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Universal health coverage and diabetes care affordable to all

Emma L. Klatman and Graham D. Ogle

Diabetes is life-long and its management can be costly both for patients and national health systems. Many people living with diabetes in high-income countries, who are financially protected by universal coverage health systems, fight for access to new technologies, such as continuous glucose monitoring. However, many health systems in less-resourced countries are not able to provide standard diabetes care to patients without exposing them to economic vulnerability.

In this issue of *Diabetes Voice*, Larry Deeb, Chair of the IDF Task Force on Insulin, Test strips and Other Diabetes Supplies, highlights continuing issues with the availability of essential medicines for people with diabetes in IDF’s new report of its *Global Survey on Access to Medicines and Supplies for People with Diabetes*. Published as a means to recognise and actively pursue improvements for the global supply of insulin and other essential diabetes medicines, IDF recommends several strategies to combat the problem including better supply chain distribution and procurement practices.

Managing diabetes requires insulin or oral hypoglycaemic agents, blood glucose monitoring, diabetes education, preventive tools, and treatment for complications. Access to trained health professionals and preventive services like education, healthy foods, and safe exercise spaces are also critical. Creating a formula that ensures equitable access to these provisions on an uninterrupted basis is not clear-cut.

The World Health Organization’s *Making fair choices on the path to universal health coverage* model provides three dimensions that help conceptualize how access to diabetes care can be achieved:

- Ensuring widespread health **coverage** for the entire population.
- Including in this coverage the full **range of services** for diabetes care.
- Making costs for the range of services provided **affordable** to all.

Today, appropriate diabetes care is particularly important at the primary care level, where most people with diabetes are treated and therefore, where a healthcare team trained on best practice for type 2 diabetes is vital for success. Pablo Aschner, Chair of the IDF Working Group for the new *IDF Recommendations For Managing Type 2 Diabetes In Primary Care* reviews the rationale, methodology and the recommendations for PCPs and diabetes teams covering all fields of type 2 diabetes management worldwide.

Generally, less-resourced countries have basic public health systems that are free or provide services at a minimal cost, and cover most of the population. Yet, various needed diabetes care components are not usually provided due to high costs. James Elliott, a Trustee of T1International, provides his thoughts on the need for people living with diabetes, who lack access to care and essential medicines, to fight back with solidarity and activism.

Some less-resourced countries endeavour to ensure access to health through both public and private healthcare insurance schemes. The schemes may provide a wider range of services but are often beyond the reach of many people as they are costly and may be exclusive to governmental employees. Douglas Villarroel, Editor-in-Chief of *Diabetes Voice*, gives us his perspective from his home country Bolivia, where the public health system is not adequately serving the needs of people with diabetes.

When public health systems in less-resourced countries do provide components of diabetes care, the range of diabetes care services is often limited due to financial constraints. Provision is often at a basic level and provides oral hypoglycaemic agents, human insulin (in vials) and care reviews—if there is capacity. Syringes and HbA1c testing may not be provided and blood glucose meters and test strips are rarely provided in low-income countries. The *SWEET Study Group* describes their multinational initiative to improve diabetes care and outcomes in youth with all types of diabetes in low- and middle-income countries. Participation in SWEET has led to improvements in local standard protocols, support for care provider education and promotion of the need for multidisciplinary approach to diabetes care in many centres.

When care components are not supplied in public health systems, they must be accessed at premium prices at private pharmacies and paid for as out-of-pocket expenditures. For type 1 diabetes care, blood glucose monitoring can be the costliest component of care. The high expense of monitoring results in infrequent usage in less-resourced countries, with consequent risks of dangerous swings in blood glucose levels in people with diabetes. Elizabeth Snouffer, Editor of *Diabetes Voice*, reports on the care of people with diabetes...
from the small province of Bali, Indonesia where she observes how access to blood glucose test strips can be the difference between a healthy future with diabetes or one at great risk for irreversible complications.

Even when some components are affordable, they may not be available due to stock outs in public pharmacies. Attaining components of care can be particularly acute for people living in regional and rural areas who often face extra financial burdens such as travel costs, accommodation, and lost salary.4 One research group, the Interdisciplinary Chronic Disease Collaboration at the University of Calgary, make it clear that even in countries where publicly-funded healthcare exists, access to all necessary care is not guaranteed. They have undertaken to better understand the role of financial barriers for patients with chronic medical conditions, including diabetes, in Canada.

It is imperative that governments use the limited resources they have equitably and wisely. For instance, it is not appropriate for a less resourced government to buy analog insulin (which is more expensive than human insulin) when other components of care are not yet adequately provided.

Access to components of care is essential for people with diabetes in low-resourced countries. At the same time, prevention is indisputably better than treatment and many cases of type 2 diabetes are preventable through public health initiatives. Resources should be applied to promote healthy lifestyles, and consideration should be given to safe exercise spaces, nutrition guidance and other programs that ameliorate the lifestyle changes that have inevitably occurred with urbanization.

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References
In every country on earth, from China to the Vatican, you will find people with type 1 diabetes. I chose to dedicate my professional life to diabetes research and advocacy. For a time, I was the manager of the Diabetes Canada Charter of Rights and Responsibilities, and more recently, I have been performing research work in the Middle East.

I have also lived with type 1 diabetes for 16 years.

Research and advocacy work have taken me to many interesting places. In Lebanon, I worked on operational research in diabetes with Doctors without Borders (MSF). There are over a million refugees of the Syrian conflict in Lebanon and where I was based, in the Bekaa Valley, many live in shacks beside the road.

Before the war, Syria had about the same proportion of people living with diabetes as did the United States, roughly 9 percent of the population. One fellow I met in Syria was living with type 1 diabetes. We asked him a series of questions about his diabetes to assess his self-management skills. He got every answer right. As it turned out, his father had also lived with type 1 diabetes. Somehow this person living with type 1 diabetes had to balance his insulin dosing without testing his blood glucose alongside a diet of nothing more than the potatoes a farmer gave him for free.

In my travels in Lebanon, I also made it a habit to ask young people with diabetes: “What is the hardest thing about living with diabetes for you, right now?” The answer was always the same, male or female: “I don’t think anyone will ever marry me.” Their words really stuck with me. When children are forced to work in the fields instead of going to school because there isn’t much money or food, few families are willing to take on the added expense of insulin, needles and test strips.

Over the last three years, I’ve dedicated a lot of my time and effort to T1International which is an international organization dedicated to the rights of people with type 1 diabetes. The organization is especially focused on the right of every person with diabetes to access insulin, upon which every person with type 1 diabetes depends for survival. Our slogan is #insulin4all which does a good job of summing up T1International’s core mission. We want to show the world people in need of insulin, like those in Lebanon, or rural America, exist and can be helped. We bare witness and help advocates fight for change at local, national and international levels. Recently, I coauthored correspondence for The Lancet, entitled “Access to insulin: patients will pave the way” along with other Trustees and Elizabeth Rowley, Founder and Director of T1International which reflects the need for collaboration in prioritising insulin access for all people who live with diabetes.

What I’ve come to realize is that every person with diabetes, whether type 1, type 2 or otherwise, must realize we are in this together. When we hear about people dying from lack of insulin, or we see senior White House officials stigmatizing people with the disease on the news, we must understand we are all being threatened. No one is going to care about diabetes more than the people who live with it. We need to support each other with donations and by advocating for ourselves and for those who are suffering. We need to raise the visibility of people living with diabetes and frankly, convince politicians and industry that our lives are worth saving.

What I’ve seen is that with creativity and just a bit of money, diabetes is a survivable condition in nearly every setting. Santé Diabète’s work in Mali is a great example. If you can treat diabetes successfully in Timbuktu, diabetes management can be done anywhere.

