IMPROVING DIABETES CARE
WITH ACCESS AND EDUCATION
EYES ON DIABETES

Over 400 million people currently live with diabetes. Diabetes can lead to eye disease which can cause blindness if not caught early.

Screening for diabetes complications is important to ensure optimal health.

ACT TODAY TO CHANGE TOMORROW

www.worlddiabetesday.org
HEALTH DELIVERY
Early detection can prevent or delay retinopathy
Linda Hill and Lydia Makaroff

CLINICAL CARE
#WeAreNotWaiting: type 1 diabetes community leads innovation for optimal management
Timothy Omer

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THE GLOBAL CAMPAIGN
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DIABETES IN SOCIETY
Voices of diabetes: Where I find the best information about my diabetes
Hello and welcome to *Diabetes Voice*. It is a great pleasure to introduce myself as the new Editor-in-Chief. On behalf of the Diabetes Voice Editorial team, I would like to express warmest thanks to Professor Rhys Williams who served as an exceptional Editor-in-Chief for a total of six years. His diligence and ingenuity helped establish Diabetes Voice as a solid publication in the field of diabetes.

I graduated from Medical school in Bolivia, and trained as an endocrinologist in Mexico. For more than a decade I was suffering from chronic kidney disease and 22 years ago, I had a kidney transplant.

Being a specialist in diabetes has allowed me not only to take care of the health of people with diabetes but, what is even more important, to be part of their lives, to share their hopes and anguish, to give reassurance and support.

My years of living with kidney disease and the impact of my kidney transplant were transforming experiences. Being so close to death yet overcoming the threat and surviving with a donated kidney has been a great gift. This experience has allowed me as a physician and as a person to have more sensitivity towards human pain and a better understanding of what it means to live with a chronic disease.

**Importance of diabetes education**

Today it is undeniably clear that diabetes complications and disease progression can be delayed and often prevented with improvements in managing blood glucose, blood pressure, and lipids. People with diabetes, especially with the aid of self-management education, can empower themselves to make wise choices for healthy living throughout the day, everyday. When this happens, outcomes, costs, and quality of life can improve.

History tells us that battles of humanity against disease have been decisively won only with the proper knowledge and awareness among people. It is therefore very important that all levels of our society contribute to change the impact of diabetes.

Diabetes is unlike other diseases, where medication alone can often successfully treat it. There are so many other components to diabetes such as: the diabetes disease process, nutritional management, physical activity, medications, glucose monitoring, and psychosocial adjustment. Diabetes education not only provides knowledge and awareness on diabetes, it also gives people with diabetes the power to better manage it, and
hope for a healthy life.

We need to increase awareness on the importance of diabetes education because it is a benefit many people with diabetes, especially in developed countries, have access to but do not take advantage of for a variety of reasons. Furthermore, there is a growing need to develop more effective educational programs in many of the low-income and lower middle-income countries.

This issue of Diabetes Voice

The September 2016 issue is a fine example of the complexities of diabetes management and how diabetes education and care are key to a better, healthier life.

In The future of type 1 diabetes care we have a contribution in the form of an “expert opinion” by Dr. Andrew Drexler about access to care for adults living with type 1 diabetes. Dr. Drexler believes the shortage of endocrinologists specialising in the care of adults with type 1 diabetes is becoming a crisis and will only get worse in the decades ahead. He offers insight and solutions which will be, we hope, the start of a broader discussion in the diabetes community on this particular issue.

The Diabetes Association of Bangladesh has contributed a country report on their progress, entitled Diabetes care model in a lower middle-income country. It is a fine example of a successful national diabetes education program, and shows great evidence of its role in enhancing diabetes care in the country.

With small numbers of endocrinologists in certain geographic areas, especially in developing countries and lower middle-income economies, many children with type 1 diabetes have to travel long distances to receive diabetes care. This places a hardship on families and the alternatives may not be ideal for achieving the best outcomes for diabetes health. This problem is discussed in the article Type 1 diabetes paediatric care challenges in Bolivia.

There is a strong association between diabetes and depression, but Lawrence Fisher, PhD, Professor Emeritus, Department of Family and Community Medicine at the University of California, San Francisco tells us (Diabetes distress: a real and normal part of diabetes) that symptoms of depression in people with diabetes can be significantly reduced through interventions for diabetes distress, suggesting that much of what is being labelled as depression may not be a co-morbid psychiatric disorder after all, but rather a reaction to living with a stressful, complex disease that is often difficult to manage.

In the article, #WeAreNotWaiting: type 1 diabetes community leads innovation for optimal management, Timothy Omer discusses the limitations of type 1 diabetes care technology, the industry’s lack of data sharing and how a new global group of health hackers like himself are creating home grown diabetes systems for better blood glucose results.

Lydia Makaroff and Linda Hill (Early detection can prevent or delay retinopathy diabetes) discuss the importance of screening for eye disease because retinopathy is avoidable and related blindness can be delayed. Unfortunately, even today, the awareness of retinopathy “remains uneven and low.” Learn more about key action points in the new educational guide, “Diabetes Eye Health: A guide for health professionals”, co-developed by The Fred Hollows Foundation and IDF in collaboration with a group of medical and educational experts.

Wrapping the issue up, we have people living with diabetes tell us where they go for the best information about diabetes. (Where I find the best information about my diabetes.) The feedback has been interesting.
THE FUTURE OF TYPE 1 DIABETES

Andrew Drexler

I have spent the last 38 years primarily treating individuals with type 1 diabetes. In that time, I have been involved with over 400 pregnancies of individuals with type 1 diabetes with virtually no complications, and in the last twenty years, I have no cases of blindness, renal failure or amputations. Looking back, I am extremely pleased with the career choice I made. While not the most lucrative career, it has been extremely satisfying.

Unfortunately, I do not believe nearly enough individuals will pick a career focusing on type 1 diabetes in the next ten years leading to a major shortage and a concomitant decrease in care for the individual with type 1 diabetes. A study by the Association of American Medical Colleges (AAMC) suggests there will be a shortage of 5,100 to 12,300 physicians in medical specialties by 2025. This covers all medical specialties. Already today there is a 15% deficit in endocrinologists but unfortunately there is no good data on the shortage of physicians treating type 1 diabetes among endocrinologists. Among the last ten endocrine fellows I have trained only two have expressed any interest in primarily seeing individuals with type 1 diabetes and even their future plans are not certain. In other parts of the world, the situation is even worse.

Young physicians pick their specialties during their training. Medical students decide which residency which defines which specialty, residents which subspecialty, and postdoctoral fellows which emphasis and this is where the decision to focus on diabetes is made.

When this decision is made, it is based on multiple factors including, which field seems exciting, which field will provide sufficient remuneration to pay off college and medical school debts, and what choice, based on a variety of factors, will provide the best quality of life.

In 1970, the UGDP (University Group Diabetes Program) was released with results that showed that no treatment program for diabetes had any impact on mortality. Most physicians found this very discouraging but it led to research that profoundly altered the future of diabetes treatment. These changes included the understanding of HbA$_1c$ measurements, patient self blood glucose testing, better understanding of insulin treatment protocols in part from studies of the Biostator (a short term use closed loop system) and insulin pumps. This period of innovation lasted from about 1977 to 1983. Most of the individuals I know who now treat individuals with type 1 diabetes got their training during this period, myself included. As a group we are getting older and are approaching retirement over the next ten years. The question is: are we being replaced? For the most part, the answer is no. At present, I have seen no data as to the eventual shortfall, but I can envision a scenario where there are 50% fewer physicians treating adult individuals with type 1 diabetes in 10 years. Not one endocrinologist I have spoken with has disagreed with this assessment.

Some will argue that this is a non-problem since we will have either or both, an artificial pancreas or encapsulated stem cells within ten years. If true, this would be wonderful but can we...
depend on it? Wisdom suggests that we plan for a future where this does not happen. How then do you generate more physicians to treat individuals with type 1 diabetes? I would suggest the following changes would help.

First, medical residents and postdoctoral fellows need more exposure to treating individuals with type 1 diabetes and exposure to a broader range of patients. Although this is changing somewhat, most medical training occurs in the hospital, while the best treatment for individuals with diabetes is in the outpatient setting. The majority of patients with type 1 diabetes that the average medical resident sees are individuals with frequent admissions for diabetic ketoacidosis. The well-motivated patient who is taking good care of themselves is rarely seen in the hospital and hence, the resident isn’t exposed to these patients. Centers of excellence in the treatment of type 1 diabetes must be identified and medical residents and postdoctoral fellows provided with stipends to spend elective time at these centers. As a minimum, this should be offered as an option to all postdoctoral fellows in endocrinology.

