More than **200 million people** worldwide have diabetes. Many of them do not receive the care they need.

The International Diabetes Federation has chosen 2006 as the year of the disadvantaged and the vulnerable.

www.idf.org

World Diabetes Day is an initiative of the International Diabetes Federation and the World Health Organization.
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Unite for diabetes

The vulnerable and the underserved are most likely to suffer most the impact of growing shortcomings in healthcare worldwide. Most countries are experiencing a lack of trained personnel. With current demographic and epidemiological transitions driving changes in health threats, the situation looks set to deteriorate in both developed and developing countries.

The World Health Organization (WHO) has established a cut-off point in terms of workforce density, below which the provision of essential healthcare is unlikely. According to WHO estimates, there is a global deficit of nearly 2.5 million doctors and nurses. Not surprisingly, the shortages are greatest in Africa. The size of the population in South-East Asia makes deficits in that region huge. The solution is far from straightforward. Addressing healthcare personnel needs will involve cooperation between the public and private sectors, educational bodies, healthcare planners and those funding and managing the healthcare systems, as well as the healthcare providers themselves.

Initiatives like the one described by Sanjay and Bharti Kalra offer a model for optimizing limited human resources. In India, major gaps in the provision of healthcare, including specialist diabetes care, have resulted from increasing migration of health professionals to wealthier countries. The multipurpose diabetes workers described in Kalra’s article are contributing to a response by an already overstretched system – in a region where diabetes care needs are soaring – to the debilitating ‘brain-drain’ of skilled labour.

The constellation of modern-day market forces lies behind rising levels of stress and distress among migrants and refugees. Manuel Carballo and Frederik Siem describe the diabetes-related effects of forced migration, citing evidence that migrants are more likely to develop diabetes than non-migrants. The psychosocial impact of migration is considerable and it appears that this in turn has negative effects – one of these is an increase in the incidence of diabetes.

Cultural, linguistic and social issues compound the demands placed on migrants and refugees in terms of geography and physical environment; these are many and complex. This is an area which demands further study, particularly because of the scale of suffering involved – and the already existing potential to reduce it. There are hundreds of millions of migrants worldwide. It is essential that we have as accurate a description as possible of their healthcare status. I look forward to an update on the study by the International Centre for Migration and Health of diabetes among migrants in Europe and Canada.

The difficulties that are highlighted in the 2006 World Diabetes Day campaign require efforts beyond the healthcare sector. Stakeholders in nutrition – the food and drink industry, nutritionists, educators and the community at large – must play a key role. Ida Nicolaisen alerts us to the plight of indigenous people, like Pacific Islanders, who over the past 40 years, have experienced the erosion of their food security, engendering a reliance on imported food and resulting in a steep rise in rates of obesity and type 2 diabetes.

The array of interrelated issues underpinning the global epidemic of diabetes can only be addressed effectively by a coordinated multi-sectorial and global approach. ‘Unite for Diabetes’, an IDF-led campaign for such an approach, is underway. The article by IDF President-Elect Martin Silink describes an ambitious campaign with an integrated strategy that blends direct advocacy with broader grassroots communications activities. In this, the largest push for diabetes advocacy ever seen, IDF will inform, motivate and mobilize the global diabetes community and target the global media. Our immediate goal is to secure a United Nations Resolution on diabetes that will provoke multi-governmental action to improve the prevention and treatment of diabetes and inspire medical science in its quest for a cure.
Balance and transparency, please!

Following the sudden and unexpected death of Lee Jong-wook, Director-General of the World Health Organization (WHO), the spotlight will inevitably be turned on the priorities of that organization with respect to improving world health. Dr Lee became WHO Director-General in May 2003 and very soon put his stamp on the organization by making the battle against HIV and AIDS one of WHO’s priorities. The slogan ‘Three by Five’ was coined to symbolize the goal of bringing effective antiretroviral treatment to 3 million people within a rapid – some said too rapid – timescale. This goal became somewhat sidelined by the topic of H5N1 avian flu. However, Dr Lee and WHO were committed to ‘Three by Five’ and other communicable disease programmes, focussed particularly on developing countries. His deputy, Anders Nordstrom, will succeed him until a replacement is found.

One of the avowed aims of this year’s World Diabetes Day campaign is to increase awareness among organizations like WHO and the international assistance community in general of the need to invest in non-communicable disease prevention and control. In 2002, WHO spent only 3.5% of its surprisingly precarious budget of 43.6 million USD on the prevention and control of non-communicable diseases, including diabetes — and there is no reason to believe it is any different now.

