Lack of Access to Insulin among People with Type 1 Diabetes in the US

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Summary+
Insulin is a life-preserving medicine for individuals with type 1 diabetes. Insulin is especially inaccessible in the United States compared to other high-income nations due to patents and production monopolies, insufficient insurance coverage and other barriers to healthcare, and increased use of insulin analogs. As a result, individuals affected by this face a series of challenges, from turning to insulin rationing, and high rates of diabetic ketoacidosis, to a high mental toll. While this remains a complex issue, policy measures may be an effective way to make insulin more accessible for more Americans. Education on the need for better access to insulin is also an important practice to mitigate the issue. The complexities are vast, but the issue is crucial to address to help people with type 1 diabetes live prosperous lives.

Key Takeaways+

- The issue of insulin access is a matter of life and death for people with diabetes because of the nature of type 1 diabetes and the role of insulin in its management.
- The root causes of lack of access to insulin in the United States are complex because of the unique market for insulin and the workings of the US health system. Ultimately, insulin is unaffordable.
- The negative effects of lack of access to insulin go beyond just physical symptoms and have large effects on the mental well-being of people with type 1 diabetes.
- Creating and passing policy to regulate the cost of insulin may be a promising practice to improve this issue for people with type 1 diabetes.

Key Terms+

**Type 1 Diabetes**—Type 1 diabetes occurs when the pancreas in the body cannot produce insulin. It is a chronic condition that has no known cure and is treated with artificially made insulin. ¹

**Insulin**—Insulin is a hormone produced in the pancreas that changes glucose in the blood into energy that cells use to perform their functions. ²

**Insulin Pens**—A vial of insulin inside a reusable syringe that a disposable needle is attached to inject the desired insulin dose into the body. ³

**Analog Insulin**—Analog insulin is produced in a lab and is intended to mimic the function of pancreas-produced insulin. It has an altered molecular structure from normal lab-produced insulin to increase the speed of reaction in the body and improve diabetes control in people with type 1 diabetes. ⁴

**Health System**—Health system is the combination of people, institutions, and resources that function together to deliver healthcare to a population. In this case, the health systems of nations are delivering healthcare to the population of that nation.

**PTSD**—Post Traumatic Stress Disorder. PTSD occurs when a person has trouble recovering after experiencing a terrifying event and can manifest in anxiety, depressed mood, nightmares, and unwanted memories, especially surrounding triggers of the terrifying event.
Diabetic Ketoacidosis—This occurs when the blood glucose level in the body is too high, typically due to a lack of insulin. Diabetic Ketoacidosis results in the overproduction of blood acids called ketones which are dangerous to the body. 

Patent—An exclusive right granted by law to protect a new invention or method of doing something so that it cannot be imitated for profit by others.

Blood Glucose Level—Refers to the concentration of glucose in someone’s blood at a given time. The United States typically measures Blood Glucose Levels in mass concentration in the United States in units of mg/dL (milligrams of glucose per deciliter of blood). A typical healthy target level range for blood glucose is 80–130 mg/dL.

Context

Q: What are diabetes and insulin, and how do they affect the human body?

A: Diabetes is a chronic health condition that prevents the body from being able to transform carbohydrates into usable energy due to issues with insulin production or absorption. When a person consumes carbohydrates, the digestive system breaks them down into sugar, or glucose, entering the bloodstream. Insulin is the hormone that helps cells absorb the sugar and use it as energy. Insulin is a hormone naturally produced by the body in the pancreas, and all human beings require insulin to live. Most often, those who have type 1 diabetes require insulin produced in a lab because their pancreas fails to produce insulin naturally. It is the only drug that serves the needed purpose of changing carbohydrates in the form of glucose into energy the body can use. Without treatment, people with diabetes acquire excess glucose in their blood, eventually leading to diabetic ketoacidosis. Over time, this causes life-threatening health complications such as heart disease and kidney disease.
Q: What are the different types of diabetes? Which type requires insulin?

A: The 2 main types of diabetes are type 1 and type 2. Those with type 1 produce no insulin, while those with type 2 either do not produce enough insulin to keep blood glucose levels at a healthy level or the insulin they produce is not absorbed properly. Blood glucose levels that are higher or lower than the healthy target level (80-130 mg/dl) present dangerous health side effects, so people with type 1 diabetes aim to keep their blood glucose levels in a healthy range using insulin. Both types of diabetes can be developed at any point throughout life; however, most people develop type 1 in childhood and adolescence and type 2 in adulthood. Type 1 diabetes is developed due to an autoimmune reaction in which the body attacks itself and destroys insulin-producing cells in the pancreas. The triggers for this autoimmune reaction are generally unknown but may include viruses or genetic factors. Therefore, type 1 diabetes requires pharmaceutical insulin for survival. There are 1.6 million Americans currently living with type 1 diabetes, and there are 64,000 diagnosed each year. People with type 1 diabetes make up 5-10% of all diabetes in the United States, with the other 90-95% having type 2 diabetes. These percentages mean that about 37 million Americans have diabetes, which is 12.3% of the American population.

