



Insulin Rationing in High-Income Settings: Cost-Related Non-Adherence and Its Clinical Signature

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Received: 25 January 2024; Accepted: 12 July 2024; Published: 7 December 2024

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Abstract

Cost-related insulin underuse is common in wealthy countries and its prevalence has not moved. A survey at a single academic diabetes centre found that 51 of 199 respondents, 25.5 per cent, had used less insulin than prescribed because of cost in the previous year, and those who had were three times as likely to have an HbA1c above 9 per cent after adjustment. The same survey repeated at the same centre seven years later, after a series of policies intended to limit out-of-pocket insulin costs, found 48 of 199 respondents, 24.1 per cent, doing the same thing, a difference that was not significant. Two further findings sharpen the picture. Counting insurance delays and pharmacy shortages alongside cost raised the figure to 37.7 per cent, so price is not the whole barrier. And the share of those rationing who had type 1 diabetes rose from 43.1 to 63.0 per cent, concentrating the behaviour in the group for whom omission is most dangerous. This review sets out what is measured, what it predicts, and why the policy response has not registered.

Keywords: Insulin rationing; Cost-related non-adherence; Medication access; Glycaemic control; Health policy

Introduction

Insulin has been available for a century and is on every list of essential medicines [1,2]. In several high-income countries its price to the patient has nonetheless risen to a point where some people take less than they are prescribed in order to make a supply last [3,4,19,21]. The absence of a generic insulin has been traced to the history of the product itself [34], and the market structure to barriers to competition [18].

The behaviour has a specific clinical signature. Reducing or omitting insulin produces hyperglycaemia that is invisible between appointments and, in type 1 diabetes, carries a direct risk of ketoacidosis [5,6]. Deaths have been reported in young adults who rationed after losing insurance coverage [3,7,22]. Catastrophic out-of-pocket spending on insulin has been quantified directly [29,30], and rationing among young people described separately [31,32].

This review examines how often cost-related underuse occurs, what it predicts, whether policies intended to address it

have changed the figure, and what the measurement does not capture.

Material and Methods

Search strategy: PubMed and the archives of the major diabetes, general medicine and health policy journals were searched for studies of cost-related insulin underuse. Search terms combined insulin with rationing, cost-related non-adherence, underuse, affordability and out-of-pocket cost. Reference lists of the principal surveys [8,9] were screened by hand for related analyses.

Eligibility: Studies were included if they measured cost-related insulin underuse with a defined instrument in a described population, or related it to a clinical or utilisation outcome. Adherence studies not distinguishing cost as the reason are cited for contrast and identified as such.

Data extraction and handling: Setting, sampling frame, response rate, the definition of underuse and the reported

estimate were extracted as published. The definition used is stated alongside every prevalence figure, because instruments counting six behaviours return higher figures than those counting one, and because counting non-cost barriers alongside cost changes the answer substantially. No pooling or re-analysis was performed. Figures 1 to 6 and Tables 1 to 3 reproduce published values only. This is a narrative synthesis and was not registered as a systematic review.

Results

How underuse is measured: The instrument used in the principal surveys counts a positive response to any of six questions about the previous 12 months: using less insulin than prescribed, trying to stretch insulin out, taking smaller doses than prescribed, stopping insulin, not filling a prescription, and not starting insulin, in each case because of cost (Figure 6) [8].

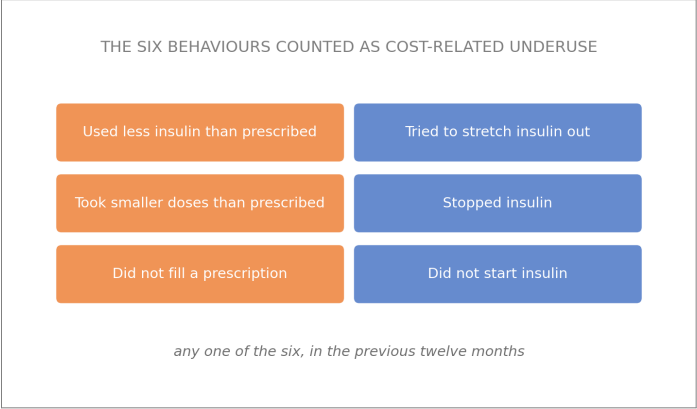


Figure 6: The six behaviours counted as cost-related underuse [8]

