COSTS AND RATIONING OF INSULIN AND DIABETES SUPPLIES:

FINDINGS FROM THE 2018 T1INTERNATIONAL PATIENT SURVEY

SUMMARY

Insulin is necessary to survive with type 1 diabetes. The rising costs of insulin and other diabetes supplies are attracting greater scrutiny, especially in the USA. It has been reported that one out of every two people globally in need of insulin cannot access or afford it. A worrying number of people are rationing insulin, suffering devastating personal and financial consequences.

T1International conducted an online survey of patients with type 1 diabetes. The survey covered out-of-pocket costs associated with type 1 diabetes, insulin rationing, rationing of blood glucose testing supplies, degree of financial coverage and sources of financial support. The survey was disseminated using social media, the T1International website, and shared via partners around the world. Study data were collected and managed using the REDCap online survey platform. Informed consent was utilized.

The survey was completed by a total of 1,478 respondents from 90 countries. In total 253 (18.0%) of all respondents reported having rationed insulin at least once in the previous year. Of USA respondents, 162 (25.9%) reported having rationed insulin in the previous year. Among high income countries excluding the USA, only 6.5% reported rationing in the previous year. Widespread rationing of blood glucose testing supplies (33.5%) was also found, and a total of 976 (66.6%) responded there was no financial coverage whatsoever for their out of pocket diabetes costs.

Insulin rationing is widespread among people living with type 1 diabetes. Respondents from the United States of America reported the highest percentage of insulin rationing of any high income country surveyed. Many countries still lack financial support systems for people with type 1 diabetes, many of whom struggle to afford their insulin and other diabetes care costs.

BACKGROUND

Type 1 diabetes is an autoimmune condition characterized by the destruction of insulin producing beta cells in the pancreas. It is estimated that between 19 and 38 million people live with type 1 diabetes world-wide[1]. Insulin is essential for the survival of people with type 1 diabetes. However, one out of every two patients worldwide in need of insulin cannot access or afford it[2]. This is despite the approach of the centennial of insulin's discovery by Banting, Best and colleagues at the University of Toronto in 1921[3].

Patients with type 1 diabetes also require syringes or other delivery devices to inject insulin, regular blood glucose monitoring, and access to emergency glucagon injections and ketone testing strips to successfully self-manage and avoid life-threatening situations. Many patients also rely on insulin pump and continuous glucose monitoring technology[4,5].

Insulin is increasing in cost globally, particularly in the USA. Since the 1990s the cost of analog insulin has increased well over 1000%[6]. Patient activism challenging this rise has gained national and international attention[7,8]. Over the past 10 years, the "Big 3" insulin manufacturers - Eli Lilly, Sanofi, and Novo Nordisk - have raised their prices in lock-step[9]. In 2012, a vial of Humalog insulin was priced at $130. By 2016, the same vial was priced at $255. During that time patients' costs for insulin also doubled[10].

There is no evidence that insulin manufacturing costs have risen, yet prices have continued to increase. A recently published estimate put the cost of production for a vial of analog insulin at between $3.69 and $6.16[11].

These high costs are forcing patients to make huge sacrifices in order to afford their medication. Many have died because they rationed their insulin, including in the USA[12]. Rationing can lead to medical complications such as lower limb amputation, kidney-failure and blindness. If blood glucose levels run too high for an extended period of time, diabetic ketoacidosis (DKA) is likely and, if left untreated, it will lead to coma and death. Rationing insulin due to cost was the leading cause of DKA admissions in inner-city minority patients, and a recent Yale study found that 1 in 4 respondents was rationing insulin due to cost[13,14].

In 2016 T1International completed an online Access Survey, the results of which are available online[15]. The aim of this study was to build on T1International’s 2016 Access Survey results and ascertain a contemporary understanding of out of pocket costs, extent of rationing insulin and supplies, and degree of financial coverage people with type 1 diabetes are experiencing across the world. This report focuses primarily on the USA rationing and health coverage results as they compare to those of other countries.