Recent changes in medical care have focused on improving productivity. For most large groups this means seeing more patients in less time. Even in most universities, this has meant shortening visit times for a follow-up visit from 30 minutes to 15 minutes. An individual with type 1 diabetes will often present with data from a glucose meter, an insulin pump and a continuous glucose monitor (CGM). This level of information is now invaluable in making better decisions in pattern recognition prior to adjusting insulin dosing but requires time. Two issues need to be addressed. The software available today for analyzing the data provided above has only limited functionality beyond what was available with the first programs from the 1980s such as Glucofacts, despite the
tremendous increase in computing power since then. Advances in pattern recognition have been made in the research on the artificial pancreas but this understanding has not been made available to clinicians seeing patients. Computer programs that assist in routine practice would both shorten the time necessary for visits and improve the clinical decisions made. No group seems to be working on the next generation of software necessary beyond better graphics. I am aware of companies whose current software has less functionality than was available years ago. A major problem here is that since 95% of individuals with diabetes in this country have type 2 diabetes and are seen by general internists, the available software has been simplified rather than become more sophisticated to meet the needs of endocrinologists specializing in seeing individuals with type 1 diabetes. This technological inertia has a broad impact on the endocrinologist’s ability to care for the person living with type 1 diabetes.

Secondarily, the time to analyze the data provided by an individual with type 1 diabetes is much larger than most visits with a medical subspecialty physician, and certainly much greater than the time needed for an endocrinologist to treat an individual for an alternative endocrine disorder such as Hashimoto’s Thyroiditis. At present, reimbursement rates don’t reflect the increased time required and there is a financial penalty for physicians who see large numbers of patients with type 1 diabetes.

Finally, type 1 diabetes is to some degree an orphan disease. There is no organization that sees improving the current care of individuals with type 1 diabetes as its primary mission. The JDRF states that its primary mission is to cure type 1 diabetes, and they have broadened their primary mission to include “treatment” (developing new devices and therapies) and “preventive therapy research.” JDRF argues that it is the mission of the American Diabetes Association to advocate for best practice medical care for type 1 diabetes and to assess progress of type 1 care, but the ADA sees its major mission as advocating for the 95% of the total population: people with type 2 diabetes. Likewise, the IDF has a wider global mission that includes the care, prevention and cure all of people living with (all types) diabetes. None of the above organizations are oblivious to the needs of individuals with type 1 diabetes, but none see advocating for the special medical care requirements of people living with type 1 diabetes as their primary mission. Moreover, no group has developed a program or initiative to increase the number of physicians treating adults living with type 1 diabetes. The absence of a group primarily focused on the current treatment of adults with type 1 diabetes explains why some of the above issues have not been addressed.

Dr. Andrew Drexler received his M.D. from the New York University School of Medicine in 1972, completed his residency in Internal Medicine at Barnes Hospital (1975-1976) and fellowship in Endocrinology at Washington University School of Medicine (1976-1978) in St. Louis, Missouri. He spent two years at the National Institutes of Health in the Public Health Service at the Laboratory of Immunology, NIAID (1973-1975) then joining the faculty of New York University School of Medicine, as Clinical Associate Professor in 2003. He was the Director of the Diabetes Clinic in Bellevue Hospital (1980-1998), and the Director of the Mount Sinai Diabetes Center in New York (1998-2002). In the 1980’s, Dr. Drexler was among the most prominent practitioners of intensive insulin management, tight glycemic control during pregnancy and insulin pump therapy, all of which was very new at this time. Additionally, he was responsible for facilitating the transfer of over thirty pancreas transplant patients with type 1 diabetes and end stage renal disease. From 2002-2016, Dr Drexler was Director of the The Gonda (Goldschmied) Diabetes Center at UCLA. Today he is in private practice in Los Angeles, California, USA.
WORLD DIABETES DAY 2016

TEST2PREVENT

The campaign theme of World Diabetes Day (WDD) 2016 is **Eyes on Diabetes**. IDF’s activities and materials for the WDD 2016 campaign focus on promoting the importance of screening to ensure early diagnosis of type 2 diabetes and early treatment to reduce the risk of serious complications.

The **Eyes on Diabetes** campaign has one overriding advocacy initiative. The International Diabetes Federation (IDF) is asking all individuals who may be at risk of type 2 diabetes, people living with diabetes, diabetes associations and health professionals worldwide to take action to help identify people with undiagnosed type 2 diabetes, those at risk of developing it in the future, and ensure early diagnosis and treatment of diabetes, including complications such as retinopathy.

Test2Prevent, the primary campaign initiative, is calling for advocacy action. IDF hopes to achieve 1 million individual screenings recorded on the World Diabetes Day website [www.worlddiabetesday.org](http://www.worlddiabetesday.org) during the month of November, 2016.

More information and details on how individuals and associations can participate in Test2Prevent will be published on the World Diabetes Day website in September.

Get involved in WDD 2016 by learning more about the campaign and accessing resources at [http://www.idf.org/wdd-index/resources.html](http://www.idf.org/wdd-index/resources.html).
OBITUARY

WIM WIEN TJENS
(1937-2016)

The International Diabetes Federation (IDF) was informed of the passing of Dr. Wim Wientjens on 28 July 2016. For over 30 years, Wim was a tireless advocate, who served and represented the Federation in a variety of roles, both regionally and globally. Wim provided inspiration for countless individuals living with diabetes worldwide.

Wim joined the IDF European Region as a country representative in 1997 and became an IDF Board member in 2000. He was voted President-Elect of IDF Europe in 2002 and served as President of the Region from 2003 to 2006. In subsequent years he was appointed as Vice-President of IDF (2006-2009) and most recently, was nominated IDF Special Ambassador for the Rights of People with Diabetes (2012-15). All these activities were carried out with endless commitment, enthusiasm and passion.

Wim was also very active in his home country, the Netherlands, serving as President of the Dutch Diabetes Association (1993-2005), Vice-President of the Dutch Diabetes Federation (1995) and a member of the Board of the Dutch Diabetes Foundation (1996-2002).

Throughout all these activities, Wim was fueled by his experiences as a person who had been living with type 1 diabetes since 1951. “As a person living with diabetes for 53 years and after a very active life as a biochemist and director of a research institute, I am very happy to give much of my free time to the benefit of people with diabetes” he said in 2004, “Not only because of the epidemic growth of diabetes and the necessity for good treatment and prevention, but also and even more because the quality of life of all people with diabetes needs to be improved with better diabetes education, with the right to human and social rights and without any discrimination.”

The Diabetes Voice Editorial team joins the IDF President, Board and the 240 IDF members in 168 countries in expressing their deepest condolences to Wim’s family. He will be sadly missed but his example will live on in IDF’s continued efforts to defend and strengthen the rights of people with diabetes and to end all forms of discrimination people with diabetes often face.
An independent, international consortium of research institutions, philanthropic foundations, non-government organisations, and companies launched the EAT–Lancet Commission in June 2016. The international group hopes to scientifically assess whether a global transformation to a food system delivering healthy diets from sustainable food systems to a growing world population is possible, and what implications it might have for attaining the Sustainable Development Goals and the Paris Climate Agreement.

According to Dr. Gunhild A. Stordalen, Founder and President of the EAT Foundation /EAT Stockholm Food Forum, “The world is undergoing a dramatic nutrition transition to western diets. Wealth, industrialisation, and rapid urbanisation are driving a surge in resource-intensive meat and dairy products and ultra-processed foods. The western dietary shift is the main cause of an exponential rise in obesity and noncommunicable diseases such as type 2 diabetes. In addition, this overconsumption of unhealthy foods is one of the leading drivers of environmental damage to the planet. To date, no universal and comprehensive research has been done on how to implement sustainable and healthy eating patterns on a planetary scale.”

Worldwide, in 2014, about 1.9 billion adults were overweight, of whom 600 million were obese.

The Commission’s global assessment, due for completion in 2017, will be delivered by an interdisciplinary group of world-leading experts from health, economics, behavioural psychology, food systems, governance, and earth system science. The objective is to provide the foundation for an evidence-based roadmap that links policy, behavioural change, business practices, and technology out to 2050.
“Since the June 2016 launch of the EAT-Lancet Commission on Healthy Diets from Sustainable Food Systems, the Commission has already made significant progress. Five working groups have been established and have begun work on defining healthy diets and sustainable food systems, assessing the major shaping trends in global diets today and the implication of these trends, analysing the pathways for achieving healthy diets from sustainable food systems and recommending solutions and policies,” says Dr. Stordalen. At the end of September, the EAT-Lancet Commission will host its second meeting in London to continue working on the report.

The Commission will also launch a website that will provide more detail about the background, aim and scope of the Commission as well as policy briefs, info-graphics and information about future events and launches.

For more information:

IDF APPOINTS NEW DIRECTOR OF EXTERNAL AFFAIRS

The International Diabetes Federation (IDF) recently welcomed Donald de Korte as its new Director of External Affairs, based at IDF headquarters in Brussels, Belgium.

Donald de Korte is a medical doctor (University of Auckland) and an epidemiologist (London School of Health and Tropical Medicine) with more than 30 years of experience in the healthcare sector. During his career, with a strategic focus on developing and emerging markets, he occupied leadership roles for Servier, MSD (Merck & Co Inc.), Novartis and the Bill & Melinda Gates Foundation in western and eastern Europe, the Middle East, Africa and Southeast Asia. Donald founded the Ethics Institute of South Africa (EthicSA) and the African Comprehensive HIV/AIDS Partnership (ACHAP). He has a broad network in global health and a deep understanding on the importance of strengthening patient access, disease prevention, advocacy and external communications for IDF on behalf of all people living with diabetes worldwide. In his new role, Donald will concentrate initially on resource mobilization and stakeholder engagement.
Theresa May, who was diagnosed with type 1 diabetes in 2013, is the first world leader who lives with the condition. She became Britain’s second female Prime Minister on July 13, 2016 after David Cameron stepped down in the wake of the country’s referendum vote to leave the European Union.