Prevalence: Of 354 patients prescribed insulin who attended an academic diabetes centre in July 2017, 199 (56.2 per cent) completed the survey. The respondents were 50.8 per cent female, 60.8 per cent white and 41.7 per cent had type 1 diabetes. Fifty-one (25.5 per cent) reported cost-related underuse in the previous year (Figure 3) [8].

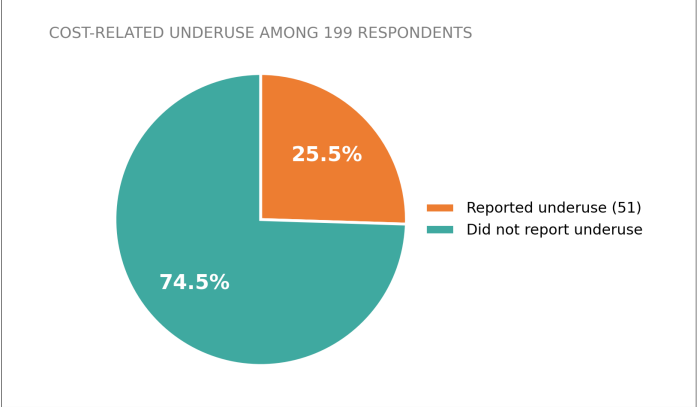


Figure 3: Cost-related underuse among 199 respondents in 2017 [8]

What it predicts: After adjustment for age, sex, diabetes duration and income, those reporting cost-related underuse had three times the odds of an HbA1c above 9 per cent compared with those who did not (Figure 4) [8]. National analysis using

2021 survey data defined rationing as skipping doses, delaying purchase or taking less than needed to save money, and examined emergency department attendance, overnight hospitalisation and urgent care visits in relation to it [10,11,32]. Adherence to diabetes medication generally has been characterised in large claims datasets, without separating cost as the reason [25,28].

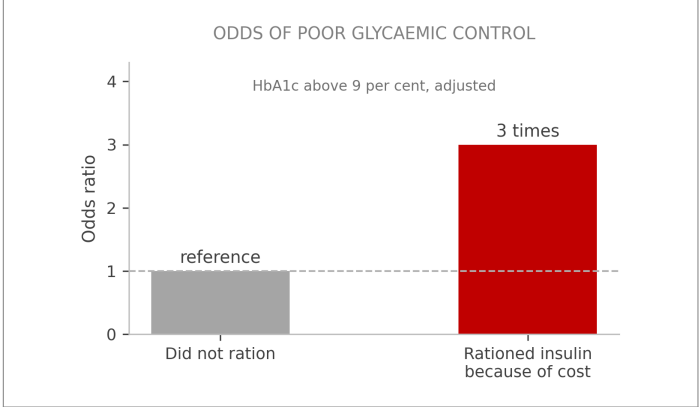


Figure 4: Adjusted odds of poor glycaemic control among those rationing insulin [8]

Seven years and a series of policies later: The same survey was repeated at the same centre in 2024, after multiple policies intended to limit out-of-pocket insulin costs had been introduced. Of 199 respondents (mean age 52.4 years, 47.7 per cent female, 58.3 per cent white, 47.2 per cent type 1 diabetes), 48 (24.1 per cent) reported cost-related rationing, against 51 (25.5 per cent) in 2017. The difference was not significant ($p = 0.41$) (Figure 1) [9].