METHODS

We conducted an online survey of people with type 1 diabetes around the world. The survey was disseminated using social media platforms, the T1International website and through partner organizations. Some partners printed out the survey and collected responses from patients who did not have access to the internet and then transcribed their responses into the online platform.

Ethics

A statement providing information on the type of data to be collected and explaining that the survey was completely voluntary was provided. Respondents were also informed that no identifiable information would be collected, and that they would receive no compensation or other financial reward for participating. Informed consent to participate was built into the survey and was required to proceed to the survey questions.

Survey Design

This online survey was conducted using the Research Electronic Data Capture (REDCap) system[16]. REDCap is a secure, web-based application designed to support data capture for research studies. Out of pocket costs were defined in the beginning of the survey and a tool to convert other currencies to US dollars was provided[17]. Data on out of pocket costs will be reported on the T1International website rather than in this report which focuses on rationing and financial coverage.

The study was developed by people living with type 1 diabetes to ensure the questions made sense to patients and to ensure the most appropriate data was collected. The study was exclusive to type 1 diabetes and responses were sought directly from patients and/or direct caregivers of patients. The previous 2016 T1International Access Survey was used as a starting point and past experience helped further develop and improve the questionnaire for 2018.

Prior to launching the survey, T1International utilized a pilot group of n=10 volunteers from around the world. These volunteers covered the continents of North America, South America, Europe, Asia and Africa. Based on their feedback on readability, usability, and clarity of the survey questions, slight changes were made to improve the survey tool before sharing it with the wider type 1 diabetes community. The full survey can be viewed at t1international.com/survey2018.

Data Analysis

To analyze this patient-reported data, we conducted descriptive analyses using SAS 9.4 software - stratified by four country groups: i) all respondents, ii) USA, iii) high income countries excluding the USA and iv) low and middle income countries. World Bank Country Classification by Income data was used for analyses by country-groups[18].

Respondents with missing country information were excluded. When a respondent did not answer any specific survey question, it was considered to be ‘missing data’.

RESULTS

The survey was completed by 1,478 participants from 90 countries (see Figure 1). After excluding those with missing country information, 1,425 respondents were included in our analyses.