Individual advocates need to call a spade a spade. I often read in academic journals how the diabetes movement must look to the HIV/AIDS movement for inspiration. HIV/AIDS activists were loud, organized and powerful, but what is often forgotten is that access to HIV/AIDS treatment wasn’t solved by Bill Gates or Bono. It was driven by patient-led groups like Treatment Action Coalition. They were the

catalysts for change, rejecting rubbish statements like “HIV is too expensive to treat in Africa” or “those people with HIV did it to themselves”. These statements are today too familiar to some diabetes advocates.

I encourage all advocacy organizations to have people living with diabetes in leadership positions – as executives and as board members. That’s certainly what we are trying to do at T1International. We must not be afraid of being the “wrong” sort of advocate or being an “angry” advocate. Our lives are at stake. We need to be direct and fearless in our advocacy for the rights of people with diabetes. We are all entitled to live strong, healthy lives.

Every person with diabetes, whether type 1, type 2 or otherwise, must realize we are in this together

Too many people who need insulin are not getting it regularly or affordably which is an avoidable calamity. The inventors of insulin clearly and explicitly wished that insulin be accessible for all. We need drops of it for a lifetime to stay alive.

My significant other’s grandmother has type 1 diabetes. She’s nearing 80 years old and has lived with diabetes for 70 years. When she was younger she had only urine dip sticks for blood glucose measurement. She also had to regularly boil her glass syringes to sterilize them. Though this may seem prehistoric to some of us, I think the fact that type 1 diabetes is a cause of death and bankruptcy of so many is going to look woefully prehistoric before too long.

James A. Elliott is a researcher of diabetes health system policy and global health, and a T1International Trustee.

For more information: www.t1international.com
IDF highlights access to care as leading concern at World Health Assembly

Access to diabetes care remains inadequate and unaffordable in many countries, making it the leading concern of people living with diabetes. On 23 May 2017, on the occasion of the 70th World Health Assembly, the International Diabetes Federation (IDF) held a panel discussion in Geneva between people with diabetes and healthcare professionals on priority solutions to overcome national gaps between provision and availability of diabetes care and treatment among underserved populations.

The event highlighted the central role of people with diabetes in all aspects of diabetes management, care and prevention and introduced IDF’s new network, the Blue Circle Voices. It also featured the critical perspective of frontline health workers in achieving quality care and optimal health outcomes.

During the event, IDF disseminated the findings of the IDF Members’ Survey on Access to Medicines and Supplies for People with Diabetes to inform discussion on what is needed to achieve WHO 2025 targets at national levels.

Speakers and panellists included Professor Nam Cho, IDF President-Elect; Dr Etienne Krug, Director of WHO’s Department for Management of Noncommunicable Diseases, Disability, Violence and Injury Prevention and the following representatives of IDF Blue Circle Voices: Vanessa Pirolo (Brazil), Stela Prgomelja (Serbia) and Riva Greenberg (USA).

To mark the event, IDF collaborated with its Members and Blue Circle Voices in Brazil and South Africa to develop policy recommendations to improve diabetes care in their respective countries.

IDF School of Diabetes launches certified courses for healthcare professionals

One in five healthcare professionals do not receive any postgraduate training in diabetes and less than 1 in 2 people with diabetes and 1 in 4 family members of people with diabetes have access to diabetes education programs. Education of people with diabetes is a critically important, fundamental and integral component of diabetes care that should be available and accessible to everyone.

The International Diabetes Federation (IDF) recognises the value of providing continued professional education for healthcare professionals and resources for people with diabetes and caregivers in a sustainable and convenient manner. To this end, IDF recently launched the IDF School of Diabetes Certified Courses, a set of online courses tailored to the needs of a variety of healthcare professionals.

Available courses include:

- IDF Certified Course for Diabetes Educators: a customised set of modules promoting education of people with diabetes, healthier lifestyles and effective diabetes management.
- IDF Certified Course for Primary Care Physicians/General Practitioners: a comprehensive range of modules addressing the ongoing needs of physicians and general practitioners (medical doctors) in the prevention, detection and management of diabetes.
- IDF Certified Course for Specialists: an advanced series of modules containing the latest advances in the treatment and management of diabetes, targeting diabetologists, endocrinologists and equivalent specialists.

To mark the launch, IDF is offering the full courses at discounted rates until 31 July 2017.

For registration and to start your free trial go to www.idfdiabetesschool.org
IDF and Lilly announce second phase of BRIDGES

In a further effort to help spread lessons learned from clinical research to benefit the more than 400 million people affected by diabetes worldwide, IDF and Eli Lilly and Company (Lilly) have come together for the second phase of Bringing Research in Diabetes to Global Environments and Systems program (BRIDGES 2), reaffirming their commitment to helping people with diabetes effectively manage their condition.

BRIDGES 2 will build upon the work undertaken and the lessons learned during the initial phase of the program, which operated from 2007 to 2015. The program will fund and replicate a selection of projects from the initial phase, placing an emphasis on the secondary prevention of diabetes and a strong involvement of local public health authorities.

“Our goal is to translate evidence-based approaches from the first round of BRIDGES to other contexts and countries to improve the lives of people living with diabetes” said Robert A. Gabbay, Chair of the Steering Group of BRIDGES 2. This will enable the implementation of established evidence-based interventions and approaches to diabetes care. BRIDGES 2 will further build on the achievements of the initial phase that resulted in 41 diabetes prevention and treatment projects supported in 36 countries.

BRIDGES 2 issued a request for grant proposals in June 2017. All grant proposals will be peer reviewed and prioritised by a cross-disciplinary external review group under the coordination of IDF. A steering committee composed of experts appointed by IDF and Lilly will determine the selection of projects and types of grants that will be available.

“IDF is proud of the achievements of the first phase of BRIDGES, and we are delighted to have the opportunity to further replicate the findings of the completed projects. We want to spread best practices to those who need it most and help shape a better world for the millions of people currently living with diabetes and the many more at risk,” said Shaukat Sadikot, IDF President.

For more information about BRIDGES 2, please visit www{idf.org/bridges

IDF-SACA holds collaborative and pioneering forum

The Second International Diabetes Forum, held in the Dominican Republic from April 27-30, 2017 has been called a pioneering initiative between IDF South and Central America Region (IDF-SACA) and the Latin American Diabetes Association (ALAD) with collaboration from the Dominican Republic Society of Endocrinology and Nutrition (SODENN), the National Institute of Diabetes (INDEN) and the Dominican Society of Diabetes (SODODIA).

At this year’s second Forum, more than three-hundred endocrinologists, diabetologists, diabetes educators and other professionals from throughout Latin America and the Caribbean attended. The event represents an opportunity for Latin American and Caribbean specialists and stakeholders to discuss important issues and strategic solutions for diabetes professionals and for people at living with or at high risk for diabetes.

In the opening ceremony, representatives of the organizing institutions, Ammar Ibrahim, Chair of the International Diabetes Federation South and Central America, IDF-SACA, Dolly Mejia, President of SODENN; José Mesa, President of ALAD; Aura Mota, Director of INDEN; José Rodriguez, President of SODODIA; and Nam Han Cho, President-Elect of IDF were all present to welcome participants.

Leading national and international faculty speakers presented material including clinical guidance and scientific research to benefit regional attending physicians and other healthcare professionals. Forum coordinators believe the Forum’s intensive continuing education program will have a positive outcome on the care of people with diabetes and self-management education directed at patients in Latin America and the Caribbean.

