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One Hundred Years of Insulin for Some

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Citation: Moran-Thomas, Amy. "One Hundred Years of Insulin for Some." *New England Journal of Medicine* 385 (July 2021): 293-295. © 2021 Massachusetts Medical Society

As Published: <http://dx.doi.org/10.1056/nejmp2105697>

Publisher: Massachusetts Medical Society

Persistent URL: <https://hdl.handle.net/1721.1/131131>

Version: Final published version: final published article, as it appeared in a journal, conference proceedings, or other formally published context

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regarding moral issues. The alternative approach — indifference — reflects the narrow view that being political is not what doctors do.

Dante Alighieri, who was educated as an apothecary and died 700 years ago this September, had so little tolerance for indifference that he relegated bystanders to the worst part of his hell: the Ante-Inferno. The ancient Greeks simply called people who refused to get involved “idiotes.” We believe that indifference in times of challenge and

controversy is akin to complicity. Covid-19 may finally force our profession to understand that an essential competency of medical trainees should be advocacy and activism.

Disclosure forms provided by the authors are available at NEJM.org.

From the Humanities Track and the History of Medicine Series (S.M.), and the Office of the Dean (M.L.T.), Sidney Kimmel Medical College, Thomas Jefferson University, Philadelphia.

This article was published on July 17, 2021, at NEJM.org.

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DOI: 10.1056/NEJMp2103050

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One Hundred Years of Insulin for Some

Amy Moran-Thomas, Ph.D.

There is not one story of insulin; there are many. As a young child, Mr. J. lost his mother to what was presumed to be type 1 diabetes. He recalled taking whatever kinds of insulin he could get for his own type 1 diabetes growing up, thanks to the generosity of his neighbors and extended family. But after going without countless times, he now faced frequent seizures and diabetic comas, he told me a few months before his death at 21 years of age. Ms. C., meanwhile, had been diagnosed with type 2 diabetes, only to be told years later that she actually had type 1. Because of this misdiagnosis, it took years before her treatment included insulin — and by then, each injection that brought her blood sugar into the “normal” range made her feel violently ill. She died at 36. I met both these patients in 2010 as part of an ethnographic project about peo-

ple's experiences living with diabetes in Belize. Statistics on type 1 diabetes weren't being kept in the country at the time, as is the case in many overstretched health systems, so Mr. J.'s and Ms. C.'s dilemmas — like their deaths — weren't registered as part of global diabetes figures.

As the story is often told, 100 years ago — on July 27, 1921 — two young researchers in Canada, Frederick Banting and Charles Best, isolated the hormone insulin. Within months, doses began reaching patients. In 1923, the collaborating inventors sold the insulin patent to their university for \$1 each, with the goal of keeping treatment affordable and accessible for everyone. Ensuing narratives often depict linear timelines of scientific progress stretching toward the present day: glucose-monitoring devices, miniature insulin pumps, insulin analogues, the promise of the bionic pan-

creas, and numerous therapeutics that have hugely increased chances for survival.

But these narratives often eclipse more uneasy stories: Mr. J.'s and Ms. C.'s situations give a glimpse into struggles happening every day throughout the world.¹⁻³ Patients without other options inject expired or suboptimal types of insulin or ration their supplies, and safer analogue insulins and pumps remain unavailable to many. Caregivers fight for basic tools; some explained that they were afraid to prescribe insulin for home use after knowing patients who died from overdoses because they couldn't afford glucose-measurement tools. Families face impossible choices as they attempt to procure treatment in regions where insulin for a child with type 1 diabetes can consume most of a household's budget.³ Today, more children with type 1 diabetes worldwide benefit from

insulin-donation programs, but those who manage to survive are often phased out of access programs as young adults.