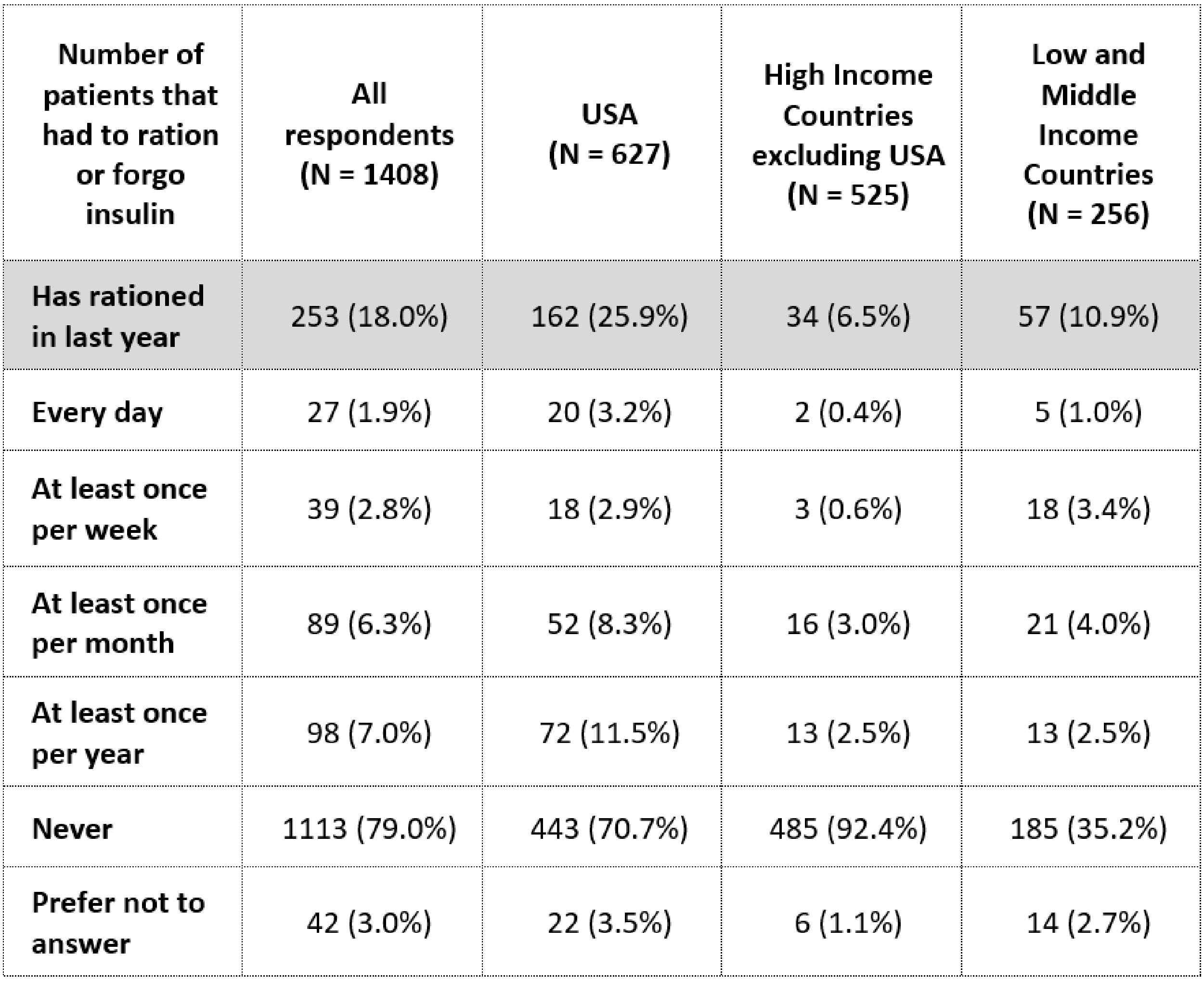
Of all the 1,425 study participants, 1,033 (72.5%) lived with type 1 diabetes themselves, while 346 (24.3%) were parents/caregivers and 21 (1.5%) were partners/relatives of someone with type 1 diabetes. A further 25 (1.8%) respondents had some other connection to someone with type 1 diabetes.

The highest number of participants (n = 631; 44.3%) resided in the United States of America (USA). See Table 1 for a breakdown by participants from the USA and other countries.

Figure 1: Participants of the T1International Out of Pocket Survey by country

Insulin Rationing

In total, n=253 (18.0%) respondents reported having rationed insulin during the previous year (see Table 1). In the USA, this number was even higher at 25.9% of respondents (n=162). By contrast, high income country respondents excluding the USA reporting rationing in the last year at only 6.5% (n=34).



Number of patients that had to ration or forgo insulin	All respondents (N = 1408)	USA (N = 627)	High Income Countries excluding USA (N = 525)	Low and Middle Income Countries (N = 256)
Has rationed in last year	253 (18.0%)	162 (25.9%)	34 (6.5%)	57 (10.9%)
Every day	27 (1.9%)	20 (3.2%)	2 (0.4%)	5 (1.0%)
At least once per week	39 (2.8%)	18 (2.9%)	3 (0.6%)	18 (3.4%)
At least once per month	89 (6.3%)	52 (8.3%)	16 (3.0%)	21 (4.0%)
At least once per year	98 (7.0%)	72 (11.5%)	13 (2.5%)	13 (2.5%)
Never	1113 (79.0%)	443 (70.7%)	485 (92.4%)	185 (35.2%)
Prefer not to answer	42 (3.0%)	22 (3.5%)	6 (1.1%)	14 (2.7%)

