The Price of Inequality in Type 1 Diabetes Management

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Abstract

The purpose of this paper is to examine the compounded disparities in diabetes management and how disease burden is amplified by socioeconomic conditions. Access to tools that equip care is explored in relation to income, education, race, and insurance coverage. Commentary is also provided from the perspective of a patient who has managed diabetes for 25 years and is currently a third-year medical student. From this experience, she understands firsthand the demand and complexity of disease management. Through her observations in the hospital, she also identifies how disparities shape care for individuals managing this challenging disease. Lower socioeconomic status, education level, non-White race, and noncommercial insurance are among variables that restrict access to technology. The various influences that shape technological access in combination with the observations from a patient managing T1D serve to demonstrate the multifactorial challenges encompassed in care acquisition.

Key Words: type 1 diabetes, continuous glucose monitor, access, equity, technology, patient, race, care

Abbreviations: CGM, continuous glucose monitor; T1DM, type 1 diabetes

Type 1 diabetes (T1DM) is a chronic autoimmune metabolic condition that requires blood glucose monitoring and insulin administration to prevent acute and long-term complications. Patients with T1DM experience autoimmune destruction of the insulin-producing beta cells in the pancreas, which requires patients to manage insulin administration and blood glucose levels. This requires constant diligence to fluctuations in blood sugar readings, adjustments in insulin dosing, and responsiveness to a variety of factors that prove multiplicative and complex. These factors extend beyond the biophysical phenomena of condition management and are inclusive of many other features that can create financial and psychological burden for patients. Transport to clinics, equipment costs, nutritious food, lost work compensation, diagnostic fees, and medication charges are just a few things that challenge an already cumbersome condition to manage. These barriers compound and create situations of sacrifice especially in lower income settings. In such environments, limitations on healthcare exist because of poverty, and trade-offs in household financial decisions between food, education, transportation, and medicine.

I have been exposed to the complexity of care coordination on a personal and clinical level. I have lived with T1DM for over 25 years and can appreciate the constant demand blood glucose control requires. I also acknowledge that it is tiring and often changes each day. With regards to managing this complex condition, I have been particularly struck by the growth of technology, which has completely changed my care. When I was diagnosed at age 2, blood glucose meters took 60 seconds to register a blood sugar. Continuous glucose monitors (CGMs) were a distant concept. My chunky toddler legs were very familiar to insulin injections. I have only recently started using a CGM and cannot speak enough about the clinical advancement it has provided as well as the stress it has alleviated. I have been able to achieve the lowest hemoglobin A1C in my record while coping with the turbulent workload of my third-year studies in medical school. I feel much less burdened by my disease, and I am informed without the guesswork of wondering where my blood sugars are headed or how a situation outside of my typical routine is faring from a diabetes management perspective.

I have managed my care with various models of insulin delivery and blood glucose devices. Prior to my use of a CGM and insulin pump, I was completing multiple daily injections with long- and short-acting insulin. This regimen consisted of daily basal injections and, on average, 6 injections of short-acting insulin for regulation of food consumption and blood sugar deviations over the course of the day. In my first year of medical school, I decided to change my approach because I desired a system that would provide continuous access to blood glucose data. I also was drawn to the ability to adjust my insulin rates with greater precision than carrying out 1 basal measurement would allow. I first seriously considered getting a CGM because of my time spent in the anatomy lab. While working on dissection, I would be away from my devices for hours on end and found it easier to glance at a screen rather than deglove and check my blood sugar. This is a perfect example of reduced disease burden in the context of my studies. I was able to access information that equipped me to continue without delay or be concerned about where my blood sugar was headed for the next couple hours. This informational access has similarly made me more comfortable while conducting hospital rounds. I can take a quick look at my levels and keep moving or grab a sip of juice to power through the rest of the patient list. The comfort this provides...
and the concern it alleviates is incredibly helpful. Not only does it provide relief by granting immediate knowledge of my blood sugars, but it provides a robust wealth of data when reviewing my trends so I can make adjustments with the information at my disposal. The CGM technology comes with access to an interface that describes my time in range over certain intervals in the day, so I can adjust my targets accordingly. When reviewing my data, I do not need to wonder what happened over a 5-hour interval during which I did not check my blood glucose, because the information is recorded on my device. This was not the case when I used a meter; I was unaware how the data trended between testing intervals and therefore felt underinformed in making decisions about how to best take care of my health.

Despite my ability to utilize this technology, I recognize this is not the reality for many patients who manage diabetes. As a third-year medical student, I am continuing to learn about diabetes management in the context of diverse patient populations. These individuals are often using outdated tools, dealing with insufficient supplies, and living in very challenging socioeconomic situations. I have been involved in the care of expectant mothers managing diabetes with under-resourced financial and social support, intravenous drug users who enter diabetic ketoacidosis secondary to infection from an injection site, and people who have had to undergo amputation from longstanding insufficiency of diabetic care. The control in these patients often includes tremendous fluctuations in levels, historical records of acute hypo- and hyperglycemic events, and the development of other comorbidities due to complications of their disease.

In caring for these patients and understanding firsthand the constant demand of diabetes, I wanted to consider what amplifies the challenges of an already difficult condition. Rapidly escalating insulin prices have come under scrutiny for exacerbating inequalities and prohibiting patients from lifesaving medicines. Here, I highlight CGM use to indicate how disparities in diabetes are also driven by blood sugar–monitoring devices. Furthermore, I explore how coordination of care and management decisions are often compromised in vulnerable populations.