The Prime Minister’s diagnosis came after she sought medical attention for sudden weight loss - a classic symptom of diabetes along with increased thirst, tiredness and urination. Doctors had originally misdiagnosed Ms. May, who is 59, with type 2 diabetes in the winter of 2012, but then changed her diagnosis to type 1 diabetes in 2013.

“[Type 1 diabetes] doesn’t affect how I do the job or what I do. It’s just part of life… so it’s a case of head down and getting on with it,” May told the Mail on Sunday in July 2013.

Robin Hewings, Diabetes UK Head of Policy, said: “Since her diagnosis Theresa May has spoken very openly about living with type 1 diabetes, which has really helped to raise the profile of the condition. Her rise to Prime Minister is a great example how having type 1 diabetes doesn’t have to hold you back and that you can live life to the full and accomplish your ambitions.”
Metformin, as a first-line therapy for type 2 diabetes, has been called out as causing lactic-acidosis, a rare but life-threatening condition. The complication of lactic acidosis is serious and potentially fatal, especially in people with renal impairment.

The problem: The likelihood of metformin-associated lactic acidosis is substantially higher in patients with kidney impairment and also among those with seemingly normal kidney function who are at risk of acute kidney injury (AKI). To use or not to use metformin is a very real issue for clinicians who are caring for people with type 2 diabetes – it is estimated that 40% of patients with type 2 diabetes have higher urinary albumin excretion consistent with underlying renal disease and 17% of patients with diabetes have chronic kidney disease (CKD). It’s no surprise that regulatory agencies in many industrialized nations have maintained strict renal restrictions surrounding metformin.

The upshot: Improved clinical outcomes with metformin have been reported in observational studies of patients with diabetes and renal impairment (estimated glomerular filtration rate [eGFR] 45 to 60 mL/min).1,2 Following a comprehensive literature review, the US Federal Drug Administration (FDA) is requiring labelling changes for metformin-containing medications stating that the drug can be prescribed to patients with mild renal impairment and, in some cases, moderate impairment. The FDA is also recommending that clinicians use estimated glomerular filtration rate (eGFR) to assess kidney function rather than blood creatinine concentration because eGFR takes into account factors such as patient age, gender, race, and/or weight. Clinicians should obtain eGFR at least yearly in patients taking metformin. Those at increased risk for renal impairment, such as the elderly, should be assessed more frequently.
Quantifying the global burden of physical inactivity

An international group of researchers for the Lancet Physical Activity Series 2 Executive Committee conducted an analysis to quantify the economic burden of physical inactivity worldwide. Direct health-care costs, productivity losses, and disability-adjusted life-years (DALYs) attributable to physical inactivity were estimated with standardised methods and the best data available for 142 countries, representing 93.2% of the world’s population.

Globally, summed across five major noncommunicable diseases (NCDs), the researchers estimated the health-care costs of physical inactivity to be $53.8 billion in 2013. Of this, $5 billion were spent on coronary heart disease, $6 billion on stroke, $37.6 billion on type 2 diabetes, $2.7 billion on breast cancer, and $2.5 billion on colon cancer. Physical inactivity related deaths cost $13.7 billion in productivity losses in 2013. When indirect costs were combined with direct costs, physical inactivity was responsible for a total cost of $67.5 billion worldwide.

Overall, the committee concluded the total economic burden of physical inactivity in 2013 was estimated to range from $67.5 billion (18.5–182.1) in a conservative analysis to $145.2 billion (47.0–338.8) in a less conservative analysis.

“Physical inactivity is a strong risk factor for type 2 diabetes. If the promotion of regular physical activity worldwide is prioritised and everyone engages in at least 150 minutes of physical activity per week, we could have avoided 37.6 billion international dollars/year of spending on type 2 diabetes,” says Melody Ding, study author and Postdoctoral Research Fellow at the University of Sydney, Australia.

More information:
In April 2016, Ecuador experienced two major earthquakes. A request was sent from Fundacion Vivir con Diabetes (FUVIDA) to Insulin for Life Australia (IFLA) for urgently needed donated insulin to save the lives of children and adults living with diabetes.

The International Diabetes Federation (IDF) covered transport and handling costs for the donated insulin to assist those affected by Ecuador’s disaster. The project was very successful and saved many lives. The relief effort received great exposure on the IFLA social media pages with an influx of people worldwide wanting to assist through donations of no longer needed, in-date (with at least 4 months before expiration) and unopened diabetes supplies. Insulin Zum Leben, Germany, an affiliate of Insulin for Life, also sent emergency insulin supplies to FUVIDA, and many other people and organisations assisted in other ways.

FUVIDA’s Founder and President, Aracely Basurto Calderon, is a pharmacist who became impassioned about diabetes and established FUVIDA after her own daughter’s diagnosis of type 1 diabetes. This also led to her to become aware of the great unmet need of many Ecuadorian children with diabetes for insulin. FUVIDA co-operates with other Ecuadorian diabetes organisations including the Fundación Diabetes Juvenil Ecuador (FDJE) to distribute supplies to where they are needed in a timely manner. Aracely’s family was heavily impacted by the destruction of the earthquake having property and personal belongings destroyed. After the quakes, Aracely told us, “The first thing we did to assist others was to communicate using different forms of social media indicating that if a person needed insulin to contact us... my phone did not stop ringing. Insulin is life! Without insulin, children or adults who are insulin dependent will die.”

The Ecuadorian earthquake diabetes relief effort also received significant exposure from the Ecuador Secretariat of Risk Management who stated that FUVIDA reached hundreds of people with diabetes in need of insulin thanks to Insulin for Life and the IDF. One of the major newspapers in Ecuador, El Universo, reported on the life-saving relief effort.

The aftermath of natural disasters for people with diabetes is an extremely volatile time and there’s hardly a second to lose when insulin is not available. Many children and adults were saved by the relief effort, including one boy who “lost everything, he had no glucometer, no syringes or insulin,” said Aracely. “Such situations emphasise the devastating reality for people with diabetes whose lives can often become vulnerable and dependent on the help of others.”

Talia Raab is Social Media Manager for Insulin for Life Australia.
IFL volunteer giving insulin to earthquake survivor

FOR MORE INFORMATION:
www.insulinforlife.org
www.facebook.com/InsulinForLife
DIABETES CARE IN A LOWER MIDDLE-INCOME COUNTRY

In developing countries there is lack of organized care for noncommunicable diseases (NCDs) like diabetes, hypertension, stroke, and pulmonary disease, even though these diseases have become the leading cause of death in the world. Like so many developing countries, the prevalence of diabetes in Bangladesh is on the rise and was estimated at 7.4% by IDF’s Diabetes Atlas in 2015. The Diabetic Association of Bangladesh (DAB) has developed a sustainable model of healthcare for people with or at risk for diabetes in Bangladesh. The DAB model shows that with proper planning and dedicated leadership, it is possible to create healthcare for diabetes and other chronic diseases even in lower middle-income countries.

Organizational Framework

The global burden of diabetes is increasing rapidly with almost 75% of the total number of people with diabetes living in low- and middle-income countries. In developing countries, healthcare is still focused on acute, episodic care which is suitable for communicable diseases. Diabetes and other NCDs need lifelong care involving proper health education and follow-up. Despite being a lower middle-income country, overwhelmed with a large number of people living with diabetes, DAB has developed a highly-structured and organized system of diabetes care which is democratic, transparent and supported by the government and civil societies. DAB adopted a decentralized model yielding a total of 61 Affiliated Associations (AAs) (almost one in every district) and seven sub AAs. For the last six decades, DAB has been working to develop a proper organizational framework to include healthcare and educational institutions, rehabilitation facilities for people with diabetes living below the poverty line, and appropriate diabetes prevention and education programs. Capital development has been sourced from those projects financed by the Bangladesh government, but operational costs are managed by cross-financing surplus income generated from patient fees and diagnostic services.

Developing Healthcare Networks

DAB is currently looking after 35% of all people with diabetes in Bangladesh and is hoping to cover 50% of the total number of people with diabetes in the country by 2020. Since its establishment, DAB has focused on growth and today owns more than 109 institutions, and 100 large, medium and small size hospitals totalling 3,762 beds. DAB hospitals provide primary, secondary and tertiary care in all disciplines including organ transplantation (kidney, liver), and cardiac bypass. DAB employs 1,560 physicians, 1,595 nurses, 118 diabetes health educators and 2,252 lab technicians to provide comprehensive care. Diabetes care is provided to approximately 4,500 people at DAB centers on a daily basis, including care for 75-100 newly diagnosed cases of diabetes.
Professional and vocational development

DAB owns and maintains three medical colleges, three postgraduate institutes, one dental college, two nursing colleges and one vocational training institute. Workforce development is a priority of DAB, executed through formal and informal programs. The formal programs include regular post-graduate courses and diplomas in basic and clinical sciences under Bangabandhu Sheikh Mujib Medical University and a certificate course following a distance learning program (DLP). Sponsored by DAB, the Bangladesh University of Health Sciences (BUHS) was established in 2012 to develop qualified and skilled human resources in all areas of the health sciences and to create a multidisciplinary environment in biomedical research. The BUHS initiative encompasses biological, physio-chemical, clinical as well as social science programs, relevant to healthcare. Today, BUHS has 25 undergraduate and post-graduate academic programs under four faculties. At the Bangladesh Institute of Research and Rehabilitation in Diabetes, Endocrine and Metabolic Disorders (BIRDEM), the central institute of DAB also facilitates 16 postgraduate courses including doctor of philosophy (PhD) programs focused on different aspects of diabetes. Ibrahim Medical College (IMC), attached to BIRDEM Hospital, has already emerged as a leading medical college in Bangladesh for providing graduate medical education.