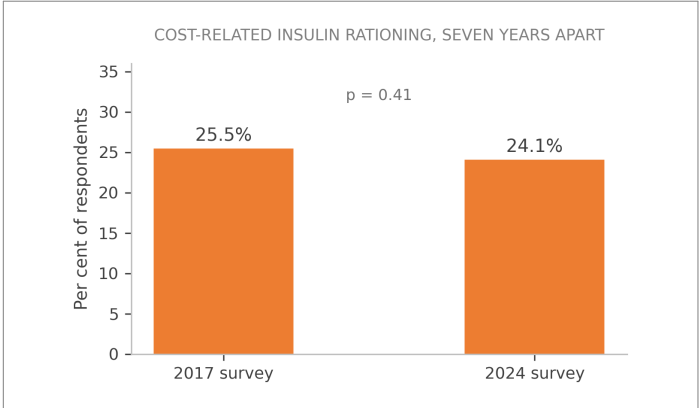


Figure 1: Cost-related insulin rationing at the same centre, seven years apart [8,9]

Cost is not the only barrier: When the 2024 survey counted rationing due to cost, insurance delays or pharmacy shortages together, 75 participants (37.7 per cent) reported it, against 24.1 per cent for cost alone (Figure 2) [9]. A measure restricted to price therefore understates the number of people not taking the insulin they are prescribed by about half as much again.

Measure	2017 survey	2024 survey
Respondents	199 of 354 (56.2%)	199 (60.1%)
Cost-related rationing	51 (25.5%)	48 (24.1%)
Difference	—	p = 0.41
Type 1 among those rationing	43.1%	63.0% (p = 0.05)
Any access barrier	not reported	75 (37.7%)

Table 1: The two surveys compared, as reported by the original investigators [8,9]

Barrier	Addressed by a price cap?
Out-of-pocket cost of insulin	Yes, in principle
Insurance authorisation delays	No
Pharmacy supply shortages	No
Loss of coverage on ageing out of a plan	Only if the cap applies
Cost of supplies other than insulin	Not covered by insulin-specific caps

Table 3: Barriers to insulin access and whether a price cap addresses each [9]

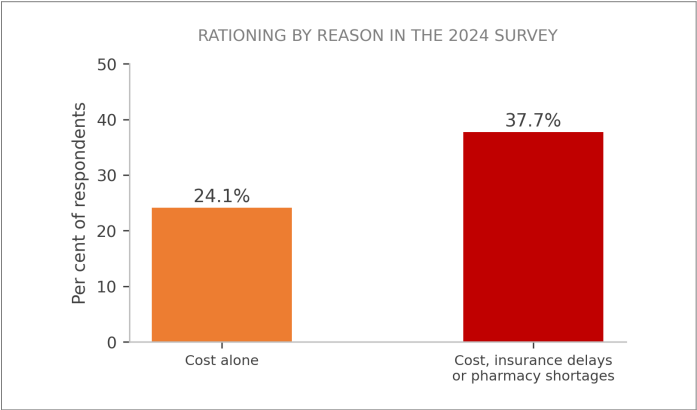


Figure 2: Rationing by reason in the 2024 survey [9]

Who is affected has shifted: The characteristics of those reporting rationing were broadly similar between the two surveys, with one exception. The proportion with type 1 diabetes among those rationing rose from 43.1 per cent in 2017 to 63.0 per cent in 2024 (p = 0.05) (Figure 5) [9].

What insulin costs the patient: Out-of-pocket spending has been quantified directly, and a proportion of insulin users meet definitions of catastrophic expenditure, meaning that insulin alone consumes a substantial share of household income after other essentials [29,30]. That framing matters because it locates the behaviour in a budget rather than in a choice: a person who rations is not prioritising badly but allocating a fixed sum across competing necessities [14,16].

Rationing at particular ages: Young adults are described repeatedly as a group at risk, both because coverage frequently changes at the point of leaving a family plan and because type 1 diabetes is concentrated in younger cohorts [7,31]. Analyses of rationing among youth and young adults report it alongside adverse outcomes, and the deaths that brought the issue to public attention occurred in this group [3,32].