Several lifestyle and genetic factors can cause type 2 diabetes. Individuals who are not physically active and overweight or obese are more likely to develop type 2 diabetes. People with type 2 diabetes manage their diabetes with various treatments such as exercise, diet, oral medication, and at times, insulin. Individuals with type 2 diabetes may produce different insulin levels or find other treatments effective, so reliance on insulin varies.

Other types of diabetes include gestational diabetes during pregnancy and diabetes caused by pancreas removal due to cancer or other illnesses. Though there are other types of diabetes besides type 1, this brief will focus on type 1 diabetes and barriers to insulin access for that population due to their high reliance on insulin.

Q: What are the different kinds of insulin, and how are they used?

A: The 2 primary types of manufactured insulin (made in a lab) are human insulin and insulin analogs. Both have the same function of transforming glucose into usable energy; however, insulin analogs are designed to mimic insulin naturally produced by the pancreas more closely with faster action times once injected. Human insulin can also be less predictable in its effects on blood sugar. Human insulin was produced before analog insulin and is now slowly being pushed out of the market as people with diabetes view
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insulin analogs as the better treatment option. However, human insulin is still around because analogs are often more expensive to acquire.26 The recommended dosage of manufactured insulin depends on the person as well as their carbohydrate consumption. On average, people with type 1 diabetes require 0.5-0.8 units of insulin per kilogram of body weight per day.27 Insulin is most commonly injected by people with diabetes using syringes, pens, or pumps.28

Q: What has been the impact of insulin?

A: Diabetes was once a death sentence, but with the assistance of insulin, it has become a manageable condition. This effect happened almost immediately after its discovery in the early 20th century. Before discovering insulin, patients with type 1 diabetes were treated with strict diet regimens, and life expectancy after receiving a diabetes diagnosis was less than 3 years.29 Even currently, "the main cause of mortality for a child with type 1 diabetes is a lack of access to insulin.30 Using insulin therapy, the current life expectancy of a person with type 1 diabetes has increased to almost 70 years for both men and women.31 Due to the discovery of insulin, the quality and quantity of life for people with diabetes have dramatically increased.32

Q: When did insulin become so inaccessible?

A: Insulin was first discovered in Canada in 1921 by Dr. Frederick Banting and Charles Best. After receiving the Nobel Prize for their discovery, Banting and Best sold the patent for $1.00. They intended that insulin "belong to the world" and be accessible at little or no cost, due to its life saving nature.33 However, this is not currently the case. Inaccessibility to insulin is a growing problem due to cost increases from monopolies held by pharmaceutical companies and the unchanging demand for insulin. In the late 90s, a vial of insulin cost between $25.00-$40.00, and now a 10 mL vial costs between $175.00-$300.00.34,35 Prices of insulin have risen 15% on average per year since 2012.36 This shift results from various factors, including monopolies on the insulin market, patents, and a steady demand for insulin.

Q: Where is lack of access to insulin a problem?
Insulin access is an issue globally in both high and low-income countries, but barriers to insulin manifest in different ways. For instance, the life expectancy of a child with type 1 diabetes in sub-Saharan Africa can be as low as 1 year because they lack access to insulin. Among high-income countries, the problem is especially prevalent in the United States where insulin prices are higher than other high-income countries and continue to rise. Though sources vary on the exact pricing of insulin depending on brand and manufacturer, as well as the year data is recorded, pharmaceutical data shows that the average cost per standard vial of insulin for individuals in 2018 was $7.52 in the UK, $12.00 in Canada, and $6.94 in Australia, compared to $98.70 in the United States.

These prices also depend on insulin insurance coverage. On average, uninsured patients in the United States, pay between $175.00 and $300.00 dollars for individual vials of insulin. These prices are not dependent on geographical region. With most people with diabetes requiring 3 or more vials per month, the total cost each month comes out to between $525.00-$900.00 dollars. Extensive research has shown that type 1 diabetes is a unique chronic illness because only insulin can treat it. Insulin has no generic options on the market, while many other chronic illnesses can be treated using a variety of generic drugs available on the market.