Initially, DAB utilized hands-on training for general practitioners at its central institutes and through organized workshops, but this type of training had many constraints such as difficulties in physician engagement from their workstations. Additionally, the output of these programs could not keep pace with the increasing demand. Moreover, both the rapid rise in number of patients with diabetes requiring care and the continuous evolution in diabetes treatments made scaling up the required physician training a difficult endeavour. DAB took initiatives in 2004 to train doctors employed by DAB and general practitioners in diabetes care through its distance learning programme (DLP). DLP began with Regional Tutorial Centers (RTCs) country-wide in Bangladesh. To date, DAB has been able to train more than 10,000 doctors and DLP is credited with revolutionizing diabetes care in Bangladesh. IDF endorsed the DLP course in March, 2015 and research shows that DLP is highly effective in improving diabetes care in Bangladesh. DLP continually updates programs and provides certificate courses

Bangladesh

Country at a glance

Current population is approximately 161 million.

National prevalence of diabetes is 7.4%.

Estimated 7.1 million people have diabetes.

Highest population density in the world.

Around 47 million people live below the poverty line.

Aspiring to be a middle-income country by 2021.

Life expectancy at birth: 72 years in 2014 (versus 55 years in 1984).

in other disciplines including hypertension, asthma, coronary artery diseases, cerebrovascular disease, chronic obstructive pulmonary disease (COPD), and emergency medicine. In addition, DLP has converted from tutor centered face-to-face programs to e-learning programs by 75%. The digital change is creating a platform for DLP physicians to engage in online consultation, referral, and has created a social network to share medical information and consult with peers.

Today, DAB is stepping forward to extend diabetic care from the district level to the Upazila level (the second lowest tier of regional administration in Bangladesh) by appointing 500 accredited physicians to each Upazila from the DLP trained GPs who are already practicing there. This effort will be complete in 2018. In addition, each of these GPs will have glucometers, blood glucose testing strips and mini refrigerators for storing insulin to care for their diabetes patients. This initiative has expanded diabetes care, including availability of insulin in remote areas. Today, DAB has 350 accredited diabetes centers and will open another 150 in 2017.

Role of the Diabetes Educator

The role of the diabetes educator is of critical importance within the diabetes care team. DAB has developed a month-long certificate course for diabetes educators. Anyone with a background in biological sciences especially with nutrition certification is eligible for participating in the DAB course. The diabetes education training program has 13 modules and it includes more in-depth theoretical and practical inputs with emphasis on teaching and enhancing communication skills and techniques, which enables the training of trainers (ToTs) to provide guidance not only to people with diabetes and the public, but also to fellow healthcare workers. Approximately 150 educators have already completed their training and are working in different DAB institutions nearest to their home. More than 350 thousand people with diabetes have also been given education by DAB trained diabetes educators. DABCare and Effect of Changing Diabetes in Children (CDiC) on clinical outcomes studies in Bangladesh have found that on average, people with diabetes who receive basic diabetes education have better glycaemic outcomes than people who do not receive such education.4 Today all DAB institutions provide individual and group education programs for people newly diagnosed with diabetes and follow-up patients.

The success of the DAB healthcare model shows that with proper planning and dedicated leadership, it is possible to develop diabetes and other NCD healthcare services in a lower middle-income country. We believe that the DAB model deserves attention from healthcare planners, healthcare professionals and governments, worldwide.
**Bishwajit Bhowmik** is Coordinator, Centre for Global Health Research, Diabetic Association of Bangladesh, Dhaka, Bangladesh.

**A K Azad Khan** is President, Diabetic Association of Bangladesh, Dhaka, Bangladesh.

**References**

Children and young people with type 1 diabetes (T1D) in Bolivia, a country situated in the heart of South America, have limited access to care, insulin, and supplies including glucometers, test strips, and syringes for injecting insulin. There is a healthcare provision for the very youngest children with T1D; the Bolivian government covers treatment for all children under the age of five years, but any child diagnosed or living with diabetes over the age of five years does not receive this benefit. For children and youth above 5 years, some families are making great sacrifices to pay for all the medical necessities out-of-pocket, while others cannot afford the cost of treatment at all.

Currently, IDF’s Diabetes Atlas estimates that the prevalence of diabetes for Bolivia is 6.5% of the total population estimated to be around 369 thousand people. It is not known exactly how many children live with T1D in Bolivia. Type 2 diabetes accounts for 90-95% of all cases of diabetes in Bolivia.

Two-thirds of the nearly 11 million people of Bolivia live in urban areas. As a lower middle-income country, Bolivia has been experiencing impressive growth for the past decade. Its economy is forecasted to grow by 5% this year and is projected to have the highest GDP in South America at a time when most of the neighboring...
economies are shrinking or are in a deep crisis. Bolivia's success comes in part from gas and oil revenues, and today the government is increasing spending on healthcare. Even so, the Bolivian government has not yet addressed the issue of care and medicines for children and youth with T1D.

**Limited access limits life**

Insufficient healthcare coverage isn't the only problem for children and young adults with T1D. There are many other healthcare inequalities including quality of care and its relationship to a person's geographical location (urban vs. rural), and limited country data on diabetes, especially for the type 1 diabetes population.

It is estimated that 59 endocrinology specialists are practicing medicine in Bolivia today. According to country data, the majority of endocrinologists in Bolivia serve people with diabetes in highly populated cities, and few to none can be found in smaller states and rural locations. Only seven of the 59 doctors are paediatric specialists—all of whom practice medicine in urban locations.

In Bolivia today, there are several internal medicine doctors who have been trained to specialize in diabetology. These doctors are treating children and youth with diabetes to help close the shortage gap of paediatric endocrinologists. However, because medical specialists are concentrated in urban areas, children with T1D and their families have to travel, sometimes long distances, for a medical checkup to the nearest city.

Currently, there are no studies about the incidence of type 1 diabetes in Bolivia. However, in Santa Cruz, one of the largest cities in Bolivia, the Santa Cruz Regional Health Office, through the Noncommunicable Disease (NCD) Program has a patient database that lists around 300 people with T1D, which comes to a ratio of around ten T1D patients for each 100,000 inhabitants. Most of them come from low income families, and are above five years of age, therefore with no access to health coverage.

As a result of the lack of access to diabetes medical supplies and care in Bolivia, it has been observed that several children and youth with T1D have died due to acute complications including hypoglycaemic coma, renal disease, and amputations with septicemia. Some children with chronic complications on hemodialysis are waiting for kidney transplantation, while others have lost sight or live with severe peripheral neuropathies.

**Helping children and families**

At present, there are a number of children with T1D in Bolivia that receive support through IDF's Life for a Child program facilitated by the “Vivir con Diabetes Foundation” located in the city of Cochabamba, Bolivia's fourth largest city. Unfortunately, there are many children and youth living with T1D who cannot access this program because they live in cities further afield. In Santa Cruz, the Regional Health Office through the local NCD program has looked for solutions to close this gap with the help of institutions or local foundations including Fundacion Niño Feliz, Fundación de diabetes infanto-juvenil Eira, and from Cochabamba with Fundacion Vida Plena.

Very often critical diabetes supplies are collected for children and youth with T1D from donations and foreign funds. Many very low-income children receive medical care at no cost through the voluntary work of local endocrinologists.

In order to achieve successful outcomes in children and young adults living with T1D, continuous diabetes education is essential. There are a variety of options for delivering support and education including: programs through medical personnel, nutritionists, psychologists and other medical professionals. Peer meetings and diabetes camps are extremely empowering for adolescents living with T1D. Technology plays a role as well. Young professionals with T1D in Bolivia have...
formed a Foundation called “Fundacion de diabetes infanto-juvenil EIRA”: eira means honey in the native language Guarani, and through the application of WhatsApp these advocates are building a T1D community, even from rural areas, and helping each other with essential diabetes supplies.

Other activities include:

- In 2003, a monthly T1D support group for children and their families was initiated and led by volunteer endocrinologists and nutritionists. Since its start, it has been observed that hospitalizations and illness decreased in 80% of participating children and diabetes outcomes improved, reflected in lower HbA1c levels.

- Fundacion Vida Plena from the city of Cochabamba, with coordination from the NCD Programme of Santa Cruz, formed a national diabetes camp called “Campo Amigo Bolivia.” Children and young adults with T1D from all over the country have an opportunity to participate in a four-day camp with recreational and educational activities.