Table 1: Frequency of insulin rationing comparison by country group

Blood Glucose Testing Rationing

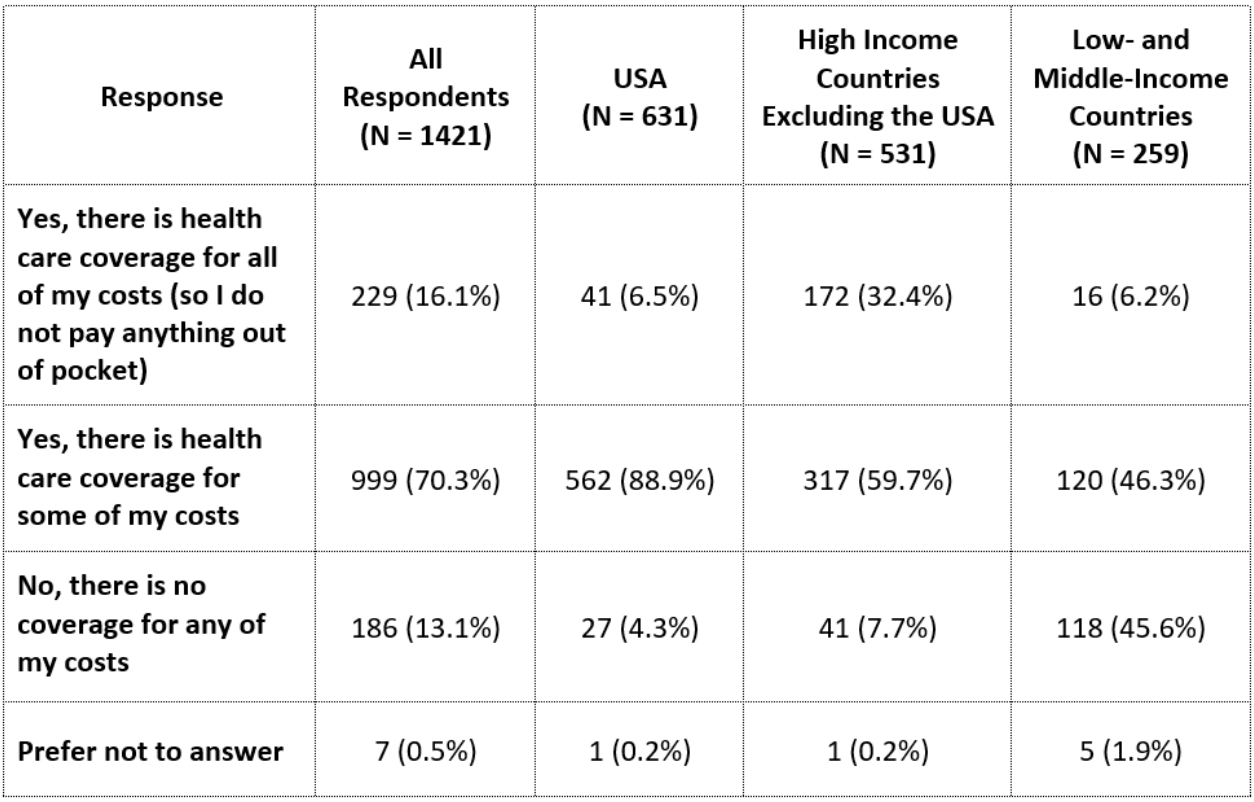
Rationing of blood glucose testing supplies was more common among respondents than insulin rationing (see Table 2). Rationing of blood glucose testing supplies in the previous year was most common in low and middle income countries (55.5%, n=142), followed by the USA (38.6%, n=142).

Response	All Respondents (N = 1411)	USA (N = 627)	High Income Countries Excluding USA (N = 528)	Low- and Middle-Income Countries (N = 256)
Has rationed in last year	472 (33.5%)	239 (38.6%)	91 (17.2%)	142 (55.5%)
At least once per year	120 (8.5%)	75 (12.2%)	32 (6.1%)	13 (5.1%)
At least once per month	130 (9.2%)	74 (11.8%)	27 (5.1%)	29 (11.3%)
At least once per week	138 (9.8%)	58 (9.4%)	15 (2.8%)	65 (25.4%)
Every day	84 (6.0%)	32 (5.2%)	17 (3.2%)	35 (13.7%)
Never	913 (64.7%)	378 (61.3%)	428 (81.1%)	107 (41.8%)
Prefer not to answer	26 (1.8%)	4 (0.6%)	9 (1.7%)	7 (2.7%)