In the United States, many young adults encounter similar issues when they age out of family insurance plans and face insulin prices that have spiraled upward for years. Scholars have outlined the range of reasons that insulin and its associated technologies remain costly or otherwise inaccessible in various health systems, often intensifying racial disparities and other global inequities.^{1,3} Families of people who died because of lack of insulin in the United States have led recent protests, carrying loved ones' ashes and leaving cardboard tombstones on the doorsteps of companies that steadily increased prices.

These memorials are also reminders that if worldwide diabetes-related losses were plotted alongside scientific discoveries during insulin's 100-year story, the resulting picture would show a century of not only breakthroughs, but many kinds of systemic breaks.

Questions about global access — and responsibility — are as old as insulin itself.² In the 1920s, the Rockefeller Foundation launched a philanthropic program to supply insulin to certain North American hospitals. At the time, the foundation's International Health Board operated extensive global programs for various infectious diseases, including malaria, tuberculosis, and hookworm. But as letters pleading for insulin access poured into its headquarters from people throughout the world, the U.S.-based foundation developed a standard reply: "[our insulin provision] activities, however, have

not gone beyond this country."² Even then, in contrast to infectious conditions, diabetes was being framed as an individual responsibility — not as a condition requiring urgent societal solutions or one bound by ethical mandates for global action. Such deferred action from well-funded transnational health institutions soon came to characterize the global response to many diseases labeled noncommunicable.

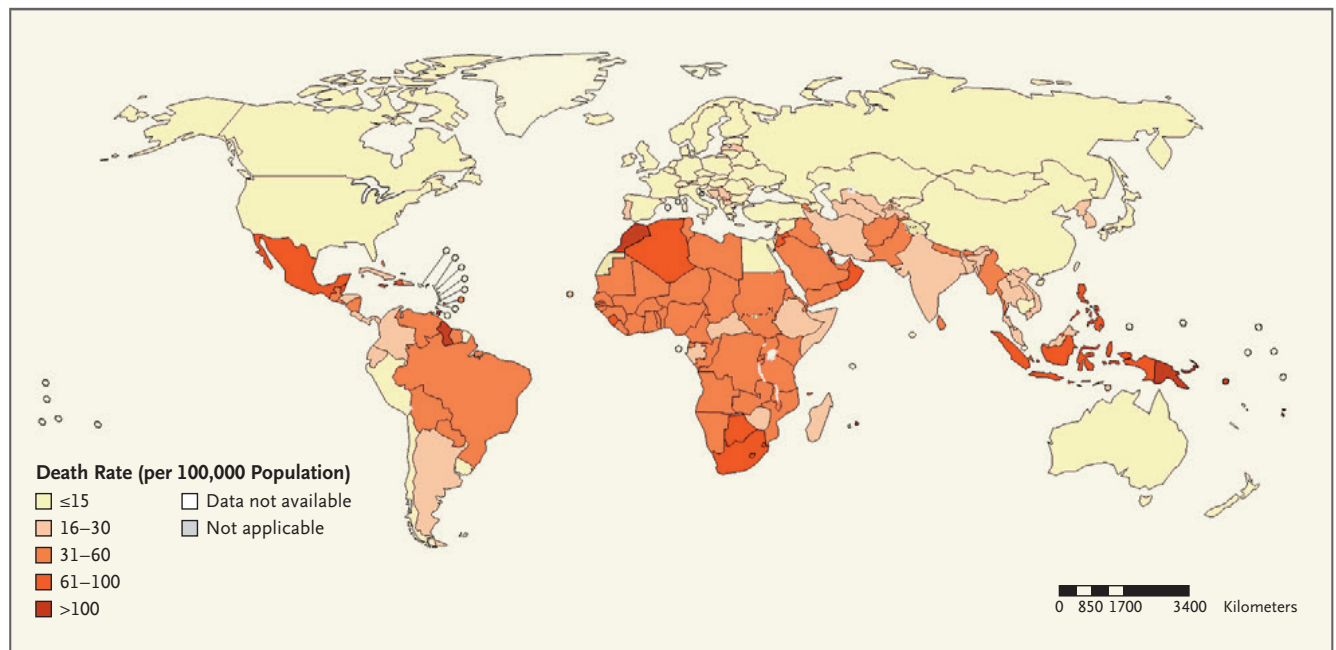
The discovery of insulin profoundly changed the lives of people who had access to it — but also the lives of people who didn't.^{2,3} It's one thing to live with a condition for which no treatment exists; it's another to live with the knowledge that lifesaving treatment exists but is out of reach. Attributions of responsibility (and blame) have deeply affected how patients and families seek out care and imagine their futures.

