin, 1 in 5 reported rationing insulin because of cost. Approximately 71% of all adults who reported rationing insulin because of cost were younger than 65 years and would be ineligible for out-of-pocket limits on insulin set by the Inflation Reduction Act.

On March 1, 2023, Eli Lilly capped the out-of-pocket cost of its insulin to \$35 a month for uninsured patients and those with commercial insurance.² Two weeks later, Novo Nordisk reduced the list price of its most prescribed insulins by up to 75%³ and Sanofi limited the co-pay for its insulin to \$35 a month.⁴ These changes may improve affordability for patients not included in the Inflation Reduction Act because these 3 manufacturers make up approximately 90% of the US insulin market.

Rationing insulin has important clinical implications, especially for younger patients. In 2005 to 2012, only 30.3% of US adults younger than 50 years treated with insulin monotherapy and 12.1% treated with both insulin and oral diabetes medications met the typical hemoglobin A_{1c} target of less than 7%.⁵ From 2009 to 2015, hospitalizations for diabetic ketoacidosis increased from 24.4 to 43.5 per 1000 adults with diabetes in those aged 18 to 44 years.⁶

These findings are consistent with previous work examining the prevalence of cost-related insulin rationing¹ but extend existing research by characterizing differences within adults younger than 65 years and assessing ineligibility for insulin co-pay limits introduced by the Inflation Reduction Act.

This study had several limitations. First, there may be misclassification because all data in the NHIS were self-reported. Second, estimates were imprecise because of limited sample size, particularly in subgroups. Third, the response rate in the NHIS was 50.9%. However, analyses incorporated recommended sample weights to mitigate nonresponse bias.

Extending co-pay limits to all patients using insulin would likely improve affordability.

Notes

Section Editors: Jody W. Zylke, MD, Deputy Editor; Kristin Walter, MD, Senior Editor.

Notes

Supplement 1.

eMethods

Supplement 2.

Data Sharing Statement

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Figures and Tables

Table 1.

Percentage of US Adults Aged Younger Than 65 Years With Diabetes Who Reported Rationing Insulin Due to Cost Over the Past Year, 2021 National Health Interview Survey^a

Characteristic	Individuals rationing insulin because of cost, unweighted No.	Individuals with diabetes using insulin, unweighted No.	Individuals rationing insulin because of cost, weighted % (95% CI)
Total	93	495	20.4 (16.2-25.3)
Sex			
Men	46	242	21.3 (15.3-28.9)
Women	47	253	19.3 (14.3-25.6)
Born in the US			
No	8	69	10.5 (4.7-21.5)
Yes	81	410	22.0 (17.3-27.6)
Race and ethnicity ^b			
Hispanic	16	84	21.4 (12.2-35.0)
Non-Hispanic Black	23	100	26.7 (16.0-41.2)
Non-Hispanic White	51	279	19.4 (14.5-25.6)
Income-to-poverty ratio			
<175%	31	187	18.2 (11.6-27.4)
175%-349%	40	143	30.2 (21.7-40.3)
≥350%	22	165	13.8 (8.9-21.0)
Insurance coverage ^c			
Adequately insured	41	340	14.3 (10.3-19.4)
Underinsured or uninsured	52	152	33.7 (25.2-43.5)
Diabetes			
Type 1	26	123	23.6 (15.7-33.9)
Type 2	67	372	19.3 (14.7-25.1)

^a Rationing was defined as skipping insulin doses, using less insulin than prescribed, or delaying the purchase of insulin over the past year to save money.

^b Race was self-reported by participants from a list created by National Health Interview Survey researchers (African American, Alaska Native, American Indian, Asian, Black, Native Hawaiian, Pacific Islander, White, and other). Participants could select more than 1 race. Participants also self-reported whether they were “of Hispanic or Latino” origin. We classified participants as being Hispanic, non-Hispanic Black, non-Hispanic White, or other. Estimates for participants from other racial and ethnic backgrounds were not included because of small sample size. The “other” group included participants who were Alaska Native, American Indian, Asian, Native Hawaiian, Pacific Islander, multiracial, or other race. Race and ethnicity were assessed in this analysis to explore potential disparities in insulin rationing.

^c Being adequately insured was defined as having health insurance and not struggling to pay medical bills over the past year; being underinsured or uninsured was defined as having no health insurance or having health insurance but struggling to pay for medical bills over the past year.

Table 2.

Percentage of US Adults With Diabetes Who Reported Rationing Insulin Due to Cost Over the Past Year and Were Younger Than 65 Years, 2021 National Health Interview Survey^a

Characteristic	Individuals aged <65 y rationing insulin because of cost, unweighted No.	Individuals rationing insulin because of cost, unweighted No.	Individuals <65 y rationing insulin because of cost, weighted % (95% CI)
Overall	93	142	71.1 (62.0-78.8)
Sex			
Men	46	73	72.4 (60.2-82.0)
Women	47	69	69.6 (55.6-80.6)
Born in the US			
No	8	13	67.6 (34.1-89.4)
Yes	81	122	71.6 (61.5-79.9)
Race and ethnicity ^b			
Hispanic	16	20	87.4 (69.7-95.4)
Non-Hispanic Black	23	34	70.8 (49.9-85.5)
Non-Hispanic White	51	84	66.1 (54.8-75.7)
Income-to-poverty ratio			
<175%	31	46	76.9 (60.5-87.8)
175%-349%	40	67	64.4 (50.4-76.3)
≥350%	22	29	79.1 (60.9-90.2)
Insurance coverage ^c			
Adequately insured	41	71	68.5 (55.8-79.0)
Underinsured or uninsured	52	71	73.6 (60.1-83.8)
Diabetes type			
Type 1	26	27	98.5 (89.7-99.8)
Type 2	67	115	64.0 (53.0-73.7)

^a Rationing was defined as skipping insulin doses, using less insulin than prescribed, or delaying the purchase of insulin over the past year to save money.

^b Race was self-reported by participants from a list created by National Health Interview Survey researchers (African American, Alaska Native, American Indian, Asian, Black, Native Hawaiian, Pacific Islander, White, and other). Participants could select more than 1 race. Participants also self-reported whether they were "of Hispanic or Latino" origin. We classified participants as being Hispanic, non-Hispanic Black, non-Hispanic White, or other. Estimates for participants from other racial and ethnic backgrounds were not included because of small sample size. The "other"

group included participants who were Alaska Native, American Indian, Asian, Native Hawaiian, Pacific Islander; multiracial, or other race. Race and ethnicity were assessed in this analysis to explore potential disparities in insulin rationing.

^c Being adequately insured was defined as having health insurance and not struggling to pay medical bills over the past year; being underinsured or uninsured was defined as having no health insurance or having health insurance but struggling to pay for medical bills over the past year.