**Q: Who is most vulnerable to insulin access barriers?**

Individuals with low-income and those with inadequate access to health insurance are especially vulnerable to insulin access barriers. In the United States, blacks, Hispanics, and some Asian groups have lower levels of health insurance coverage which limits their access to prescription drugs such as insulin. Based on the health system in the US, young adults are also especially vulnerable to a lack of health insurance. At age 26, they are no longer able to receive benefits from their parents' insurance. but they may not have a high income or good insurance of their own to cover their insulin needs.

**Contributing Factors**
Patents and Insulin Production by Private Companies

Insulin production by private companies, patents on insulin delivery methods, and an increased use of insulin analogs have created much higher insulin prices, making it much harder for people with type 1 diabetes to afford needed insulin. Though insulin is a life sustaining medicine, it is produced by private companies that are influenced by business markets and competition. Approximately 90% of insulin globally, and almost 100% used in the United States, is produced by the same three multinational companies; Eli Lilly, Sanofi, and Novo Nordisk. These three companies, often called "the big three", are able to control much of the market for insulin. As a result, other insulin manufacturers struggle to break into the market with lower prices than these competitors. As with any monopoly situation, "the big three" are able to charge 8 times more for their product to consumers in the United States than other high-income countries, because there are no other entities offering the same product at a lower price and prices are not capped by law in the US. For people with type 1 diabetes who are required to buy insulin to live, these high prices often force people with diabetes to buy insulin at unaffordable costs.

Though insulin production is not limited by patents, there are patents on various insulin delivery methods, such as injection devices like insulin pens and omnipods. In many cases, insulin is inseparable from the delivery method because they are manufactured as the same item. For example, insulin pens are made with a cartridge of insulin already inside, so they cannot be bought separately. Therefore, these patents play a major role in increasing costs of insulin. For a company outside of the "big three" to enter the market with insulin, they would have to create a new delivery method in addition to insulin because of those patents. This obstacle discourages other companies from entering the market due to high production and innovation costs. Therefore, people with type 1 diabetes rely on the expensively priced insulin.

Insufficient Insurance Coverage and Other Barriers to Healthcare
Conditions in the US health insurance system provide challenges for certain groups of people to get insurance coverage. For uninsured people with type 1 diabetes (about 10% in 2012), these conditions create a greater barrier to insulin access because the uninsured are required to pay out-of-pocket for insulin.49 Prior to the Affordable Care Act (ACA) of 2010, individuals with preexisting conditions such as diabetes could be denied coverage or be required to pay much higher premiums because of the increased likelihood of needing medical care costs covered.50 This affected over 100 million people who have pre-existing conditions that could make them uninsurable without these policy changes from the ACA.51

The ACA makes it illegal to deny coverage or charge higher premiums based on preexisting conditions. However, even with health coverage expansions brought about by the Affordable Care Act, 30.4 million people remained uninsured in the United States in 2018.52 The remaining number of uninsured individuals can be attributed to a myriad of factors, including political healthcare policies. For example, the “coverage gap” describes individuals with a high-enough income to disqualify them for federal health insurance (Medicaid), but still cannot afford private insurance.53

Low-income, Latino, and individuals under the age of 35 make up a disproportionate number of the uninsured working-age adults in the United States.54 Current regulations dictate that individuals can stay on their parent’s insurance plans until the age of 26 before they must get their own insurance.55 Data in 2019 showed that the uninsured rate for 26 year olds was 18.3%, which was the highest rate of uninsured followed by age 27 at 17.5%.56 These rates of uninsured affect more people than just people with diabetes, but being uninsured can be particularly dangerous for people with diabetes because of the added barriers to affordable insulin. Though numbers change year to year, the trends remain the same. In 2012, 2 million individuals with diabetes between 18-85 were uninsured in the United States.57 Even for insured people with diabetes, the variability in plans and coverage mean that certain types of insulin may not be covered.58 Once again, without insurance coverage, the cost of insulin is much higher for the patient.

A lack of insurance can prevent patients from being able to buy insulin, but lack of insurance can also prevent patients from being able to afford going to the doctor to receive a prescription when coupled with high costs of doctor visits.59 A 2017 study reported that individuals without insurance were much more likely to postpone or forgo care due to cost.60 In addition, 19% of those without insurance reported postponing or not getting a needed prescription drug due to cost, compared to 3% of those with private or employer provided insurance.61 Where people have insurance coverage, several access barriers may still
prevent them from the care they need. Individuals may not have adequate transportation to and from a care center, they may not have options for childcare, or they may not be able to take time off of work to get to a doctor. These factors can prevent individuals from seeking medical care, which impacts the ability of a type 1 diabetic to receive the proper prescriptions to access necessary insulin. In the United States, a prescription is required to obtain most forms of insulin. There are some exceptions to this. For instance, human insulin can be bought without a prescription at Walmart, but it is an older form of insulin that takes longer to metabolize and perform its function in the body. Buying this type of insulin means that patients are getting a less effective form of treatment. In addition, various sources report that it is a major risk to patients to use these insulins without a prescription and doctors involved to help calculate dosage. In this sense, barriers to healthcare also cause barriers to insulin.