- The regional NCD program has also provided a platform to teach diabetes education to primary healthcare personnel in urban and rural healthcare centers.

Although there is much to be done to improve the situation of children with T1D in Bolivia, progress has been made in recent years towards better joint collaboration with various institutions. Ultimately, this translates into many lives saved and better hope for the future.

Elizabeth Snouffer is Editor of Diabetes Voice; Roxana Barbero is an endocrinologist with a Masters of Public Health who was formerly responsible for the NCD program for the Gobierno Autonomo Departamental de Santa Cruz-Bolivia for 12 years (2004-2016).

References

DONATE TO THE IDF LIFE FOR A CHILD PROGRAMME
The increased prevalence of diabetes means that more and more people are also developing diabetes complications, such as diabetic retinopathy. It is important that health practitioners and people with diabetes are aware of the potential of developing diabetic retinopathy and the steps that can be taken to reduce the risk of visual impairment. Blindness from diabetic retinopathy is largely avoidable but it does require greater awareness of the need for early detection and timely treatment.

Diabetes causes high levels of glucose in the bloodstream. Diabetic retinopathy occurs as a result of chronic high blood glucose, causing damage to the small blood vessels of the retina in the eye. There are no symptoms initially, and many people with diabetes will not realise they have diabetic retinopathy until the condition has developed and often only when their vision starts to be affected. The only way to know if retinal damage has occurred is to have the eyes examined (screened) every one to two years.

Every person living with diabetes is at risk of developing diabetic retinopathy, with over one third of people with diabetes developing diabetic retinopathy during their lifetime. This can lead to blindness if untreated. The risk of diabetic retinopathy is greater in those people who have been living with diabetes for a longer time, as well as those with high blood glucose and blood pressure levels.\(^1\)

Early detection and timely treatment of diabetic retinopathy can prevent or delay diabetic related blindness. Despite this, even with the increasing prevalence of diabetes and the profound impact this may have on vision, the awareness of diabetic retinopathy remains uneven and low.\(^1\)

It is essential that both people with diabetes and health professionals are educated and supported to access the right care. Three key actions are:

- Helping people with diabetes to optimise their blood glucose levels and blood pressure to slow down the progression of diabetic retinopathy.
- Ensuring that people with diabetes have access to regular eye screening and timely treatment when required.
- Educating and supporting people with diabetes to manage their diabetes, including their eye health.

As hypertension is the most common, independent risk factor for the development and progression of diabetic retinopathy, it is important that people with diabetes work with health professionals to focus on strategies to optimise blood glucose levels and blood pressure levels, which will decrease their risk of diabetic retinopathy.\(^2,3\) This may require taking medication and reviewing lifestyle factors such as diet and exercise. Screening for diabetic retinopathy is crucial, as the first stages of diabetic retinopathy are asymptomatic. Eye screening for people with diabetes involves...
checking visual acuity (checking visual clarity and sharpness) and performing a retinal examination. This can be done using retinal photography or using an ophthalmoscope. Often eye drops are used to dilate the pupil so that the back of the eye (retina) can be seen clearly. Telemedicine-based screening involves digital retinal photographs being taken by a trained primary health professional and then sent electronically for remote interpretation by trained graders and eye specialists. This strategy can be cost-effective, and result in wider coverage, improved screening rates and less vision loss in some settings.¹

Screening for diabetic retinopathy should be done immediately after receiving a diagnosis of type 2 diabetes. People diagnosed with type 1 diabetes should be screened for diabetic retinopathy within five years of diagnosis. After initial screening, if no abnormalities are detected, both people with type 1 and type 2 diabetes should be screened every one to two years.⁴ If diabetic retinopathy is diagnosed and treatment is required, patients should be referred to an eye health professional. People with diabetes must have access to appropriate health education to manage their disease. People with less health education have a two-fold greater risk of developing diabetic retinopathy compared to people with sufficient health education.⁵ Group educational courses that provide information about how to eat balanced food, the importance of physical activity, and how to improve metabolic control can significantly reduce the risk of severe diabetic retinopathy.⁶ Diabetic retinopathy education and prevention may require a different approach in low-resource settings compared to high-resource countries.⁷

The International Diabetes Federation (IDF) has joined with the International Federation on Aging and the International Agency for the Prevention of Blindness to conduct the Diabetic Retinopathy Barometer project. This project assessed the awareness and access to diabetic retinopathy

### Timing of Eye Screening

<table>
<thead>
<tr>
<th></th>
<th>Type 1 Diabetes</th>
<th>Type 2 Diabetes</th>
<th>Gestational Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Initial</strong></td>
<td>Five years after diagnosis of diabetes</td>
<td>As soon as possible after diagnosis of diabetes</td>
<td>As soon as possible after diagnosis of diabetes</td>
</tr>
<tr>
<td><strong>Ongoing</strong></td>
<td>Every one to two years</td>
<td>Every one to two years</td>
<td>If diabetes resolves after pregnancy, no further screening needed</td>
</tr>
</tbody>
</table>

Source: Diabetes Eye Health: A guide for health professional
screening services and treatment in over 40 countries. Interim results suggest that people with diabetes reported that barriers to screening include long waiting times for appointments, expense, long waiting times on the day of screening and physical distance from screening centres. Over half of all health professionals reported that they did not use a guide or protocol to improve diabetic eye health.

IDF has also partnered with The Fred Hollows Foundation to raise the profile of diabetic retinopathy. The mission of The Fred Hollows Foundation is to work towards a world where no person is unnecessarily blind. In 2015, the Foundation conducted 12,486 diabetic retinopathy treatments, trained 35,185 community health workers and built, renovated or equipped 110 medical facilities. The Foundation works to restore sight to millions of people in more than 25 countries, including Australia, Pakistan and the Solomon Islands.

Diabetes Eye Health: A guide for health professionals is an accessible and approachable educational guide for all the professionals caring for people with diabetes on the physician-coordinated team. It was co-developed by The Fred Hollows Foundation and IDF in collaboration with a group of medical and educational experts. The guide is based upon the International Council of Ophthalmology guidelines and contains recommendations for improving eye health through improved diabetes management, regular...

"OVER A HALF OF ALL HEALTH PROFESSIONALS REPORTED THAT THEY DID NOT USE A GUIDE OR PROTOCOL TO IMPROVE DIABETIC EYE HEALTH"
screening and timely treatment and includes practical recommendations for enhancing treatment support, preparing patients for treatment and post-treatment support. It is available for free in Arabic, Chinese, English, French, Russian and Spanish at www.idf.org/eyehealth.

The theme of World Diabetes Day this year is IDF’s educational campaign declaring “Eyes On Diabetes”. The campaign emphasises the importance of integrating screening for diabetes complications into ongoing care for people living with diabetes, and mandates how all people with diabetes should be screened for diabetic retinopathy every one to two years. IDF encourages all people with diabetes who have not had their retinas screened in the past two years to speak to a health professional about receiving retinopathy screening as soon as possible.

Linda Hill is the Global Lead (Diabetes) at The Fred Hollows Foundation.

Lydia E Makaroff is the Epidemiology & Public Health Manager at the International Diabetes Federation.

References


The Diabetic Retinopathy Barometer Project is supported by Bayer Pharma AG. Diabetes Eye Health: A guide for health professionals is supported by Bayer Pharma AG and Novartis Pharma AG. World Diabetes Day is supported by AstraZeneca, Boehringer Ingelheim, Lilly Diabetes, Merck Sharp & Dohme, Novo Nordisk and Sanofi Diabetes.
Living successfully with type 1 or type 2 diabetes requires the very large task of managing a serious chronic condition. The tasks associated with diabetes can be complex and demanding and most people in their life journey with diabetes report great frustration with the burden of the disease. These physical and emotional demands generate emotional distress that can include worry, fear, sadness and anger regarding the emergence of complications, hypoglycaemic episodes, unpredictable blood glucose and feelings of ‘diabetes burnout’. Diabetes Distress is distinct from clinical depression, but high levels of distress are linked to poor glycaemic “management” and problematic self-care behaviours. Diabetes Distress often leads to the thought pattern of “I just can’t do this anymore” and for the primary diabetes healthcare provider, this is a signal that an open discussion can help individuals connect all the things they must ‘do’ with all of the emotions a person living with diabetes ‘feels’.

Lawrence Fisher, PhD, from the Department of Family and Community Medicine and the University of California, San Francisco and William Polonsky, PhD, at the Department of Psychiatry, University of San Diego California developed the Diabetes Distress Scales (DDS) for people with type 2 diabetes and the T1DDS for people with type 1 diabetes to help providers and their patients gain a better understanding of the emotional side of diabetes, recognize barriers to care and take steps for overcoming them. This month, Elizabeth Snouffer, Editor of Diabetes Voice had the opportunity to speak to Professor Fisher about Diabetes Distress (DD), the value of the Diabetes Distress Scales (DDS) and how healthcare providers can help people with type 1 and type 2 diabetes by acknowledging emotional distress and giving it some perspective.