One of the most successful events at the Forum was a symposium on diabetes education and advocacy attended and coordinated by Betsy Rodriguez, Manny Hernandez, Mila Ferrer and Marina Gomez as well as other representatives of the IDF-SACA Region.
American Diabetes Association advocates for healthcare rights

Advocating for the rights and welfare of all people living with or at risk for diabetes, the American Diabetes Association is urging legislators (US Senate) to reject the American Health Care Act of 2017 (AHCA) on behalf of all people in the US living with or at risk of diabetes. It has been projected that up to 24 million people in the US will lose their coverage should the AHCA repeal and replace the Patient Protection and Affordable Care Act (ACA) and become law.

Access to adequate and affordable healthcare allows individuals with diabetes to obtain the necessary medical services they require to manage their disease and prevent devastating complications.

The AHCA will weaken current requirements for essential health benefits and health status and give insurers the ability to charge people with pre-existing conditions, such as diabetes, higher prices. The new bill will also allow insurers to deny people with diabetes coverage for the care and services they need to treat their condition. Waiving protections for people with pre-existing conditions would likely result in higher premiums, long waiting lists and inadequate healthcare coverage.

In addition, if the AHCA is enacted, the legislation repeals the Prevention and Public Health Fund after year-ending 2018, eliminating almost 40 percent of the Center for Disease Control and Prevention’s (CDC) chronic disease prevention and health promotion budget—a drastic step backwards for diabetes prevention.

Since it was founded in 1940, the American Diabetes Association has been committed to its mission to prevent and cure diabetes and to improve the lives of all people affected by diabetes; currently more than 29 million people live with diabetes in the US.

Read more on the ADA website.

New partnership helps students with diabetes transition to college

The College Diabetes Network (CDN) and the Juvenile Diabetes Research Foundation (JDRF) announced their national partnership (May 17, 2016) to support CDN’s Off to College Program to ensure that more high school students and their families have the information and support they need to successfully prepare for and transition into college with diabetes.

With 71 percent of students currently reporting difficulty managing diabetes in college, this program provides critical resources for the transition to independence. CDN’s Off to College Program offers resources for everyone involved including printed booklets for students and families and informational toolkits for health clinics. Resources are provided at no cost and can be requested for both electronic download and hard copy booklets. CDN’s Off to College Program is the most comprehensive diabetes education program for young people living with diabetes and their families.

“The transition to college is an exciting but stressful time for young adults with diabetes and their families. These booklets aim to help make that transition easier so that families are more prepared for college.” said Christina Roth, CDN’s CEO and Founder. “With JDRF’s chapters and Type One Nation Summits, more families will have access to these resources.”
“JDRF is thrilled to partner with the College Diabetes Network. Type 1 diabetes is 24/7 with no breaks or holidays,” said Aaron Kowalski, PhD, Chief Mission Officer at JDRF. “We know college is a stressful time with numerous adjustments and changes in routine, and providing appropriate support and resources is critical. We are grateful for these opportunities to help drive awareness and increase our vision of a world without type 1 diabetes.”

About the College Diabetes Network

The College Diabetes Network (CDN) is a non-profit organization whose mission is to provide innovative peer based programs which connect and empower students and young professionals to thrive with diabetes. To connect with other young adults, or to find out more, go to www.CollegeDiabetesNetwork.org

Connection between diabetes and infectious diseases in tropical countries

In the June 2017 edition of *The Lancet Diabetes and Endocrinology*, researchers from the Netherlands and the UK published a significant review emphasising the interaction of diabetes and infections in tropical countries. Tropical countries are experiencing a substantial rise in type 2 diabetes, which is often undiagnosed, diagnosed after complications develop and poorly controlled. Diabetes is a risk factor for many infectious diseases which the authors believe is adding to the large infectious disease burden in tropical countries.

In their review, the authors highlight the risk from diabetes for infectious diseases in general, referring to potential underlying mechanisms: factors which contribute to a higher burden of diabetes-associated infections in tropical countries—specifically referring to diabetic foot and tropical diabetic hand syndrome; the association between diabetes and tuberculosis and HIV; and what is known about diabetes with respect to malaria, emerging viral infections, and neglected tropical diseases (NTDs).

The authors point to several mechanisms which contribute to the increased frequency and severity of infections in people with diabetes. Diabetes is associated with decreased host immunity to infections, diabetic neuropathy, macroangiopathy and microangiopathy contribute to increased rates of skin lesions and poor wound healing as well as many other factors. In addition, epidemiological studies have linked hyperglycaemia with increased infection rates and mortality, increased risk of hospitalisation from pneumonia, some bloodstream infections, and urinary tract infections.

The authors argue that even without data, it is likely that patients with diabetes in tropical countries are at increased risk for common bacterial and other infections for several reasons. Diabetes is more likely to be undiagnosed (and therefore unmanaged) in resource-constrained tropical settings and usually associated with poor glycaemic control; unavailability, insecure supply, or high costs of diabetes medication, and issues related to not correctly storing and administering insulin; food insecurity and access to healthy lifestyle as low priorities; the slight number of healthcare providers available to properly educate, treat, and monitor diabetes; and reduced access to diagnostic and therapeutic services, or access to good-quality care for infections are among the most profound reasons for the increased risk for people with diabetes for infections.

The authors call for an urgent need for more research to address all these issues, and for efforts to better link or integrate care for communicable and noncommunicable diseases. Determining the interaction between diabetes and infectious diseases may also improve prevention and management of diabetes in high-burden tropical countries.

Reference

The recent publication of the report on the *IDF Global Survey on Access to Medicine and Supplies for People with Diabetes* highlights continuing issues with the availability of essential medicines for people with diabetes. Regrettably, progress has been slow over the recent decades.

I write this with a very long historical perspective. I have served the IDF Task Force on Insulin, Test Strips and Other Diabetes Supplies since 1991. IDF as an organization recognized and actively pursued improvements firstly for the global supply of insulin and subsequently, other essential diabetes medicines.

The first survey was undertaken in the early 1990s and published in *Diabetes Care* in 1994. Then there were only 85 IDF Member Associations and the survey was conducted by mail. Response fact checking was impossible. The current survey was distributed electronically to 230 IDF Member Associations in 170 countries and territories, and when more than one in-country response was received, electronic interactions and clarifications were possible. It is very apparent that the IDF world was much different at the time of the first survey so that must be considered in making comparisons.

Important highlights from that first survey where 65 associations responded include:

- 78% said insulin was always available.
- 18% said insulin was available from 25% to 99% of the time.
- Two countries said insulin was available less than 25% of the time.

The survey questions and the makeup of IDF were very different in the early 1990s, but the reader can keep these responses in perspective as we review the most recent study.

The current report rightly points out the dramatic increase in diabetes worldwide and perhaps more importantly, the increase in diabetes prevalence in low - and middle - income countries which has occurred in a very disproportionate way. Likewise, WHO developed a Model List of Essential Medicines, which includes short and intermediate acting insulin, glucagon, glicazide and metformin.

The current report also includes inquiries about other essential medicines for people with diabetes which protect from cardiovascular complications. These include hypertension and lipid lowering drugs. The current report is based on a study comprised of two distinct components:

1. Access survey on government provision and availability.
2. Access snapshot on prices.

This second and important component of the current evaluation was the use of IDF’s Young Leaders, a group of 184 committed volunteers across the globe who were asked to visit outlets for medicines such as pharmacies and hospitals to enquire about availability and price.

The access survey on government provision and availability has received data from about a third (82) of IDF Member Associations contacted. When divided into high, middle and low income countries the response rate was similar, but
110 countries are counted as middle income. The access snapshot by Young Leaders reached 34 countries. Clearly neither survey represents a random scientific sample, but together they provide useful data.