Discussion

The most useful result in this literature is the one that shows nothing happened. Between 2017 and 2024 a series of policies were introduced to limit what patients pay for insulin, and at the centre where the original measurement was made the proportion rationing went from 25.5 to 24.1 per cent, a difference with a p value of 0.41 [8,9]. That is a repeated measurement in the same setting with the same instrument, which makes it a stronger test of policy effect than most before-and-after comparisons.

Two explanations sit behind that non-result, and the 2024 data support both. The first is that price is not the only obstacle: counting insurance delays and pharmacy shortages raised the figure from 24.1 to 37.7 per cent, so more than a third of patients were not taking their insulin as prescribed for reasons a price cap does not touch [9]. The second is that caps are conditional on the plan a person holds, and those most exposed are frequently those whose coverage is unstable or absent.

The shift in who is rationing deserves particular attention. The proportion with type 1 diabetes among those rationing rose from 43.1 to 63.0 per cent [9]. Insulin omission in type 1 diabetes is not equivalent to omission in type 2: there is no endogenous secretion to fall back on, and the risk is ketoacidosis within days rather than gradual hyperglycaemia [5,6]. The behaviour has concentrated in the group where it is most dangerous.

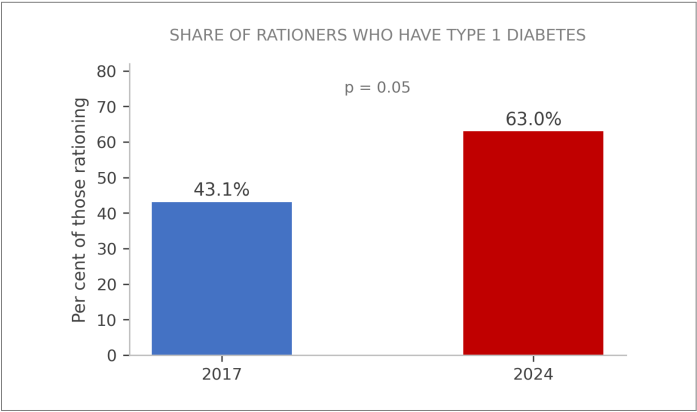


Figure 5: Share of those rationing who have type 1 diabetes [9]

Consequence	What has been reported
Glycaemic control	Three times the odds of HbA1c above 9% [8]
Emergency care	Examined against ED visits and admissions [10,11]
Ketoacidosis	Direct risk of omission in type 1 diabetes [5,6]
Mortality	Deaths reported after loss of coverage [3,7]

Table 2: Clinical consequences associated with cost-related insulin underuse

For clinical practice the relevant point is that this is measurable in a consultation and largely is not measured. A patient with an unexplained HbA1c above 9 per cent has three times the odds of having rationed, and the question that would detect it is one of six short items [8]. Treatment intensification in someone who is not taking the insulin they already have is not merely ineffective; it raises the cost of the regimen and may worsen the underlying problem.

A caution about generalisation is warranted, and it cuts in an unusual direction. These surveys were conducted at a specialist centre in a country with an unusual insulin pricing system, and the figures should not be transferred to settings where insulin is supplied at low or no cost [12,13]. But cost-related non-adherence to other medicines is documented in many health systems, and the mechanism, that a person facing a constrained budget rations the thing they can ration, is not specific to insulin or to one country [14,15,17]. Access to insulin is a recognised global problem with a different shape in lower-income settings [13,33], and cost-reducing behaviours have been described across chronic disease [16].

It is worth separating two claims that are often merged in commentary. That insulin is expensive in some markets, and that the reasons are structural rather than related to manufacturing cost, is well documented and not seriously contested [18,19,34]. That any particular policy will reduce rationing is a separate empirical question, and the repeated survey is among the few pieces of evidence that bears on it directly [9,20]. Its answer, at one centre over seven years, was that the measured prevalence did not move.