Can you please define Diabetes Distress (DD)?
“DD refers to fears of complications, worries about hypoglycaemia and the variety of stresses, strains and concerns people with diabetes have on a day-to-day basis. Describing the term as such makes it more specific and alive to individuals who live with diabetes. We also need to include family members that care for people with diabetes, including parents of children and partners of adults with diabetes, because they too can experience emotional distress related to diabetes.”

Who is at risk for DD?
“Everyone who lives with diabetes is at risk, but I would like to look at it a slightly different way. Everybody who lives with diabetes is going
to experience distress at some point in their diabetes career. One important question to ask is ‘where in the diabetes trajectory are people at the greatest risk?’ There are identifiable, targeted periods during which people have the greatest probability of feeling elevated levels of distress about their life with diabetes. For example, the following time points are often associated with increased levels of DD:

1. Around the time of diagnosis and at the time of learning how to self-manage diabetes;
2. At the emergence of a complication;
3. Adding to or switching a medication;
4. Switching healthcare plans;
5. Switching healthcare providers (finding a new doctor).

All of these are situations when some people experience higher levels of emotional distress. The best way to handle it is through prevention and helping people understand that how they feel about diabetes is as important as what they do. It’s important that people with diabetes understand and are prepared for those times when they will feel upset and concerned, and healthcare providers need to help patients recognise these periods and offer to help.

Is DD considered a complication of diabetes?

“No, here’s why. The emotional side of diabetes is simply part of having diabetes. An individual may not be feeling particularly distressed at one point in time, but become upset and distressed at another point in time, perhaps around the time of the emergence of a complication, a switch in medication, or a change in a healthcare provider – there are all kinds of things that can be distressing about diabetes. If we consider DD a separate diagnostic category or a sub-category or complication, then DD can be seen as a complication and not as something that is simply part of having diabetes.

What we’re arguing for is that the management of distress should be a regular part of diabetes care since distress is so ubiquitous, and since it is to be expected that diabetes is tough. This means that along with attending to blood glucose numbers and disease management, we also need to pay attention to feelings – how people are managing the emotional side of diabetes. All three of these are important parts of good diabetes care.”

Since you brought it up, how does DD differ from clinical depression?

“That is a really good question and it comes up very often. Let me start by explaining that by ‘clinical depression’, we mean Major Depressive Disorder (MDD), a well-defined DSM5V diagnosis. Among those with diabetes, the false positive rate of diagnosing MDD using screening instruments is enormous, ranging from 54-75% in our studies. The prevalence of classically defined MDD using a structured psychiatric interview - highly reliable and replicable is about 4-6% in people with type 1 or type 2 diabetes. The prevalence of MDD in the general community is also about 4-6%. This is not to say that people with diabetes don’t have elevated depressive symptoms from time to time or that they never have MDD. Like all people, they do. But we find no significant data to support the conclusion that the rates of clinical depression are significantly higher in the total diabetes population than they are in community settings.

What we have instead are enormous rates of emotional distress about diabetes, which gets confused with depression. It’s much easier for a

“WE ARE NOW BEGINNING TO UNDERSTAND THAT HOW PEOPLE FEEL, AFFECTS HOW THE BODY FUNCTIONS AND VICE VERSA.”
The seven major sources of DD among T1D adults

1. Powerlessness
Feeling that one’s blood sugar numbers have a life of their own; e.g., “feeling that no matter how hard I try with my diabetes, it will never be good enough.”

2. Negative Social Perceptions
Concerns about the possible negative judgments of others; e.g., “I have to hide my diabetes from other people.”

3. Physician Distress
Disappointment with current healthcare professionals; e.g., “feeling that I don’t get help I really need from my diabetes doctor.”

4. Friend/Family Distress
There is too much or too little attention paid to diabetes amongst loved ones; e.g., “my family and friends make a bigger deal out of diabetes than they should.”

5. Hypoglycaemia Distress
Concerns about severe hypoglycaemic events; e.g., “I can’t ever be safe from the possibility of a serious hypoglycaemic event.”

6. Management Distress
Disappointment with one’s own self-care efforts; e.g., “I don’t give my diabetes as much attention as I probably should.”

7. Eating Distress
Concerns that one’s eating is out of control; e.g., “thoughts about food and eating control my life.”

 clinician to say ‘Oh, this patient is depressed’, so they either give the person an anti-depressant or refer them to a mental health specialist. In most cases, these individuals are simply experiencing high levels of emotional distress associated with their diabetes and its management.”

Where can healthcare professionals receive training so they can help patients with DD?

“This is a very difficult area. I find that this is something you just can’t lecture a healthcare professional about with any success. It really is a stylistic matter. This is about learning how to listen to your patients and identifying the underlying feelings that can drive distress and influence management. It’s about learning to stop doing all the talking. It’s about learning to ask open-ended questions. Finally, it’s about helping practitioners recognize that one of their most powerful tools is helping patients talk about the experience of having diabetes, identifying the specific sources of their distress, normalizing these feelings, and making all of this part of regular diabetes care.”

Can you discuss what has given evidence to the idea that patient quality of life is a better predictor of mortality and morbidity than some biologic measures?

“The classic example are the data on depression and myocardial infarction (MI) or heart attack in men. The data in this sphere clearly show that the presence of depression/major depressive disorder either prior or immediately after a first MI is a better predictor of one-year mortality than most other biologic variables. It’s thought to be linked to an underlying mechanism of inflammation. We are now beginning to understand that how people feel, affects how the body functions and vice versa.”

What is the Diabetes Distress Scale (DDS)?

“The DDS is a validated survey instrument that assesses diabetes-related emotional distress. Today, we have multiple distress scales for a variety of different people connected to diabetes, clinician to say ‘Oh, this patient is depressed’, so they either give the person an anti-depressant or refer them to a mental health specialist. In most cases, these individuals are simply experiencing high levels of emotional distress associated with their diabetes and its management.”

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including scales for adults with type 1 diabetes (T1DDS), adults with type 2 diabetes (DDS), parents of adolescents with type 1 diabetes, and spouse/partners of adults with diabetes. The difference between the scale for adults with type 1 diabetes (T1DDS) and type 2 diabetes (DDS) has to do with the different sources of distress that each patient group may experience. Many healthcare providers in the current environment are no longer screening for depression, but they are starting to screen for DD, since DD has a much higher prevalence than depression in this population.

The diabetes distress scale can easily identify the primary sources of distress and it can become a tool for initiating a discussion about the emotional side of diabetes and the specific things about diabetes that are upsetting to a particular individual. If a patient scores high on feeling powerless, and most do, the healthcare provider can center the discussion around powerlessness and then engage with the patient to find ways to address the problem. The results from the distress scales are very actionable and help both the provider and the patient know what to focus on."

What are the symptoms/signs from a doctor’s perspective that a person may be distressed?

“Well, for example, if a HCP observes a person who has been getting pretty good HbA1c results for months or years and all of a sudden there is a big shift in the wrong direction, focusing only on the numbers is a huge mistake. People get divorced, lose their jobs, experience other losses and real-life stressors, and these important life experiences rarely get addressed. It's important to recognize that if there is a change in diagnostic test results, the clinician needs to open the door and ask, “How are you doing? Have there been any major disruptions in your life?” In addition, we believe that it is important to ask these questions at every visit. It is as important to assess how people are doing emotionally with their diabetes as it is to check their latest HbA1c. Some clinicians feel very comfortable asking these kinds of questions in a meaningful way and others do not. These are stylistic issues and it certainly doesn’t mean that everyone on the medical team needs be talented in this arena, but someone on the medical team needs to have the skill and interest to address this important part of diabetes and its management.”

How do low DD, medium DD and high DD correlate with HbA1c outcomes? Does one cause the other?

“Very interesting question. They co-vary together over time. If DD goes up over time, you’ll usually see a corresponding increase in HbA1c and vice versa. To say one causes the other is a very different and complex question. We just published a paper that showed that individuals who are having problems taking medication have subsequently higher levels of distress, which is then associated with poorer HbA1c. It becomes a complicated picture of behaviour, feelings and the body’s reaction. It’s important to keep in mind that HbA1c is a biologic variable over a period of time, whereas emotions come and go much more quickly. Therefore, HbA1c is much more distal to the varying emotional experiences of diabetes. If a person has a hard week or two that results in a lot of distress with their diabetes, it may not have much of a direct effect in the short-term. Unfortunately, we are also seeing that chronically elevated levels of distress are significantly associated with poor HbA1c results over time.”

How can HCP’s utilise the distress scales for people with diabetes in the time available for each patient? There is only so much time and a lot to cover.

“What I like to suggest is to give all patients the scale at each visit. Even if they don’t meet predefined criteria for DD, the items in the scale can be a jumping off point for beginning a brief
conversation about how they are feeling about things. Often the patient will rate one or two items very highly and that can become the beginning of a conversation. Again, it’s asking very simple questions, like ‘I noticed you indicated frustration about … What might be going on?’”

Can an HCP offer support and self-management improvements that will lessen DD? If yes, what are some examples?