The Challenge of Insulin Analogs

Another contributor to increased prices of insulin is greater prevalence of insulin analogs. Analogs work better than human insulin due to speed of absorption and peak reaction times in the body, but are more expensive to produce, procure, and purchase. Due to their effectiveness, use has increased dramatically in the past 20 years. In 2000, only 19% of people with diabetes used analog insulin. This number rose to 92% by 2010, and by 2018 analogs accounted for 91% of insulin volume used and 92% of insulin sales in the United States. One study reported that in the United States, insulin analogs accounted for prescriptions in more than 80% of treatment visits between 2016 and 2020. Unfortunately, there are no generic versions of these analog insulins available on the market, and cheaper human insulin formulas are not as available in the United States. Without a prescription, patients can buy over the counter human insulin at Walmart, but this is tied to inherent risks with less effective insulin and limited doctor supervision. Analogs are considered the most effective form of insulin to manage diabetes, but are very costly. Without prescriptions, these high-cost insulins are the most effective options given to people with diabetes, who have no choice but to use less effective human insulin, ration insulin dosage, or choose to not buy insulin due to the high cost.

Negative Consequences

Insulin Rationing
When access to insulin is too limited to support adequate doses of the drug for proper diabetes management, insulin rationing occurs. Each diabetic has required amounts of insulin depending on their body as well as the amount of carbohydrates they consume. Insulin rationing occurs when a patient limits his or her insulin use to small dosages because their recommended dosage of insulin is too expensive.

Until recently, not much was known about the rates of insulin rationing among people with type 1 diabetes. However, in a 2018 study, 18% of respondents reported insulin rationing worldwide. A quarter of people with type 1 diabetes in the US reported the same practice—the rate of insulin rationing in the US is the highest among all high-income nations. These results and other studies have shown that insulin rationing is far more common than originally thought.

The result of insulin rationing is that blood glucose levels run much higher than is healthy. Insulin rationing can lead to diabetic ketoacidosis and severe complications. Patients who participate in insulin rationing are putting themselves at risk for blindness, kidney failure, amputations, hospital stays, and even death. From 2017–2019 alone, at least 13 individuals with diabetes died due to insulin rationing.

High Rates of Diabetic Ketoacidosis

Diabetic ketoacidosis occurs when there is not enough insulin in the body to regulate blood glucose levels. When glucose levels are high because of lack of insulin, diabetic ketoacidosis eventually occurs. This is a major problem for those who lack access to insulin or have significant insulin access barriers because they often do not have enough insulin to prevent this condition. Diabetic ketoacidosis affects both people with type 1 and type 2 diabetes, and is one of the two leading causes of hospitalization for people with type 1 diabetes.
There are both long and short-term issues associated with increased rates of diabetic ketoacidosis. Short-term effects include excessive thirst, nausea and vomiting, shortness of breath, and confusion. Diabetic ketoacidosis also often requires treatment by a doctor and a hospital stay which results in high medical bills and further challenges with insulin affordability. Long term effects of frequent or prolonged diabetic ketoacidosis can include damage to blood vessels, heart attack, stroke, and decreased sensitivity and functioning of the feet, eyes, kidneys, and other organs. Isolated and prolonged instances of diabetic ketoacidosis can also lead to coma and death. Not only is this condition a challenge for the individual, but also places a heavy burden on the healthcare system. Diabetes costs the US more than $327 billion per year for services such as hospital admissions, where 25% of people with type 1 diabetes each year are admitted for diabetes related causes.

Without access to insulin, blood glucose levels become unhealthily high and diabetic ketoacidosis is much more likely to occur. It is clear that diabetic ketoacidosis is an undesirable consequence of lack of insulin access. Diabetic ketoacidosis causes suffering to people with type 1 diabetes, as well as decreasing their ability to perform normal tasks and function in regular capacities.

**Psychological Distress**

Individuals who struggle to gain access to insulin experience high levels of stress and concern that can degrade their quality of life. Because insulin is necessary to sustain life for people with type 1 diabetes, a lack of access can create extreme stress and psychological distress.