Table 2: Frequency of blood glucose testing rationing comparison by country group

Financial Coverage for Health Care

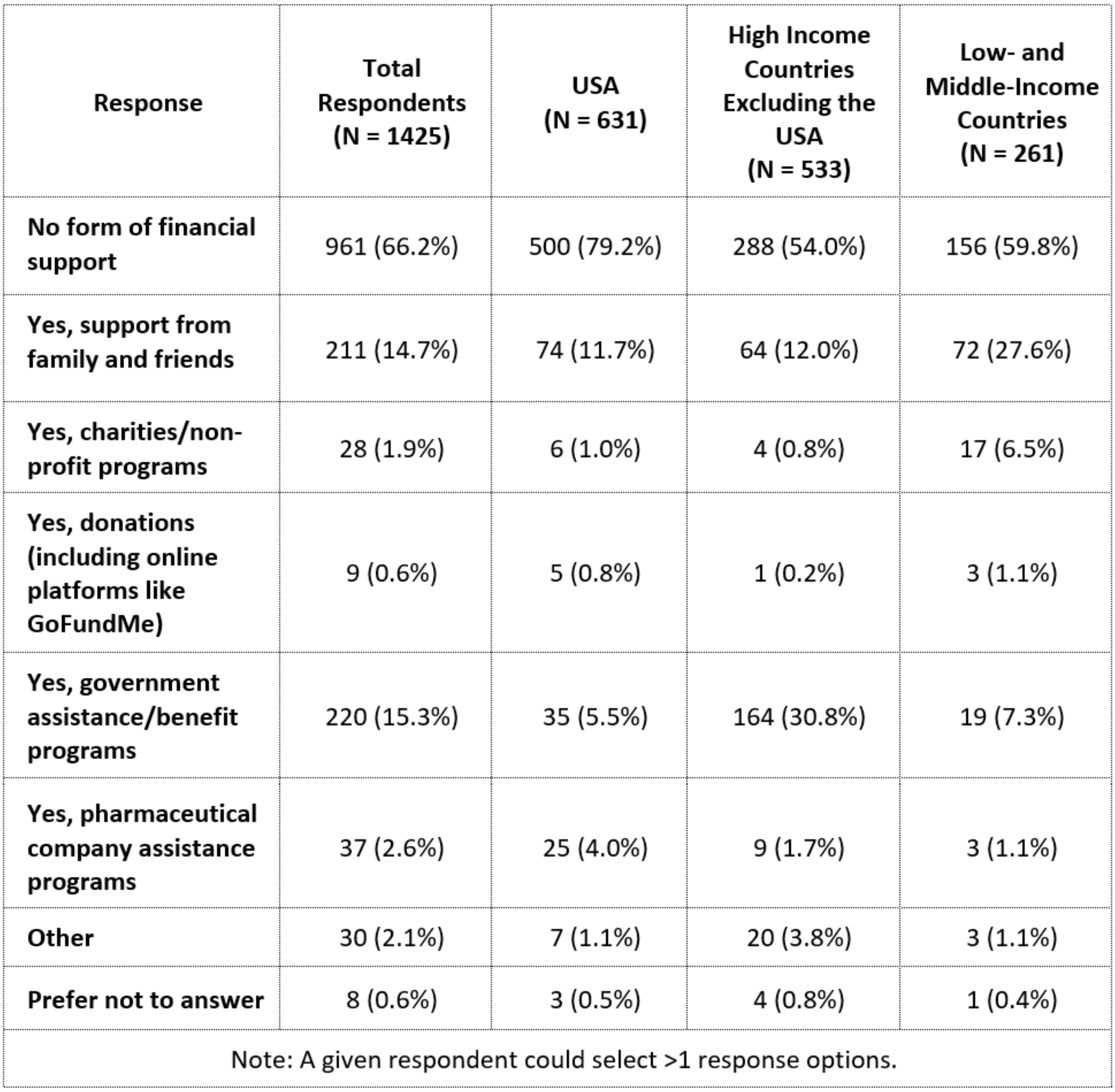
Overall, participants mainly reported that there was health care coverage for some of their costs, with 13.1% reporting no coverage at all for any costs (see Table 3). In the USA there was a much lower percentage of coverage for all costs (6.5%), while high income country respondents had a significantly higher percentage of coverage for costs (32.4%).