The results were expressed in several ways. Supply by the government vs non-governmental sources was detailed. In 81% of high-income countries short acting insulin was available 100% of the time and 84% of high-income countries for intermediate-acting insulin; the percentage in middle-income countries was 46% and 44% and low-income, not surprisingly, 0% (Figure 1). In high- and middle-income countries, the government provided insulins in 70% and over 50%, respectively, and as might be expected 0% in low-income countries. In addition, the data shows that where short and intermediate acting insulin is available >75% of the time, the response is 97% for high-income countries, 89% and 94% in middle-income countries and 40% for both in low-income countries. In the snapshot study the major causes for lack of insulin included price and inadequate supply.

Data for supplies reflect the insulin data but generally were a bit lower. Cost for all essential diabetes supplies was translated into disposable income (DI) using standard methodologies. Not surprisingly, glucose testing strips were by far the most expensive item and four strips could cost as much as 50% of DI (Figure 2).

Oral agent availability reflected insulin availability across the income categories but a month’s supply was much lower in all countries. Other required drugs for hypertension and lipid control were at the 75% level in over 90% of high- and middle-income countries and in a majority of low-income countries.

This survey represents a good global look at diabetes treatment drugs and supplies. There are still very large gaps in availability. IDF recommends several strategies. Price is a barrier and better supply chain distribution, procurement practices and equity prices are potential strategies. Likewise, education of people living with diabetes as well as those in charge of procuring medicines is essential so the most expensive products do not displace less expensive and effective medicines. Across the board for all essential diabetes medicines and supplies, availability needs improving in many countries. IDF remains committed to making essential medicines available to all. This survey provides a better understanding of gaps.

Larry C. Deeb, MD is a pediatric endocrinologist in Tallahassee, Florida (USA) and Chair of the IDF Task Force on Insulin, Test Strips and other Diabetes Supplies.

References
In Bolivia, the public health system does not serve the general population. According to data from the National Institute of Health Insurance (INASES), only 38.8% of the total Bolivian population has access to any health insurance which when translated into real numbers means that approximately 6 million people do not have health insurance. There are exceptions: children under 5 years, women in pregnancy and adults over age 60 years have full access to free healthcare. Otherwise, Bolivian public hospitals have a system of a structured fee mechanism, where patients are charged the costs of care according to their economic capacity.

Although there are approximately a half million people with diabetes and many more people with pre diabetes, Bolivia does not have a diabetes policy, strategy or action plan. In many parts of Bolivia, especially in rural locations, people do not know the treatment for diabetes or have false beliefs about how to treat it. From small villages to cities, people do not have adequate diabetes education. In terms of Bolivia’s middle-class, people with diabetes who have health insurance have access to NPH (intermediate-acting) and R (short-acting) human insulins but these same individuals do not receive any essential supplies. The rest of the people with diabetes who aren't insured struggle every day to buy their insulin. Many people with diabetes seek healthcare in the private sector through out-of-pocket payments.

Although the WHO Expert Committee on the Selection and Use of Essential Medicine has concluded that insulin analogs have "no significant clinical advantage" over recombinant human insulin, little by little Bolivia is having a transition from human insulin to analog insulin but most people living with diabetes, cannot afford the cost of analog insulin, devices like insulin pens, nor can they measure their blood sugar every day. Many people do not have money to buy test strips and spend weeks without measuring their blood glucose. A person’s care varies a lot depending on their economic power.

In Bolivia, insulin analogs are five times more expensive than human insulins. The Bolivian insulin analog market is an oligopoly, and such limited market competition has implications for insulin prices and usage. While insulin biosimilars are not yet expected to hit the market, Basaglar is an example of a promising biosimilar, and there is great hope it and other biosimilars will enter the marketplace soon.

This would result in greater competition among brand-name insulins, potentially helping to bring down costs and lessen the financial burden for many families.

However, insulin alone is not enough. Syringes are required for the delivery of insulin, and they are not available in the public sector. The private sector is the main source for people purchasing supplies and like test strips and other devices for testing, the cost and availability of syringes also means that people are reusing single-use syringes or like the test strips, eliminating their frequency.

Solutions proposed have mainly focused on lowering cost, but access to diabetes care is more than just medicine. Insulin alone is not enough for proper diabetes care. To improve the lives of people with diabetes, access to medicine needs to be addressed in parallel to creating a healthcare system able to manage all aspects of diabetes care.

Douglas Villarroel is an endocrinologist, educator and Bolivian author. Currently, Dr. Villarroel is Editor-in-Chief of Diabetes Voice.
I have the honor and responsibility of coordinating with the collaboration of other several well-known colleagues, including Kamil Salamah (Saudi Arabia), Larry Distiller (South Africa) and Ramon Gomis (Spain) for the Stream, Science of diabetes complications, scheduled for the IDF Congress at Abu Dhabi in December of this year.

The great prevalence and increasing incidence of micro and macrovascular diabetic complications are likely to be initially connected with poor access to early diabetes diagnosis and treatment but also to the identification and control of an individual’s pre diabetic status. Another factor is the coinciding poor access to training available to healthcare teams on the clinical management of diabetes as well as self-management education for people with diabetes. Combined with the shortage of medicines and supplies, the result has obvious consequences: poor adherence, medical inertia and preventable, yet poor outcomes. Unfortunately, there’s a third access issue: adequate care for diabetes prevention, early diagnosis and treatment of chronic complications which are lacking in several areas of the world.

These issues above are why poor access has such a formidable place in a program dedicated to diabetic complications. Examples of Stream symposia include: “Forgotten complications of diabetes” with Richard Donnelly (UK) and Lewis Winning (UK); “Gestational diabetes and micro and macro vascular impact” with Maria Christina Faingold (Argentina) and Maria Ines Schmidt (Brazil); and “Diabetic nephropathy-From the beginning” with Alicia Ester Elbert (Argentina), Fernando Lanas (Chile) and Alexander Miras (UK). Mark Cooper (Australia) will deliver the IDF Award Lecture, “Pathogenesis of micro and macrovascular complications: are there common pathways for both?”

Presentations will be delivered by our outstanding faculty through symposia, case studies, meet the expert sessions and debates. This format assures not only the reception of new and important knowledge in these areas, but also a tremendous possibility of exchanging ideas and experiences among the delegates from all over the world and lecturers coming from different regions of the IDF.

It must also be must emphasized that issues concerning the diabetic foot—a topic where poor access has enormous importance—have been developed in a specific Stream with the leadership of Lawrence Harkless (USA).

I am convinced that the Science of diabetes complications Stream will give healthcare providers and people with diabetes new tools for diabetes management, and the 2017 IDF Congress will confirm the success of previous ones.

Isaac Sinay is an advisor at the diabetes unit at the Cardiovascular Institute of Buenos Aires in Buenos Aires, Argentina and Stream Lead, Science of diabetic complications for IDF 2017 Congress in Abu Dhabi, UAE.
Our world is confronted by many disasters today and we are witness to many of them with the help of news and digital media. There are natural disasters like hurricanes, tsunamis, earthquakes, floods, famine and pandemics such as H1N1; there are also political disasters like war & terrorism. Living with diabetes is a huge burden with many challenges even in normal circumstances, however it becomes more difficult during a period of natural disaster or war and unfortunately for many, it can be impossible to get adequate care and medicines during this time.

Previous worldwide natural disasters have taught us that people who live with diabetes face many difficulties getting essential medicines and supplies, such as insulin, blood glucose test strips, adequate nutrition, physical activity and addressing other comorbidities such as hypertension and dyslipidemia. Yet there is still little data to substantiate the urgent need for a protocol or plans to assist people with diabetes in disaster. For humanitarian workers and healthcare providers filling the gaps during disaster in developing countries, the greatest obstacles are lack of pre-disaster plans and poor local resources and thus, rebuilding and providing sustainable care can take years. The situation is even more dramatic and dangerous for individuals with diabetes living in conflict zones such as Syria.