A recent qualitative study on adults experiencing insulin insecurity studied the effect of this stressor on their mental well being. Most participants reported negative effects on mental health due to this insecurity, including; loss of sleep, high levels of anxiety and stress, and depression. Others reported experiencing PTSD from their struggles to sustain their life with insulin, as well as dangerously fluctuating blood glucose levels as a result of high stress levels in the body. Even after adjusting for other potential mental health factors like poverty and marital status, diabetic Americans are 20% more likely to be diagnosed with anxiety than people without and 29% more likely to receive a depression diagnosis. These statistics only reflect people with diabetes who have received a diagnosis. One study estimates that depression rates are actually 2–3 times higher among diabetic individuals, but many do not receive a diagnosis due to the stigma surrounding mental health. Additionally, people with type 1 diabetes experience such constant stress that they experience higher rates of stress-induced physical harm.
The psychological distress that is a consequence of these insulin access barriers is closely tied to other challenges that people with type 1 diabetes face as well. Those struggling to afford insulin will likely not be able to afford mental health services to handle the stress of their situation. Handling PTSD, depression, or other challenges that may come with lack of access to a life saving drug may decrease the individual’s ability to work enough hours or access resources needed to help their situation. Psychological distress also drastically decreases the quality of life of people with type 1 diabetes.

Best Practices

Increasing Insulin Affordability through Policy

For people with type 1 diabetes across America, it is important that insulin become more affordable as soon as possible. One of the most reaching ways this can be accomplished is through federal policy that caps insulin prices. Drug price regulation is common in other western nations, although it is executed differently than it likely would be in the United States. In Germany, for example, a panel gives new drugs entering the market a maximum set price that insurers and consumers can pay; this is a practice called "reference pricing." The US does not have a singular body that designates healthcare prices, which makes this exact format unfeasible in the United States. However, drug price regulation can come in the form of legislation on Capitol Hill.

Examples of proposed legislation include the “Insulin Price Reduction Act,” the “Affordable Drug Manufacturing Act”, and most recently, an insulin price cap of $35.00 for a month’s supply of insulin included in the “Build Back Better” bill. While the exact language of the legislation differs, each of these is intended to make insulin more affordable for Americans. Though price caps on insulin typically gain bipartisan support, they often do not pass because they are included as part of bills that contain more partisan legislation. Players from the pharmaceutical lobby can also provide barriers to passing this type of legislation because they have vested interests in the profits from drugs such as insulin. As of yet, none of these proposed bills have become law, with the “Build Back Better” bill passing the House but not the Senate.
With failing legislation on Capitol Hill, some states have passed their own price caps on insulin copays. Eight states from both sides of the political spectrum (Maine, New Mexico, New York, Utah, Washington, West Virginia, Colorado, and Illinois) have capped monthly copayments anywhere between $25.00-$100.00. There is not a designated mark of affordability—insulin prices average around $10.00 for a vial in most other high-income countries. While this legislation is a major step in the right direction for residents of these states, it only eliminates some cost burden from insured individuals as it is addressing copay prices, not base insulin prices.

States that have passed legislation

Education and Awareness

Like most social issues, lack of access to insulin among people with type 1 diabetes can benefit from increased public awareness and education on the topic. There are organizations in existence that focus on bringing awareness to the importance of giving individuals access to the insulin they need to live. For example, Type 1 International is a non-profit organization based in the United Kingdom that focuses on helping people with type 1 diabetes gain access to the resources and healthcare that they need. Though it is based in the United Kingdom, this organization focuses on helping people with type 1 diabetes all over the world. Its vision is that people with diabetes everywhere can have access to what they need to be safe, healthy, and able to achieve success in their lives. It aims to accomplish this by working with local communities to support their people with type 1 diabetes. The four pillars that Type 1 International works to improve are sharing knowledge, sharing data, campaigning, and raising awareness. Type 1 International has been effective at publishing several reports that have brought awareness to levels of insulin rationing and costs of diabetes. Beyond formal organizations, there are others who also seek to bring awareness to this important issue through social media platforms and community outreach. Increased awareness will help to inform voters and policy makers and propel the United States towards greater insulin accessibility.
Hannah Randall

Hannah is studying Public Health with particular interest in domestic health policy and global health. After living with type 1 diabetes for 19 years, she understands the importance of access to insulin for all and the impacts of the health system on individuals. She hopes to apply her degree in public health as well as her studies of social impact to contribute to system improvements that will serve more individuals and groups in need. Her favorite thing in the world is traveling to new places and learning through her connections with others.