Although comprehensive data are lacking, advocates estimate that nearly half a billion people worldwide have diabetes, roughly 10% of them type 1. About one third of people with type 2 diabetes eventually also come to rely on insulin — especially when managing serious complications, which are often caused by decades-late diagnosis and deferred treatment. The International Diabetes Federation estimates that more than 4 million people die from diabetes each year, and even the more conservative mortality estimates from the World Health Organization (WHO) are startling (see map). Often following colonial and racialized contours, global inequities are made starker by a lack of access to primary care and unmet insulin needs in many regions.

Because severe type 2 diabetes can closely resemble type 1, researchers have proposed framing diabetes as a spectrum,⁴ which would also support the recognition of less common forms of diabetes that don't fit clearly into binary typing. Although many believe that rates of type 1 diabetes are lower outside North America and Europe, others argue that there is no way to assess this as long as related deaths in much of the rest of the world aren't being adequately diagnosed or counted.^{2,3}

The long-standing lack of international interest in diabetes has contributed to these vast data gaps. While diabetes advocacy efforts were being ignored on the global stage, HIV/AIDS emerged and was slowly transformed into a largely survivable disease. Yet in much of the world, insulin remains harder to obtain than antiretroviral drugs² — a side effect of the way in which "exceptionalist donor agendas have skewed health systems away from comprehensive primary care."⁵ This can have intergenerational effects. Although data on global maternal mortality and pregnancy losses caused by insufficient insulin access are lacking, inadequate treatment during pregnancy can double the risk of type 1 or type 2 diabetes being passed to children. Decades of global neglect, in other words, has played a role in amplifying diabetes case numbers throughout the world.

After years of advocacy, the #insulin4all movement is gaining hard-fought ground. The WHO recently collected input related to its Global Diabetes Compact, after opening a path to certifying generic versions of insulin. In the United States, insulin was legally recognized as a biologic drug in



Diabetes Mortality by Country, 2012.

Rates are standardized according to age. Reproduced with permission from the World Health Organization, 2014 (http://gamapserver.who.int/mapLibrary/Files/Maps/Global_NCD_mortality_diabetes_2012.png).

2020, which raised hopes that prices will become more reasonable as companies start producing their own generic versions. Yet people worldwide have reported new layers of difficulty managing diabetes during the Covid-19 pandemic. When patients and families describe navigating extremes of insulin rationing during border closures or managing compounding diagnoses, it's not the unstable presence of insulin that tends to be cast as the central miracle in their stories, but the work of the neighbors, kin, and advocates helping them maintain access to treatment against the odds.

This anniversary offers a time to mark the many social lives of insulin — including a chance to celebrate the mutual aid and endurance of patients, families, and

caregivers navigating diabetes worldwide, who have been left out of too many histories of science and medicine. At the same time, it presents a moment to grieve the millions of people — Mr. J. and Ms. C. among them — who fought for their existence but ultimately could not survive the status quo of unjust disparities in access to care. This milestone also offers a chance to step back and reflect on the next 100 years. And it leaves us with a question: How can we honor the miracles of survival that so many people living with diabetes work to create for each other every day, while shaping a future in which miracles aren't required for survival?

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From the Anthropology Program, Massachusetts Institute of Technology, Cambridge, MA.

This article was published on July 17, 2021, at NEJM.org.

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DOI: 10.1056/NEJMp2105697

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