Response	All Respondents (N = 1421)	USA (N = 631)	High Income Countries Excluding the USA (N = 531)	Low- and Middle-Income Countries (N = 259)
Yes, there is health care coverage for all of my costs (so I do not pay anything out of pocket)	229 (16.1%)	41 (6.5%)	172 (32.4%)	16 (6.2%)
Yes, there is health care coverage for some of my costs	999 (70.3%)	562 (88.9%)	317 (59.7%)	120 (46.3%)
No, there is no coverage for any of my costs	186 (13.1%)	27 (4.3%)	41 (7.7%)	118 (45.6%)
Prefer not to answer	7 (0.5%)	1 (0.2%)	1 (0.2%)	5 (1.9%)

Table 3: Comparison of level of financial coverage by country group

When it comes to financial support other than health insurance, 66.2% of all respondents said that they do not receive any kind of support to help cover their diabetes costs (see Table 4). Government assistance was more common in other high-income countries (30.8%) while in the USA, only 5.5% of respondents benefited from government assistance.



Response	Total Respondents (N = 1425)	USA (N = 631)	High Income Countries Excluding the USA (N = 533)	Low- and Middle-Income Countries (N = 261)
No form of financial support	961 (66.2%)	500 (79.2%)	288 (54.0%)	156 (59.8%)
Yes, support from family and friends	211 (14.7%)	74 (11.7%)	64 (12.0%)	72 (27.6%)
Yes, charities/non-profit programs	28 (1.9%)	6 (1.0%)	4 (0.8%)	17 (6.5%)
Yes, donations (including online platforms like GoFundMe)	9 (0.6%)	5 (0.8%)	1 (0.2%)	3 (1.1%)
Yes, government assistance/benefit programs	220 (15.3%)	35 (5.5%)	164 (30.8%)	19 (7.3%)
Yes, pharmaceutical company assistance programs	37 (2.6%)	25 (4.0%)	9 (1.7%)	3 (1.1%)
Other	30 (2.1%)	7 (1.1%)	20 (3.8%)	3 (1.1%)
Prefer not to answer	8 (0.6%)	3 (0.5%)	4 (0.8%)	1 (0.4%)
Note: A given respondent could select >1 response options.				

Table 4: Comparison of sources of financial coverage by country group

DISCUSSION

This is the largest international survey assessing out-of-pocket costs, insulin rationing, and blood glucose testing rationing experienced by people with type 1 diabetes to date. Our findings show a worryingly high number of people with type 1 diabetes are subject to life-threatening rationing due to financial costs. Our findings also reveal that most countries offer a patchwork of sources of financial coverage rather than a comprehensive safety net.

Particularly striking were the differences between the USA and other high-income countries in terms of insulin rationing, blood glucose testing rationing, government assistance (or lack thereof) and overall costs. It is no surprise that this has drawn attention in the media and in peer reviewed literature[19]. Our findings strengthen the efforts of those advocating in the United States for concrete measures to end insulin rationing and associated deaths[20].

Rationing and Financial Coverage

Our findings for the number of people with type 1 diabetes in the United States who had rationed insulin in the past year (25.9%) aligns with recent findings by Herkert et. al 2019[21]. Their study showed that one in four people with type 1 diabetes in New Haven County, Connecticut rationed insulin due to cost.