For the first time, this year’s IDF 2017 Congress in Abu Dhabi, UAE, has dedicated a special Stream program entitled “Diabetes and disasters” where experts including medical professionals, public health specialists and relief specialists will present and share experiences on the consequences of disasters for people living with diabetes, as well as discuss plans and guidelines to assist people with diabetes during disaster. The Stream program will offer panel discussions and testimony sessions. Examples of the program include the following symposia:

- Miyako Kishimoto, Chief of the Department of Diabetes and Metabolic Medicine, National Center for Global Health and Medicine in Tokyo, Japan will discuss the Great East Japan Earthquake (2011) on experiences and suggestions for survivors with diabetes.

- Tayseer Sabbagh, Deputy Chief Field Health Program, the United Nations Relief and Works Agency (UNRWA) will discuss provisions for non-communicable disease care to Palestinian refugees during emergencies in Syria.

- Krystel Moussally, Epidemiologist for the MENA region at Médecins Sans Frontières (MSF) will discuss caring for diabetes in a crisis context in the Levant.

Roundtable consultations co-chaired by Neil Donelan (Insulin for Life Australia) and Dr. Sidartawan Soegondo (Jakarta, Indonesia) will include expert speakers from UNRWA, WHO, IDF and MSF.

The “Diabetes and disasters” Stream program is an urgent platform where needed attention and guidance in preparing for disaster in consideration of people with diabetes and responding to disaster with appropriate measures will save many lives.

Nizar Albache is Co-chair of the IDF Diabetes and Disasters Committee and Chairman of the IDF-MENA region.

The global diabetes community will unite at the IDF 2017 Congress in Abu Dhabi, UAE, on 4-8 December 2017. The event will include more than 200 speakers, both world-renowned and newcomers, 230 national diabetes associations from 170 countries and high level participation from the Health Authority Abu Dhabi (HAAD) and other health organisations. To register or for more information, please visit www.idf.org/congress.
New IDF clinical practice recommendations for managing type 2 diabetes in primary care

Pablo Aschner

Diabetes, a worldwide epidemic, has become a huge health burden in most countries and calls for prompt and appropriate management to avoid long-term complications. Globally, appropriate diabetes care is particularly important at the primary care level, where most people with type 2 diabetes (T2D) are treated and therefore, where a healthcare team trained on best practice for T2D is vital for success.

The task is not easy, since the limited amount of time to solve a great variety of medical problems makes it very difficult for the primary care physician (PCP) to personalize care for every patient with T2D considering individual needs and barriers. It becomes even more difficult when having to choose among the increasing number of new medications which may have added benefits, but also risks.

Although there are special cases, particularly among patients whose T2D is recognized after they have already developed complications such as cardiovascular disease (CVD) or renal failure, there are general recommendations for treatment and goals which facilitate decision making. Currently, there are numerous global, regional and local Clinical Practice Guidelines (CPG) developed for this purpose which is why the IDF determined investigating the current CPG environment was critical. It was important to assess and understand how surveyed PCPs responded to the most common questions that address daily care of people with T2D and identify common ground in terms of T2D diagnosis, management, goal-setting and different levels of prevention. When there were clear discrepancies, the IDF Working Group made the effort to explain the reason and help facilitate the PCP towards the best choice of action.

Unfortunately, the degree of rigorousness varies greatly between current CPGs, ranging from a set of recommendations given by a group of leading medical professionals based on their expertise to an evidence-based CPG using the methodology developed by the Grading of Recommendations Assessment, Development and Evaluation (GRADE) working group. The GRADE working group has produced a common, sensible and transparent approach to grading quality of evidence and strength of recommendations which has now become the standard for developing CPG. The IDF Working Group decided to select the best CPG by assessing methodological rigor and transparency with the Appraisal of Guidelines for Research & Evaluation (AGREE) Instrument, developed to address the issue of variability in the quality of practice guidelines in order to be confident of the resulting recommendations. This tool has also become the standard for appraising CPG.

The IDF Working Group selected twelve CPGs for the treatment of T2D and included additional versions focused on specific populations such as the elderly with T2D. We identified around 40 clinical practice questions which we tried to answer by analyzing the rationale and recommendations provided by those selected CPGs and discussing the results in an International Consensus Group.

Our work resulted in the new *IDF Clinical Practice Recommendations for Managing Type 2 Diabetes in Primary Care* where we offer around 78 practical and applicable recommendations for the PCP and his or her team covering all the fields of T2D management. The Recommendations will be published with their rationale and methodology in July 2017.

### Appropriate diabetes care is particularly important at the primary care level, where most people with type 2 diabetes are treated.

#### Screening, diagnosis and targets

In brief, we recommend screening people at high risk for diabetes attending the local healthcare facilities, if possible with a validated screening test, and then use the diagnostic tests and criteria currently proposed by the WHO and IDF. We strongly recommend early treatment of those who are newly diagnosed with T2D and enrolling people with intermediate hyperglycemia (*pre diabetes*) in a diabetes prevention program.

The general target for blood glucose (BG) control should be an HbA1c < 7 percent but we included special considerations in some conditions such as old age. We emphasize the role of diabetes education at the primary care level and the fundamental role of the diabetes educator. Lifestyle changes, including diet, physical activity and avoiding unhealthy habits, are the cornerstone of diabetes control and patients should be referred to a structured diabetes education program, but meanwhile we provide helpful tips that the PCP can offer to the patient at the initial visit with
particular attention to the management of obesity.

**Pharmacological treatment**
Practically all the CPGs under review recommend starting pharmacological treatment with metformin monotherapy, but under certain circumstances initial combination therapy with metformin and another glucose lowering drug (GLD) and/or basal insulin may be a better option. If the initial treatment is not enough to achieve or maintain BG control, there are different approaches to the use of other GLDs depending on priorities such as the patient's characteristics and preferences, the generalizability of the medications, their effect on weight and/or their effect on CVD. Nevertheless, we offer the PCP the best choices for dual and triple therapy, including recommendations on when to start injectables (insulin and GLP-1 receptor agonists).

**Cardiovascular risk and complications**
A special section was assigned to the management of cardiovascular risk factors. High blood pressure should be lowered to a diastolic target of 80 mmHg and a systolic target between 130 and 140 mmHg. Smoking should be stopped. Statins should be given to most patients with T2D, particularly if they have other cardiovascular risk factors and/or a high cardiovascular risk score. In those with documented CVD, the statin should be selected and up-titrated to reach an LDL cholesterol target <70 mg/dL (1.8 mmol/L). New add-on therapies to statins are also considered. We included smoking cessation and antiplatelet treatment.

The last section was dedicated to screening for complications, including retinopathy, nephropathy, neuropathy, coronary disease, peripheral artery disease and depression. We ended by addressing referral and cost-effectiveness.

Although the recommendations presented in the new guidance are derived from more comprehensive and well-conducted guidelines, we hope to facilitate the optimal utilization of the available medications and monitoring tools at the primary care level and ultimately reduce the health burden attributable to diabetes and its complications.