“There are two parts to this. The first part is addressing the patient’s feelings about diabetes and the second part concerns addressing what can be done about it. But the first part gets missed a lot. It is very important to acknowledge that you cannot make people feel any differently than the way they do. There is no switch that can turn feelings off and on, as far as I know. People are going to get distressed, upset, frustrated, burned out, etc., and that’s OK – it is part of having diabetes. The problem is there is often no discussion about feelings and distress, and for some people there is no language for it, no way to talk about it. The scales give language to the emotions. So for example, it can be helpful if a provider asks, listens, acknowledges and reflects. It’s key for the provider to legitimize patient feelings, because it’s honest and real for the patient. In fact, it’s also important for the patient to realise that many people with diabetes feel the same way they do and this helps the person feel far less alone. What the provider is really doing is providing context, labelling and finally normalizing. If the provider helps the patient put their feelings in perspective, they become more tolerable and acceptable. This is all in part one of the discussion with the patient and, although it may sound like a lot to do, it is really a very brief conversation.
The second part of the conversation then turns to action. A provider might say, ‘Given how you are feeling, what do you think you need that would make things better, and how can I help?’

For example, if someone is feeling really scared because their vision is deteriorating because of retinopathy, then what could be suggested is ‘Let’s make an appointment with the ophthalmologist, and see where things currently stand, and then we can figure out what we can do about this.’ It’s important to create a behavioural outcome. What’s happening here is the HCP and patient are integrating feelings into action. Often, diabetes care only focuses on the doing, not on the feelings that drive behavior.”

Overall, we have been discussing how DD is an expected part of living with diabetes, not a co-morbid condition requiring referral or specialized care. How well do you think this is accepted by the medical community today?

“I think it is becoming more and more accepted. My evidence for this is the number of requests we are receiving for the different diabetes distress scales that we have developed. As an anecdote, I was also surprised by the number of people who spoke to me after my presentation at the American Diabetes Association Scientific Sessions this past June (2016). Professionals were telling me that they were using the scale with success and that it was helping them pay more attention to the emotional side of diabetes by structuring the conversation – it made all of this practical and doable in the clinical setting. The distress scales also have helped healthcare providers feel less concerned about a major healthcare fear - opening a Pandora’s box of feelings and then either not knowing how to address the feelings or not knowing how to close the box during a brief visit.”

To access and download the Diabetes Distress Scales (DDS) and related scales, please go to the Behavioral Diabetes Institute web site by clicking on the link http://behavioraldiabetes.org/scales-and-measures/

Lawrence Fisher PhD, ABPP is a Diplomate in Clinical Psychology and an emeritus professor in the Departments of Family & Community Medicine and Psychiatry at the University of California, San Francisco. Professor Fisher has been the principal investigator of several NIH-funded research programs that addressed the personal, cultural, family and care-related aspects of diabetes self-management. He has also been the principal investigator of several NIH- and ADA-funded intervention studies to assess and reduce depression and distress among people with diabetes.
#WEARENOWWAITING: 
TYPE 1 DIABETES COMMUNITY LEADS INNOVATION FOR OPTIMAL MANAGEMENT

Timothy Omer

Type 1 diabetes is a relentless 24-7 condition to manage. With access to better technology and high volumes of data many people with diabetes are becoming data rich. However, access to device data and analyses are restricted by the diabetes device providers and the wider healthcare industry. These diabetes devices (including insulin pumps, and continuous glucose monitors (CGM)) have data about my body and medication, but industry and providers have made a decision not to give me access to this data. I have a complicated condition to manage that would benefit from the additional data now, and today, the wider type 1 diabetes community has decided #WeAreNotWaiting to access and use this data to better manage our blood glucose. Here, I describe what prompted the type 1 diabetes community movement, and our progress to date.

Existing technology is unrealistic

Access to technology has improved significantly in the 22+ years I have lived with type 1 diabetes. My UK National Health Service (NHS) funded insulin pump allows me to fine-tune background basal and mealtime bolus insulin. My self-funded CGM provides real-time feedback of my blood glucose. A common comment I receive from others outside the diabetes community is the belief that with such technology, my diabetes is ‘cured’, and unfortunately this is not the case. The reality is that the management of my condition with such tools is significantly more complicated.

The recent advances in diabetes device technology provide many functions and high volumes of data and it is very welcome and useful but such systems always fail in the same area; the expectation of the person living with diabetes to understand, process and correctly act upon all of this information.

As a result, people living with diabetes and their families have become frustrated by feeling judged by healthcare professionals, and overwhelmed by vast amounts of data and diagnostic information and alert and alarm ‘shouts’ from their diabetes devices often indicating they have failed at being a ‘good diabetic’, i.e., poor blood glucose numbers. There is also a sense of disappointment summed up as: ‘my body has let me down.’

Will things get better?

People living with type 1 diabetes in developed nations are getting better at understanding the disease, causes of fluctuations and how to react, and better at technically fine-tuning treatments with more real-time information, but none of this progress helps a person process and act upon such basic information.
In fact, we may be guilty of using this very basic data feedback badly. The essential data people living with diabetes need most is locked into the device manufacturer’s products, with limited or no ability to share across devices. There is also a lack of actionable information which would give people the opportunity to analyse and review data for possible and more importantly, correct adjustments to medication (insulin). However, these analytics are far too complicated and beyond the means for most of us.

**When enough is enough**

The lack of accessible and actionable data is a common frustration in the type 1 diabetes community. With easier ways to get in contact with other people with diabetes through social media, the community has been exchanging ideas and discussing ways forward for the last few years. A pivotal moment came in the community when the first DiabetesMine D-Data ExChange event highlighted the frustration of patients waiting for data needs to be addressed. In a declaration of empowerment, the community declared ‘We Are Not Waiting,’ and the beginning of a greater movement was put in motion.

With access to global online communities, people with diabetes from all over the world particularly in the US, gave unrestricted sharing of ideas, projects and collaborative efforts to overcome challenges. Example communities include: Facebook CGM in the Cloud, Gitter Developer Chat Rooms, OpenAPS and GitHub code.

Access to less expensive technology from the Hobby Electronics movement plus the passionate well-educated pool of individuals with a common goal led to this movement. The critical mass, rallied under the hashtag #WeAreNotWaiting, saw rapid progress in the development and uptake of DIY medical devices in the type 1 diabetes community.

**Patient driven projects**

With the community driving innovation we started to see more software engineers developing edge cases that were not of interest to the medical industry due to costs and risks. With all this access to new data, creative solutions became abundant:

- Ability to monitor CGM data from your watch.
- Ability to remotely monitor your child’s blood glucose.
- Ability to provide louder alarms and real-time treatment suggestions from your data.
- Ability to analyse the data and automate medication delivery.

Timothy Omer with his insulin pump
All of the above projects empower people with diabetes who want to try to attain the best possible blood glucose results with the aid of technology and data. An individual’s new confidence comes from better use of this real-time data to help with management of a real-time condition like type 1 diabetes. For example, watching my own blood glucose rise on a smartwatch after eating a pizza is a lot more powerful than the screen on the manufactures device showing the same data in my bag.

**The path to a DIY Artificial Pancreas**

Only a year ago the thought of a DIY Artificial Pancreas system was overwhelming. The multiple components required and skill needed to provide an efficient and safe system are beyond the majority of people with some exceptions. With step by step progress in the community of accessing data from devices, merging together and processing this data to provide meaningful actionable information, the convergence of community DIY projects began to emerge. One of the outcomes is the OpenAPS project that provides the instructions and blueprint of a DIY patient built Artificial Pancreas System.

But how effective can a patient built “amateur” system be? I really could not sum this up better than a quote from a recent OpenAPS user:

**Rise of the machines**

In 2015, I decided to fork (make a copy of) the OpenAPS project and make use of the supercomputer in my pocket to assist with management of my type 1 diabetes. With the communities Open Source projects, namely xDrip and OpenAPS, I taught myself mobile development and built an Artificial Pancreas System (APS) app. I had no need to start from scratch or learn the best algorithm to crunch my data, I took what the community had already developed to kick start my own project, which allowed me to focus on building a system unique to my needs and on the additional functionality that I required.

While the system I built was an Open Loop system lacking the communication with my Insulin Pump, this was enough to significantly help me with the management and treatment of my type 1 diabetes. The system assisted with one of the most problematic areas of my care, namely me. The App is free from the frustration, impatience and at times the simple ignorance of a human, it does what I cannot perform - analyse my data every five minutes and make an unemotional logical decision.

I moved from a reactive management of my type 1 diabetes to a proactive one where the APS system would provide treatment alterations to manage the highs and lows of my blood glucose.
and at times stop such events from happening. It is a liberating feeling, for the first time in 22 years I can let my diabetes take a back seat without damaging my health.

The data rich patient

Where is this heading? Access to information, collaboration and cost of technology is only going to improve over time. As the type 1 diabetes community expertise improves we are going to start seeing more medical management challenges tackled, from understanding our condition by analysing the wealth of information that we are capturing, with access to rapid production technology producing easily accessible high quality tools, to spreading beyond the technically capable 1% with more accessible tools and sharing of knowledge with community lead workshops. This will spread beyond type 1 diabetes care to other conditions ripe for such disruption.

The type 1 diabetes community work such as #WeAreNotWaiting should not be seen as competition to the medical industry or healthcare providers but as a treatment path challenging and pushing the boundaries of what is currently possible, and producing a wealth of free data. Categorising this type of community care will give the medical industry and healthcare providers an opportunity for assessment and a chance to decide what they are willing to support.