By comparison, our study found that insulin rationing in other high-income countries was much lower. While many high-income countries have the ability to negotiate price or have systems in place which provide medicine and healthcare to their citizens, the USA is a known outlier, which may account for these results. The situation in low income and middle-income countries was mixed, with many countries reporting high levels of rationing whereas others reported low levels. Our findings broadly suggest people living with type 1 diabetes in countries with more comprehensive, publicly funded health care systems are less likely to be subjected to insulin rationing.

Rationing related to blood glucose testing was higher than insulin rationing, both in the US and other countries. Intuitively this makes sense. People living with type 1 diabetes require insulin to live, so insulin would be the last item of treatment to be subject to rationing if the person had any choice in the matter.

People with type 1 diabetes utilized a variety of sources of help in order to survive. The most common forms of support overall were help from family and friends (14.7%) and government assistance programs (15.3%). Respondents from the USA reported the lowest amount of government support (5.5%) in comparison with other high-income countries (30.8%). The majority (88.9%) of American respondents reported obtaining partial coverage of healthcare costs, but they most reported (79.2%) receiving no other financial support or assistance.

Action Needed

Globally, the public, the media, and politicians are starting to take notice of the insulin price crisis. In the USA, several Congressional hearings have taken place to explore the high cost of prescription drugs. A bipartisan investigation of Eli Lilly, Sanofi, and Novo Nordisk - the three insulin producers, who dominate more than 90% of the market by value - has also been launched[22]. Meanwhile, patients in the USA have been advocating at the state and federal level, calling for transparency and lower insulin prices. Nevada passed the first insulin price transparency bill in 2017, and other states have succeeded in passing more general transparency legislation[23].

In response to several protests and continued criticisms, Eli Lilly recently announced that they would be selling an ‘authorized generic’ at half the current list price[24]. Sanofi has also announced new assistance programs to try to fend off further outcry. These are positive results demonstrating that patient advocacy is working, but the price is still unaffordable for many.

At the international level, the plight of people living with type 1 diabetes is not receiving adequate attention at high-level forums, nor from institutions like the United Nations and World Health Organization. Type 1 diabetes is lumped into the difficult to understand category of Non-Communicable Diseases (NCDs)[25].

The imprecision around the term “diabetes” often leads to patients being blamed and policy efforts focused on lifestyle and primary prevention of type 2 diabetes. We disagree with this approach. Not only is primary prevention of type 1 diabetes not possible, blaming patients for their condition has never been a successful way to improve outcomes. Efforts must be focused on protecting the existing human rights of patients to access life-saving treatments.

Furthermore, we are skeptical about the benefits of a non-critical inclusion of the pharmaceutical industry, or groups funded by them, in setting the larger global health agenda.

It has been said in the literature that there is no civil society for diabetes[26]. This is entirely incorrect; T1International has been building a strong patient movement under the banner of #insulin4all that has been growing and engaging with civil society since 2013[27]. The literature also points to the historical success of the HIV/AIDS movement, but what is often critically ignored is that it was patients, rather than academics or health care providers, who were the vanguard for change.

What is needed now to improve the situation for people with type 1 diabetes globally is what was needed then: genuine partnerships that support patient led activism. The viewpoints of those most impacted – those risking their lives by being forced to ration their essential insulin – must be included in all spaces[28,29].

Key Take Home Messages

- Insulin rationing is widespread (18.0%) among those surveyed living with type 1 diabetes worldwide.
- At over 25% of people surveyed, the United States has by far the highest insulin rationing of any high income country.
- The United States lacks support systems for people with type 1 diabetes who struggle to afford their insulin and other type 1 diabetes costs.
- Many people with type 1 diabetes cannot affordably access insulin and other necessary supplies needed for their survival.

The above are major unmet and overlooked global health needs and a serious violation of the human rights of millions globally.

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Join our Movement

T1International is a non-profit run by people with type 1 diabetes *for* people with type 1 diabetes and we are passionate about ensuring patient voices are heard. We invite all who believe access to insulin is a human right to be part of our grassroots efforts fighting for insulin for all. We do not accept money from pharmaceutical companies or any other body that might influence our ability to speak out and fight for change.

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