Pablo Aschner MD.MSc. is Associate Professor of Endocrinology at the Javeriana University School of Medicine and Director of Research at the San Ignacio University Hospital. He is Chair of the IDF Working Group: IDF Recommendations For Managing Type 2 Diabetes In Primary Care.
Diabetes is a lifelong condition that may be difficult to live with anywhere in the world, but there is a greater degree of difficulty associated with diabetes care and self-management in settings with fewer resources available. Currently, four out of five people affected by diabetes live in low- and middle-income countries. Although very little data is available on the presentation and frequency of diabetes in childhood in these countries, reports available suggest that children who develop diabetes may die before being diagnosed or survive only a few years after diagnosis from lack of access to insulin. Programs such as IDF’s Life for a Child help provide insulin where it is needed; however, insulin is only part of the care required for children with diabetes.

SWEET is the acronym for “Better control in Paediatric and Adolescent diabetes: Working to crEatE CeNTres of Reference,” a multinational initiative to improve diabetes care and outcomes in youth with all types of diabetes. SWEET activities include benchmarking of clinical care and outcomes and sharing of information and experience between participating centres. Benchmarking involves each centre providing data on children who are followed in their clinics on a central database twice per year. This information is used to generate regular reports that allow each diabetes centre to see how they compare to others. Through this process, participating centres can learn from each other to improve provision of care to their children and achieve the best possible outcome. As of February 2017, 50 paediatric diabetes centres from around the world are contributing data. Although the majority of centres working with SWEET are from Europe, the following developing countries are also included: India (two centres), Mali, Argentina, and Costa Rica.

The challenges of caring for diabetes in children and adolescent patients in developing countries are the same as in developed countries: achieving glycaemic goals to prevent complications and providing the best opportunity for a good quality of life. The difference between care in a developed country versus a developing country are barriers related to: socioeconomic problems; lack of accessibility to diabetes supplies and education; and inequity in the assistance of vulnerable groups.

The principal challenges related to diabetes access and outcomes are:

- shortage of available diabetes supplies;
- deficits in knowledge leading to preventable death from the acute complications of diabetes;
- scarcity of medication and medical care coverage resulting in inadequate diabetes control and increasing the risk of complications and shortened life expectancy;
- lack of diabetes education for families leading to deficient compliance with regular insulin doses and blood glucose monitoring, again contributing to increased risk of complications and shortened life expectancy;
- social stigma associated with diabetes resulting in children, adolescents and young adults hiding their condition from their social circle to avoid being denied access to school, work and later, to marriage.

In the last three decades, these issues have been addressed in higher income countries by providing sufficient resources for access to testing supplies or other, insulin and education for families and children with diabetes and through public awareness of diabetes. However, in developing countries, these issues remain significant challenges for individuals affected by diabetes.

Participation in SWEET for the centres in India, Mali, Argentina and Costa Rica led to the development of a local or regional electronic registry tracking the data of the population they
serve for benchmarking. Participation in SWEET is also perceived as a means to develop or improve local standard protocols for the care of children with diabetes, support for care provider education, and promotion of the need for multidisciplinary approach to diabetes care. The following examples illustrate these benefits:

• In Buenos Aires, Argentina, since joining SWEET in 2014, the number of children being treated with multiple daily insulin injections as per the international practice guidelines has significantly increased (Figure) leading to a substantial improvement in the glycaemic targets in their population.

• In Ahmedabad, Gujarat, and Belgaum, Karnataka, India, implementation of the registry led to standardization of patient medical appointments and frequency. This standardization has resulted in increased interactions with the diabetes care team, better understanding of diabetes by families and children, improved self-management care including more accurate insulin dosing and blood glucose monitoring, and a decrease in frequency of hospitalizations for acute diabetes complications.

• In Bamako, Mali, prior to having data collected for SWEET, children would rarely attend regular medical visits or receive an HbA1c, a diagnostic blood test measured primarily to identify the three-month average plasma glucose concentration which is ideally given to children living with diabetes four times per year. Since being involved in SWEET, the frequency of medical visits and access to HbA1c testing has increased to twice per year.

Figure: Excerpt from the most recent SWEET benchmarking report for JP Garrahan Hospital, Buenos Aires, Argentina, showing increase in frequency of use of multiple daily injections.

Conclusions

All participants in SWEET share a common commitment to care for children who have developed diabetes. The centres from low-income countries show great initiative despite several barriers, challenges or difficulties. For these centres, involvement in SWEET is a significant advantage in helping providers and their patients achieve improvements in best practice and obtain further credibility and support from local health authorities. As described by one participant centre, SWEET’s benchmarking process provides a sense of healthy, positive competitiveness, thereby making each centre more productive, hardworking, efficient, and focused to produce the best possible results, regardless of its socioeconomic background. Participation from diverse paediatric diabetes centres provides a variety of valuable insights, perspectives, and opportunities that can be used to promote healthier lives and stronger futures for children with diabetes in low- and middle-income countries.
The SWEET study group is a multinational initiative to improve diabetes care and outcomes in youth with all types of diabetes.

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Carmen S Mazza MD is a paediatrician specializing in diabetes and nutrition practicing in the Nutrition Department at Hospital de Pediatria JP Garrahan, Buenos Aires, Argentina.

Dhruvi Hasnani is an assistant diabetologist at the Diacare Diabetes Care & Hormone Clinic, Ahmedabad, India.

Erick Richmond is a paediatric endocrinologist at the National Children’s Hospital and professor at the University of Costa Rica.

Stéphane Besançon is biologist and nutritionist, and CEO of the international NGO Santé Diabète (www.santediabete.org).

Sujata M Jali is professor and Head of the Department of Pediatrics at the KLE University’s JNMC and KLES Hospital, Belgaum, India.

Jean-François Lemay is a developmental paediatrician and professor at University of Calgary, Calgary, Canada.

References


Indonesia snapshot: access to diabetes care in Bali

Elizabeth Snouffer

According to IDFs Diabetes Atlas (2015), approximately 10 million adult Indonesians (20 to 79 years old) live with diabetes and as many as 6 million adults live with undiagnosed diabetes, making Indonesia’s diabetes population the seventh largest in the world. With a country population recorded currently at 263 million, and a prevalence of diabetes estimated at 6-7%, the number of Indonesians with type 2 diabetes will likely increase by half if not double by 2040. The Diabetes Atlas does not have data to report on the number of cases of type 1 diabetes in Indonesia.

Bali, a popular island and province of Indonesia, is almost solely dependent upon tourism for its economy but behind the palm trees and coastal glamour, a large proportion of more than 4.2 million people live on $146 US dollars per week minimum wage. That’s about $20 a day.

Dr. Ketut Suastika, Professor of Medicine specializing in endocrinology, and Rector of Udayana University in Denpasar, Bali knows more about diabetes than perhaps anyone else in the province. He offers me access to his diabetes team of medical professionals at Sanglah Hospital, the largest government owned hospital in Bali.

Dr. Suastika spends a good deal of his time administrating, teaching resident internists and fellows about clinical diabetes care and overseeing the most difficult cases. His leadership work with the Indonesian Ministry of Health helped push forward government initiatives which provide medicines for free to people with diabetes, including analog insulins. Indonesia considers Bali one of the most successful models of care for people with diabetes out of all the country provinces, according to Dr. Suastika.

At Sanglah Hospital, physicians and other healthcare professionals explain how the public and therefore, patients are often unaware of diabetes symptoms, resulting in late diagnosis. The status of the amputation clinic at Sanglah is full which likely reflects this problem and neuropathy is often the initial cause of the need to seek medical care leading to diabetes diagnosis. Eye disease is a close second.

While the facts are troubling, there are also signs of encouragement. Professional and patient education is evident and exciting: over one hour in the hospital diabetes clinic, I observe bustling resident fellows as they wait in line for diabetes rounds in training and briefly attend a mini-conference for diabetic nephropathy along with more than 30 other attending professionals.