Timothy Omer worked in the IT industry specialising in the implementation of business systems and processes that empower staff with the right technology. As a person living with type 1 diabetes for over 22 years, Timothy has been passionate about using his diabetes technology and data to help him manage his condition. Working with the #WeAreNotWaiting movement of citizen ‘Health Hackers’, who are producing Open Source solutions and hacking existing medical devices to their needs, he is also producing a mobile-based Artificial Panaceas System and prompting discussions about this patient-led movement at talks and conferences.
A good part of living with diabetes well is getting connected to sources of information that are reliable and relevant. For most people who develop type 1 diabetes or type 2 diabetes, that first source of information comes from the diabetes specialist or healthcare provider at diagnosis. Diabetes self-management education may continue for weeks to months with a variety of HCPs, depending upon the complexity of the treatment ranging from a change in lifestyle behaviours and oral medication for many with type 2 diabetes while those living with type 1 diabetes may be given device technology for insulin infusion and glucose monitoring. Soon however, people living with diabetes become specialists in their own right, managing their blood glucose at home, at work, at play and even monitoring during sleep in millions of places all over the world. As a person’s body ages with diabetes (all types), changes in treatment are usually required. Mild complications or other chronic illnesses may emerge and the need for information is vital. Treatments are constantly changing, guidelines are always evolving and new technologies are quickly developing. It’s a lot to keep track of and often the person living with diabetes might even find that they are more up-to-date on commercial consumer driven “diabetes developments” than their healthcare providers.

In this issue, we asked people living with diabetes where they find the best information about their condition for empowerment and confidence. Given the role of the Internet and digital healthcare technology in today’s world, we found their answers inspirational and somewhat unsurprising.
GETTING CONNECTED ON FACEBOOK FOR ANSWERS IN SERBIA

The Belgrade Diabetes Association, a member of the Diabetes Association of Serbia, known to its members as Blue Circle or ‘Plavi Krug’ is one of the first associations in Serbia providing diabetes education. Members of the Plavi Krug Facebook support group answered our question online (translated from Serbian):

One woman with type 2 diabetes, originally from Israel but currently living in Belgrade, Serbia said:

“I get diabetes information from my doctor in Israel via WhatsApp. Also, I read information on the Plavi Krug Facebook group, but I need to get more involved and take part in the diabetes association lectures.”

A mother of a teenager with type 1 diabetes said:

“We get diabetes information from the Internet, various Facebook community groups, blogs, and industry newsletters. All of this together gives us more information than what we get from our physician. I think it is a time issue, rather than the doctor not wanting to share information. People with diabetes are seen for 3 to 5 minutes every three months, and their HbA₁c results are checked. That’s it. Motivation is hard to come by on our own, but we do our best to manage diabetes, understand my daughter's test results and continue to try and do our best. We don’t get a lot from visiting the doctor. Unfortunately, we have to educate ourselves.”

From a man with type 1 diabetes who was born with a hearing and speaking disability:

“At first, I got diabetes information from my physician. Then I started to get diabetes information from the Internet, like Plavi Krug and other relevant online texts, and some books.

It can be a bit frustrating because there is a lack of information. Today, I get some necessary information from my doctor, but mostly I get diabetes information from the Internet, including information about new diabetes technology. Of course, there are things I don’t know, but I’ll learn.”

SHARING WITH OTHERS HAS TAUGHT ME A GREAT DEAL

“I was diagnosed with type 1 diabetes when I was eight-years-old. When I started taking daily injections 27 years ago, diabetes information was given to my family by the doctors and nurses who diagnosed me with type 1 diabetes. Whenever we went back for my follow-up appointments, we got advice from the doctors and nurses who were assigned to me.

In addition, right after my diagnosis, I became a member of the Ethiopian Diabetes Association and received information on how to deal with type 1 diabetes with diabetes experts. I have been a regular participant of the association's monthly education programme for the past 27 years. I have also been attending conferences and workshops and have been a guest speaker at many of them.”

Ermiyas Gebremariam
27 years and I still continue to attend these sessions.

During my teenage years, I joined a group of about 40 young people with diabetes, and we started a youth union where we shared our diabetes experiences in our family households every month. These sharing sessions taught me a great deal about life with diabetes. Our youth group also initiated the [Amharic Diabetes Information Magazine](#) of the Ethiopian Diabetes Association.

Today, this publication has become one of the major sources of information for me. Sometimes I search for new information through social media, especially on Facebook. I use Facebook to learn from others, to make new friends with diabetes and to learn from our different experiences.”

_Ermiyas Gebremariam, 35 years old, type 1 diabetes, Ethiopia_

**HCPS ARE STILL THE NUMBER 1 REFERENCE POINT**

“Today, finding information about diabetes is easy. All one has to do is go on the Internet to find it! It is what most people say in online forums. Indeed, it is not even close to the the information sources on diabetes that we had access to 50 years ago! However, living with a chronic disease like diabetes requires more than getting bits of information on the Internet because diabetes can be complicated.

As regards the diagnosis of diabetes and how to self-manage medical treatment, healthcare professionals need to remain the number one reference point. It is a difficult situation because living with diabetes is a 24-hour-a-day job that requires more than a set of instructions on a prescription. The question is “where can I find information I need in order to better live with this partner, named diabetes, with whom I have to collaborate daily?”

The [Association Francaise Des Diabetiques](#) (AFD) website, magazine, and social networks provide information on diabetes, complications, new treatments, studies dedicated to research, and campaigns for type 2 diabetes prevention. The AFD also gives nutritional advice adapted to the needs of diverse populations and invites those living with diabetes either directly or indirectly (for example, a family member) to join organized discussion groups led by experts, especially people living with diabetes. For me, peer support is the most efficient way to get reliable advice, and especially to speak freely of one’s concerns on everything related to life with diabetes.

Getting involved with an association is the best way to get information and above all, to improve one’s quality of life.”

_Marie-Laure Le Pommelec, 60 years, diagnosed with type 1 diabetes in 1967, Sainte Geneviève des Bois, France._
THANKS TO THE EDUCATION MY DOCTOR GAVE ME, I LIVE A NORMAL LIFE

The doctor that told me about my diabetes diagnosis prescribed me some pills and with some irony and cruelty, he ‘welcomed me to the diabetes world’, but he didn't offer me any kind of additional information more than telling me that ‘sugar’ was over for me. It was necessary to change doctors and to also find current information about diabetes and blood glucose medication on the Internet with my family’s help.

Fortunately, one of my sons works as a journalist and he not only found me a glucometer but he also gave me all the information needed to measure my blood glucose. Afterwards, I went to the Mexican Diabetes Federation and discovered their magazine Diabetes Hoy, which led me to Dr. Marco Villalvazo. This doctor gave me information, helped me to register my BG results in a diary, requested special tests and gave me the necessary knowledge about healthy eating and the importance of exercise and physical activity as part of the treatment. Thanks to Dr. Villalvazo and my education, my family understood more about my condition and how I could survive with diabetes and manage it, even knowing how to react to a hypoglycaemic episode. Three months ago my HbA1c result was 6.2% and I feel great. I exercise every afternoon, and every year I take part in World Diabetes Day. I live a normal life and although I take care of what I eat, I don’t deprive myself of anything. I follow my treatment. I don’t consider myself a diabetic because my condition does not define me; I am just a person living with well-controlled diabetes.

Marcela Reynoso Delmotte, 65 years, diagnosed with type 2 diabetes in 2000, Mexico City, Mexico.
Meet the next generation of diabetes healthcare professionals

Since 2006, IDF has run a grant program supporting almost 500 young researchers and healthcare professionals to attend the IDF congress.

At the recent Congress held in Vancouver in December 2015 more than 600 applications from 90 countries were received and 100 applicants were awarded with a travel grant to present their work to a global audience.

“The congress allowed me to present my research to an international audience and to receive important feedback. It allowed me to widen my knowledge about different topics directly related to my current research on diabetes.”

*Ms Carlotta Lunghi, Canada*

PHE stream: Incidence and associated factors of depression in patients with type 2 diabetes (T2D) in Quebec, Canada

“The Congress was a unique opportunity to get new evidence-based knowledge and to communicate with colleagues from all over the world.”

*Dr Ivan Pchelin, Russia*

BCS stream: Clinical correlates of serum interleukin-6 level in anemic patients with diabetic nephropathy at different stages of CKD

“My communication skills and counselling techniques have improved. I can now educate people with diabetes more effectively in short period of time.”

*Saira Shahid, Pakistan*

PHE stream: Frequency of gestational diabetes mellitus among urban and rural populations and among diverse ethnic groups

“My patients with diabetes are being treated based on evidence based knowledge on the disease, and I am more confident addressing many of the issues related to their disease.”

*Dr Etienne Amendezo, Rwanda*

EIC stream: Effects of lifestyle education programs on diabetes control among diabetics at Kigali University Hospital Rwanda

“The Congress helped me to look at the different perspectives of my practice and the practice of others.”

*Dr Mengistie Demeke Mekonnen, Ethiopia*

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- Risk factors for DKD
- How to screen for diagnose and monitor DKD
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