There is also a measurement point that limits what can be concluded from any single figure. The six-item instrument counts a wide range of behaviours, from stretching a supply to never starting insulin at all, and these differ enormously in clinical consequence [8]. A prevalence of a quarter therefore describes a heterogeneous group, and the subset at immediate risk of ketoacidosis is smaller than that and not separately reported [5,8].

A final observation concerns what the clinic can see. Rationing leaves no trace in a prescribing record: the prescription was issued, and whether the insulin was collected, and then taken as directed, is invisible unless someone asks [8,25]. Dispensing data capture the first of those steps but not the second, which is why adherence estimates drawn from claims databases and estimates drawn from patient report diverge [25,28]. The behaviour is therefore systematically underdetected by exactly the data sources that health systems use to monitor quality.

That has an implication for how these findings should be read against routine statistics. A service reporting good prescribing performance may be describing prescriptions issued rather than treatment received, and the gap between the two is concentrated in the patients least able to pay [16,17]. The

surveys reviewed here are valuable precisely because they asked a question that administrative data cannot answer [8,9].

Study limitations

The limitations belong to the underlying literature. The principal prevalence estimates come from cross-sectional surveys at a single academic centre, with response rates of 56.2 and 60.1 per cent, so non-response bias cannot be excluded and could run in either direction [8,9]. Underuse is self-reported and concerns behaviour that patients may be reluctant to disclose, which would bias towards underestimation. The association with poor control is cross-sectional and adjusted for a limited set of covariates, so residual confounding by socioeconomic position is likely and reverse causation cannot be excluded [8]. The 2024 comparison is between two independent samples rather than the same individuals followed over time [9]. Definitions of rationing differ between the single-centre surveys and the national analysis, so the figures are not directly comparable [8,10]. The evidence is overwhelmingly from one country with a distinctive pricing structure [12]. And no study reviewed here evaluates an intervention delivered in the clinic, so what a clinician should do once rationing is identified rests on reasoning rather than evidence [14,16,26,27]. Standards of care address population-level barriers but do not specify a clinic response [23], and policy analyses have proposed strategies without evaluating them prospectively [20,24].

What would help

Three things follow from this evidence with reasonable confidence. Asking about cost-related underuse should be routine where glycaemic control is unexpectedly poor, because the association is strong and the question is short [8]. Measures aimed at price should be paired with measures aimed at authorisation delays and supply, since those account for the difference between 24.1 and 37.7 per cent [9]. And prescribing decisions should treat affordability as a property of the regimen rather than of the patient, because a regimen that cannot be afforded is not being delivered whatever the record says [14,23].

What would settle more is a study this literature does not contain: a prospective evaluation of a clinic-level intervention, with rationing measured before and after and glycaemic outcomes attached. The repeated survey establishes that the problem persisted through a period of policy activity; it cannot establish what would have changed it [9,20,26].

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Conclusion

A quarter of insulin-treated patients at one specialist centre reported using less insulin than prescribed because of cost, and seven years of policy aimed at insulin prices left that figure statistically unchanged. Counting insurance delays and pharmacy shortages alongside cost takes it above a third, which explains part of why price measures alone did not register, and the behaviour has concentrated among people with type 1 diabetes, for whom omission carries the most immediate danger. The clinical implication is narrow and actionable: an unexplained HbA1c above 9 per cent carries three times the odds of rationing, and asking is cheaper than intensifying a regimen the patient is already unable to afford.

Acknowledgements

The authors thank the investigators who repeated a survey at the same centre seven years apart, which is what made the absence of change measurable, and the patients who disclosed rationing to their own clinical service.

Funding

No dedicated funding from public, commercial or charitable sources supported the preparation of this review.

Conflict of Interest

The authors declare no competing interests.

Ethics Statement

This article reviews previously published studies only. No new patient data were collected and no participants were recruited, so ethical approval was not required.

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Citation: Prosser H, Malinowski B, Grech R. "Insulin Rationing in High-Income Settings: Cost-Related Non-Adherence and Its Clinical Signature". DOI: 10.5281/zenodo.22260607