The American Diabetes Association Diabetes technology guidelines state that device selection should be made with consideration given to patients’ specific needs, desires, skill level, and availability of devices. It is also stated that upon diagnosis of diabetes that requires insulin, consideration should be given to use of CGM devices. Furthermore, the guidelines suggest how disease burden of frequent blood glucose monitoring can be reduced through adoption of CGM technology [1]. CGMs are small devices that automatically monitor the interstitial fluid to approximate blood sugar readings every 5 minutes. This allows for precise monitoring of blood sugars, display of trend lines, and enhanced ability to detect patterns through the frequent collection and representation of data. Additionally, these devices sound an alarm in the event of a hypoglycemic or hyperglycemic event.

The utility of the CGM is reflected in the blood glucose control of patients, which can be approximated by using hemoglobin A1C levels, a measure that represents average blood glucose over a period of 3 months. Data on A1C levels and experiences of patients living with diabetes are cataloged by the T1D Exchange Registry, which is a research database for individuals with T1D who volunteer their data. The T1D Exchange Registry conducted analysis of CGM use by 17,317 participants who were defined as CGM users if they had used a CGM during the past 30 days [2]. The study found CGM use to be more likely with higher education and higher household income (P < .01). The contribution of educational status and income level has been repeatedly shown to increase likelihood of CGM use. Therefore, patients of lower socioeconomic status are at risk of deprivation from technology that has been associated with higher quality of life. Despite the treatment potential of CGMs, many patients are still monitoring with intermittent testing via a blood glucose meter. This option is often a function of what is available to patients due to insurance coverage, affordability, education, and other logistical challenges associated with CGM acquisition.

In addition to educational status and income level, insurance coverage impacts access to CGM devices. The American Diabetes Association conducted a study to examine CGM access across different insurance payers and further stratified by race and income level. Compared with individuals who have a commercial health insurance plan, individuals enrolled in Medicaid are 2 to 5 times less likely to use a CGM [3]. Furthermore, of the patients with Medicaid, people of color are even less likely to have a CGM. This is reflected in the findings that states with higher rates of White Americans enrolled in Medicaid have a higher CGM use than states with higher rates of Black Americans [3]. Americans who are not White and have government insurance are therefore a highly disadvantaged group who are much less likely to utilize this technology.

In interactions with patients in the hospital, I noted that their system of management did often not include a glucose sensor. I wanted to better understand the barriers that were prohibitive in sensor acquisition and use and conducted further investigating. From a financial perspective, a sensor supply for period of 3 months, consisting of 9 sensors and 1 transmitter, totaled $350 and $250, respectively, without insurance [4]. Furthermore, without a reliable cell phone to report blood glucose levels, a patient would have to purchase a receiver at a 1-time cost of $200 to $350 [4]. For patients who are uninsured, or who do not qualify for coverage of these devices, the cost is extremely prohibitive. It also often requires supply acquisition from a vendor that does not supply their insulin, which means more coordination on the administrative side, additional bills to pay, and training sessions to attend. Worsening the additional burden, there are supply disruptions, shifts in insurance coverage, change in distribution channels, and caps on supply provision for orders. For someone who has other issues competing for their attention, dedication to this fluctuant situation becomes nearly impossible.

The diabetes consumer market is desperate, and the consequences are growing. I belong to many Facebook groups and frequently see posts of people both asking for and giving away supplies. If their coverage suspends, or an insurance formulary changes, diabetes management as they know it can quickly become disrupted. These supplies are not elective; they are life sustaining. People are scraping by with what they have, often relying on an underground market or omitting care and facing the consequences.

The current situation of blood glucose monitoring in vulnerable populations poses significant risk for episodes of
hypo- and hyperglycemia, as well as development of complications. The glimpse that clinical rotations has provided into the prevalence and complexity of these issues demonstrates a resounding need for improvement on a systems and individual level. Challenges are deeply embedded in supply access, education, and structural insufficiency that leaves the needs of many patients abandoned.

The deficits in coverage and care are multifaceted, but one particularly impactful area for improvement is expanded access and utilization of CGM systems. Patients with substantial need are often of lower socioeconomic status, lesser educational background, non-White race, and covered by noncommercial insurance, such as Medicaid. On behalf of Medicaid, the recent removal of the 4 times a day testing requirement, which has been a longstanding barrier to qualify for a CGM, is an appreciable step in facilitating access for beneficiaries [3]. However, much more action needs to be taken on a policy level to reduce the burden on CGM coverage requirements that reduce access for people with diabetes who are often low income and of minority groups. Coverage expansion will enable many of those who are struggling and often the sickest. Advocating for patient needs will help dismantle this era of unsafe internet transactions, insufficient coverage, and substandard care.

In addition to device accessibility, substantial work is needed to address education and behavioral coaching in patients subject to the unrelenting demands of diabetes. As discussed, the decision-making process involves variables such as exercise, food, stress, hormones, illness, and daily variability, which can be cumbersome and challenging in selecting for doses, adjustments, and each unique situation encountered. This is particularly relevant due to the unique nature of diabetes management, where the patients drive the dosing decisions of their medications. Increased frequency of provider contact, and ability to participate in complementary care such as behavioral healthcare, can create substantial opportunity to educate individuals on how to best manage their condition in alignment with the demands of their situation. Integration of services and offering of sessions between the traditional 3- to 6-month appointments would be highly beneficial for patients, especially those struggling to manage their condition in the complex life situations they experience.

Care for patients with diabetes must meet the demands on a condition that is multifaceted and constantly evolving, and that requires access to technology, frequent education, and personalized behavioral health strategies. Devastating situations are occurring on an individual and structural level, as evidenced by patient interactions and studies documenting the disservice in care, especially for select groups. This demonstrates that current models do not meet the needs of a patient population who are at high risk for acute and chronic effects of inadequate health maintenance. Expanded device access, implementation of care models with integrated services, and recognition that deficits are nonuniform across this patient population are the preliminary action points in generating progress for patients managing T1D.

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