“Professional education is very important, because we need to educate our patients, too.” says Dr. Wulan Dewiyasa. “If someone comes to our hospital for care, then he or she is a serious case that the local public hospital or clinic cannot manage. We diagnose and treat, provide self-management education and send them home but we will only provide one week’s supply of medicine until they are stable.” All people newly diagnosed or not maintaining blood glucose targets are required to return weekly until the diabetes team feels they can manage independently on their own.
Children and teenagers living with type 1 diabetes pose for a photo with their mothers in Bali, Indonesia. © Elizabeth Snouffer

It is not known how many children have type 1 diabetes in Bali, but Dr. Made Arimbawa is one of the few paediatric endocrinologists specifically trained on initiating and administering insulin therapy for children, teens and young adults with type 1 diabetes on the island. “It’s really tough to manage children who come from villages far away–some must travel a distance greater than 3-4 hours and we are their only connection to care.” Dr. Arimbawa says. He explains how none of the doctors in the smaller public hospitals or clinics want to take on the rigors of insulin therapy or look after children with type 1 diabetes. “I have taken on a lot of cases over the years and still keep in touch with many of my former patients, but others I just don’t know what happened.” Currently he cares for 30 Balinese children and teens with type 1 diabetes. “The greatest issue is the children are not testing and therefore not getting adequate insulin.” he explains. “It’s a frustrating situation.” In Bali, blood glucose testing equipment is not free; blood glucose test strips cost $.50 US cents and ketone strips are $3 US dollars each. “Families cannot afford these essential supplies, and without them, children don’t meet targets.” Even with abundant insulin, access to more complex education and essential supplies is poor.

Later on, I am fortunate to meet a number of Dr. Arimbawa’s patients who are visiting the clinic for the afternoon. They have each volunteered for a group interview. Faiz (13 years, diagnosed at 9), Rafi (17 years, diagnosed at 13), Rafi’s sister: Desak (14 years, diagnosed at 9) and Triyasa (7 years, diagnosed at 4) are all bright and expressive young people interested for a moment in the fact that I am not only American, but that I also have an insulin pump. No one has ever seen an insulin pump or a continuous glucose monitor, not even the medical professionals at the hospital who convey their acceptance that expensive diabetes technology is not likely to be a reality in the future.

Each of the children take turns in speaking out about their life with diabetes in Bahasa, their native language, and the attending nurses and doctors translate each word very carefully. The children’s mothers add their perspective, too.

“It’s hard not to eat sweets.” says Deshak who loves to cook and wants to be a chef. “I don’t mind injecting, I do it all by myself.”

“She’s very independent.” adds Deshak’s mother, “but I can see she is sad about her condition.”

“The schools here don’t allow the children to test their blood glucose in school.” exclaims Faiz’s mother, “and his teacher at school doesn’t even believe he has diabetes! We try to stay positive.”

Triyasa’s mother speaks out quietly, “Triyasa’s a really good boy but he was diagnosed so young at four years. I worry about his life ahead.”

The two youngest boys, Triyasa and Faiz want to be professional soccer players when they grow up and Rafi, an older teenager already suffering from severe retinopathy, is studying to be a musician. All the parents in the interview room that day are fearful that terrible complications will threaten their children’s futures and it’s hard not to share their worry; their HbA1c’s range from 9 to 13 percent.

Faiz, who has requested I send him a poster of football star, Cristiano Ronaldo, if possible, makes sure he’s able to tell me one more thing before we say goodbye. “I try to think of diabetes as a friend.” the 13-year-old explains with a smile. “It’s easier to accept my condition that way.”

Elizabeth Snouffer is Editor of Diabetes Voice. She has lived with type 1 diabetes for more than 40 years.
Access and financial barriers to care for people with diabetes within publicly-funded healthcare systems

David J.T. Campbell, Braden J. Manns, Alun L. Edwards, Kathryn M. King-Shier

There are a few contributors to this issue of Diabetes Voice who have articulated the difficulties in access to care for persons with diabetes in low- and middle-income countries. It is also important to recognize that even in countries where publicly-funded health care exists, access to all necessary care is not guaranteed. Our research group, the Interdisciplinary Chronic Disease Collaboration at the University of Calgary, has undertaken a series of studies to better understand the role of financial barriers for patients with chronic medical conditions, including diabetes, in Canada.

Significance of financial barriers
Despite the common thought that Canada has universal health insurance, approximately 12 percent of Western Canadians with chronic conditions (such as stroke, heart disease, and diabetes) experience financial barriers to care. Among those who have two or more chronic conditions, this figure is as high as 21 percent. We have also demonstrated that those who experience financial barriers have significantly higher rates of hospitalization and mortality.

In the Canadian context, many of these financial barriers may arise due to the structure of the provinces’ public health insurance plans. Hospital and physician services are universally available free-of-charge. However, insurance for pharmaceutical services is provided only to some Canadians through a variety of provincial programs.

What types of financial barriers do people with diabetes face?
We conducted a series of in-depth interviews to better understand the aspects of care to which persons with chronic diseases most commonly experience financial barriers. We asked participants (including 24 who had diabetes) to describe their experiences with financial barriers in detail. We found that in Alberta (Canada), people with diabetes frequently face financial barriers to accessing: their prescription medications, diabetes testing supplies, and healthy food.

Regarding access to medications, one participant stated:

“I stopped taking my insulin for a long time because it was just getting ridiculous…what it [insulin] was costing. We just finished paying like a thousand dollars onto the account at the pharmacy where we get our stuff.”

Many patients with diabetes face financial barriers to accessing testing supplies because they can’t afford to test as frequently as they have been asked to by their healthcare providers:

“The doctors and nurses want me to do testing in the morning, two hours after every meal, and sometimes even one hour before a meal. That adds up to 4 or 5 lancets a day, 4 or 5 strips a day… If I were doing their exact schedule I would be spending about $200 to $300 a month on lancets and strips alone. I’ve broken that schedule.”

Finally, many felt a significant tension between being able to afford their medications and testing supplies, and having sufficient funds left over to purchase the kinds of food that would enable them to adhere to the recommended diet for optimal glycemic control. One participant stated:

“We’re not necessarily eating as healthy as we should be because of the money restraints of buying groceries. We’re trying our best, but sometimes it [a food purchase] is just something that’s gonna keep us full.”

How do financial barriers affect individuals?
Throughout the interview process, we found that all aspects of some participants’ lives were dramatically affected by their financial barriers, while others experienced financial barriers that had minimal impact on them. We explored this variation through a grounded theory analysis.

The result of this research was the development of a new framework for understanding the between-patient variation in the impact of financial barriers on people’s lives and health (Figure). We found numerous protective, predisposing and modifying factors that contribute to a patients’ ultimate experience with their financial barrier. These factors, in conjunction an individual’s worldview, influence a patient’s degree of resiliency which determines how they cope with their financial barrier. Those with low degrees of resiliency appeared to be the ones most likely to experience the adverse outcomes described above.

What can be done to minimize financial barriers for people with diabetes?
Healthcare providers play a key role in modifying how patients experience their financial barriers (Figure). There are...
numerous ways that healthcare providers, including family physicians, endocrinologists, pharmacists, and diabetes educators, can be supportive of patients who experience financial barriers and those at risk of financial barriers. This often starts by asking patients about whether they have insurance that covers the cost of their medications and testing strips, and whether they struggle to afford any aspect of their care or self-management. Connecting patients to resources such as social workers or patient navigators may help patients develop strategies to reduce the impact of financial barriers. Unfortunately, providers also have the potential to exacerbate financial barriers by being unempathetic and by expecting their patients to comply with recommendations that they cannot afford. Physicians might also consider prescribing less expensive generic medications, or only those that are covered by individual insurance plans. Providers may also minimize financial barriers by limiting recommendations for self-monitoring to the minimum that is clinically indicated.

Decision-makers may be able to minimize the prevalence and impact of financial barriers, as certain healthcare and social policies may protect individuals with diabetes from facing financial barriers while others predispose them to such barriers.

While the studies presented above were within a Canadian context, where healthcare provision is presumed to be ‘universal’, these studies are important for healthcare providers and decision-makers in all nations. Numerous studies have shown that financial barriers are problematic for people with diabetes in other settings, thus we may be prone to believe that finances are only problematic for patients in healthcare systems where no universal public access is in place. This series of studies serve to remind us that the management of diabetes is complex and challenging and that health insurers, public or private, may not fully cover the full spectrum of resources that are required for effective diabetes self-management. Optimal clinical care requires sensitivity to this important issue and empathy towards people living with diabetes who may struggle not only with their chronic medical condition, but also with the financial complications that come with it.
David J.T. Campbell, MD, PhD is a clinical fellow in Endocrinology & Metabolism, Department of Medicine, University of Calgary, Calgary, Canada. Braden J. Manns, MD, MSc, FRCP is a nephrologist and the Svare Professor in Health Economics, University of Calgary, Calgary, Canada. Alun L. Edwards, MB, BChir, MRCP(UK), FRCP is an endocrinologist and professor at the Cumming School of Medicine University of Calgary, Calgary, Canada. Kathryn M. King-Shier, PhD, RN, FESC is the Guru Nanak Dev Ji DIL chair and a professor in the Faculty of Nursing and Department of Community Health Sciences at the University of Calgary, Calgary, Canada.

References
Access to diabetes care in my home country...

In May, IDFs Blue Circle Voices (BCV) network participated in a panel discussion at the 70th World Health Assembly (WHA) in Geneva. BCV members, healthcare professionals and others discussed possible solutions to overcome diabetes care and treatment gaps among underserved populations worldwide. In this Diabetes Voice segment of Diabetes in Society, we hear from three BCV members: Riva Greenberg, Roxana Vizcaíno de Jaramillo and Vanessa Pirolo are all active, experienced diabetes advocates who attended the WHA event in Geneva on behalf of IDF. We asked them to report on the status of access to diabetes education, care and treatment in their home countries and how they are working hard to make a difference.

USA

Riva Greenberg lives with type 1 diabetes. She is the 2015 recipient of the International Diabetes Federation Lecture Award for education and advocacy, international speaker, health coach, author and a contributor to the Huffington Post.

I had the privilege to introduce the Blue Circle Voices at IDF’s side panel event at the World Health Organization meeting in Geneva in May. In addition, I was asked to share the state of healthcare in America, my home country. Under our session’s banner, Access to Diabetes Medicines and Care in Underserved Populations, you might not think the US would be included. You would be wrong.

I am fortunate. I live in New York City where I have access to healthy restaurants, top physicians and sidewalks to stroll. Yet, last year I had to have my endocrinologist fight with my health insurance company to get me an insulin that better suited my needs. You may also be aware healthcare in America right now is in a state of disarray. We may discover soon that people with pre-existing conditions like diabetes will not be able to get healthcare or it will be unaffordable.

I’ve also had the privilege to travel across America for the past ten years as an A1C Champion peer-mentor. I have met thousands of people with diabetes on U.S. Medicare who are not allowed enough test strips to keep their blood glucose managed. They cannot get insulin pens, used exclusively throughout Europe, which make dosing, particularly for older people and people with type 2 diabetes, easier, more convenient and less stigmatizing.

Only a few months ago, after a long battle with diabetes organizations and patients, US Medicare gave conditional approval for life-saving CGMs (continuous glucose monitors) even though the most vulnerable population to hypoglycemia are people with type 1 diabetes over the age of 60.

What can we do? The US system of capitalism and shareholder value often sacrifices the needs of individuals to the benefit of the few. We must find a way to make necessary and life-improving drugs, and devices available and affordable. This effort may come from businesses, small start-ups and large corporations with consciences. Those whose values include service and meeting needs.

ECUADOR

Roxana Vizcaíno de Jaramillo is a mother of a child living with type 1 diabetes diagnosed in 2013.

Access to diabetes care is very limited for people with diabetes in the public Health Service for Ecuador. While there may be a belief that hospitals in Ecuador are well supplied with all the necessary treatments for diabetes, it is not the case. People with diabetes needing care at the hospital don’t receive required medicine, and are simply told there is none available. Patients must buy it themselves in the retail pharmacy where prices are too high for most to afford. In addition, the people selling the medicine in the pharmacy have no knowledge about insulin. The pharmacy doesn’t differentiate between name brands or type of insulin, and for the person who is not educated about diabetes management, he or she doesn’t know which insulin is right for them. There
is also a lack of syringes smaller in both size and number of units for children.

As a member of the Blue Circle Voices (BCV), I try to be a voice among FUVIDA (Fundación Aprendiendo a Vivir con Diabetes), the diabetes foundation where I am an active member. I am dedicated to helping families like ours who are connected to or living with diabetes. For me, educating children about diabetes, helping them feel good about themselves is key. It is important to help children and teenagers with diabetes understand that their condition should never limit them and to help them develop confidence to be able to do or participate in anything they desire. Children with type 1 diabetes deserve the same opportunities as any other child or teenager.

A recent example of my activity on behalf of BCV is a project where I work with a group who has access to Star Wars character costumes. We take photographs with positive messages and post them on social media through FUVIDA’s webpage and children with type 1 diabetes are involved. For example, messages include:

*May the force be with you for every blood glucose test you take.*

*and*

*A real Jedi knows the importance of diabetes education.*

In an example of one of the images, a child with type 1 diabetes is checking his blood glucose with Darth Vader. Our objective is to help children see that they are the main character in a life with diabetes and while it is not always an easy journey, inner strength and love from people around them are important for progress.

**BRAZIL**

**Vanessa Pirolo** was diagnosed with diabetes 17 years ago. She is a member of Council of Associação de Diabetes Juvenil, a journalist specialized in health, coordinator of advocacy for 30 Brazilian Diabetes Associations and blogger at Convivência com Diabetes.

With a diagnosis of diabetes, a person begins their journey to meet the challenges of treatment to achieve targets and health, which includes access to specialized doctors, effective medicines and diabetes education.

The following are a few examples of the problems Brazil faces with access to adequate diabetes care and treatment:

- Overcoming long queues (waitlists) to have access to a specialized doctor or a multidisciplinary team so vital for all aspects of treatment.
- Dealing with Brazil’s healthcare bureaucracy which can be a barrier to a person getting the most modern and effective medicines and supplies.
- Finding or receiving diabetes education and learning how to filter true diabetes information from false.
- Staying motivated for self-management without positive assistance or recognition from healthcare professionals.

Through the Associação de Diabetes Juvenil, we have the Programa Nacional de Jovens e Adultos com Diabetes. I represent 30 Brazilian Diabetes Associations to work on public policies to improve treatment in the country. To do this, we inform and help the Municipal Health Secretaries as well as the national media to understand the importance of access to essential medicines for people with diabetes. We help people in positions of leadership or influence understand how key it is for people living with diabetes to have adequate medicines and supplies. We also work with the Ministry of Health so that more modern medicines can be made available. In addition, we are striving to create a diabetes education program for health professionals so they can adequately serve the public with diabetes.
OUR RIGHT TO A HEALTHY FUTURE

1 in 10 women are living with diabetes.
Many do not have access to education, treatment and care.

ACT TODAY TO CHANGE TOMORROW
www.worlddiabetesday.org