This is in spite of the fact that non-communicable conditions contribute almost 60% of the causes of death in the world and more than 70% of those in developing countries. Within this non-communicable disease total, diabetes is responsible for around 3 million deaths every year, or about 3% of the non-communicable disease total. Of the 2.9 billion USD official overseas development aid to the health sector in 2002, only around 0.1% was allocated to non-communicable diseases (including mental health). A more representative balance of effort and funding would be welcome.

A vitally important topic is highlighted by Jenny Hirst’s article in this issue. She writes about the Cochrane Collaboration — a non-profit organization which strives to provide up-to-date information about the effects of healthcare. Archie Cochrane, an iconoclastic epidemiologist and staunch advocate of the randomized controlled trial (RCT), was amongst the first to advocate the systematic compilation and dissemination of periodically updated reviews of the evidence on health-related interventions.

Hirst’s plea is that no information gleaned from RCTs should remain unpublished so that these reviews can take a genuinely balanced and comprehensive view of the current evidence on whatever aspect of treatment or care they are focussed. There should be no reason for this evidence to remain unpublished simply because it is ‘negative’ or in any way fails to support the use of a particular medication.

Fortunately, the future looks brighter in this respect. Public pressure and other influences are contributing to a move for greater transparency in industry trials and the prospective registration of trials carried out in all sectors, so that a lack of efficacy and the occurrence of adverse events are reported alongside the more positive effects of interventions.

The Lancet recently included no fewer than three articles on this subject, one of which featured the minimum dataset (of 20 items) which the Clinical Trials Registry Platform, based at WHO, has drawn up for the prospective registration of trials. This dataset includes the sources of monetary or material support as well as the scientific issues of interventions, inclusion and exclusion criteria. Of the many ‘e’ words in this field — efficacy, effectiveness, equity, etc — perhaps the most important is ‘explicit’. All who strive to improve the health of the public should be explicit about what they do and the support they receive and their results must be placed in the public domain.
19th World Diabetes Congress
3 - 7 December 2006

30 June 2006
Early Registration Deadline

15 September 2006
Late Registration Deadline

www.IDF2006.org
Research

Teenagers with type 2 diabetes at higher risk of complications
According to recently published research, compared with their peers with type 1 diabetes, young people with type 2 diabetes are more likely to have high blood pressure and kidney damage, despite a shorter duration of diagnosed diabetes (Diabetes Care 2006; 6: 1300-6). The researchers highlighted the importance of screening children with type 2 diabetes for complications as soon as they are diagnosed. They also suggested that screening of children who are at risk of type 2 diabetes might result in the reversal of some complications through early treatment.

The prevalence of diabetes-related complications was studied in young people with both types of the condition – all under 18 years. On average, the children with type 1 diabetes had had the condition for nearly seven years, compared with 1.3 years for those with type 2 diabetes. Of the diabetes complications, only eye damage (retinopathy) was more common in the children with type 1 diabetes.

Although, on average, the young people with type 2 diabetes appeared to have better control of blood glucose levels than those with type 1 diabetes, higher rates of microalbuminuria – the presence of protein in the urine, signalling kidney damage – were found in the children with type 2 diabetes. Furthermore, nearly twice as many children with type 2 diabetes had high blood pressure, compared with the children with type 1 diabetes.

Ethnicity-specific heart disease test
A new test has been developed to assess heart disease risk in people from a range of ethnic backgrounds (BMJ 2006; [epub ahead of print]). This web-based risk calculator examines the risk of stroke and heart disease in people from different backgrounds in order to provide an accurate picture of their health over the next 10 years. Researchers claim that the ‘ETHRISK’ system will provide improved assessment of the risks of heart disease and stroke in seven ethnic groups.

ETHRISK was designed for use in a range of care settings and addresses concerns that certain ethnic groups have an increased risk of heart disease compared to Caucasians. The announcement of the new risk calculator follows the recent publication of the ethnicity-sensitive IDF definition of the metabolic syndrome, which indicates increased risk for diabetes and cardiovascular disease.

Obese children at increased risk of bone fractures
Recently published research findings indicate that obese children are five times more likely to fracture their bones than young people of normal weight (Pediatrics 2006; 6: 2167-74). Furthermore, obese children were found to be four times more likely to suffer from bone or muscle pain and nearly three times more likely to suffer knee pain.

The researchers encouraged certain forms of exercise to reduce weight and improve joint flexibility. Non-weight-bearing activities, such as cycling or swimming should be promoted.

Groundbreaking new treatment for nerve damage
Researchers in the UK have discovered that diabetes-related nerve damage (neuropathy) may be prevented by injecting people with a protein that binds to DNA (Diabetes 2006; 6: 1847-54). According to the researchers, their approach can potentially prevent thousands of foot amputations each year. In the tests, an injection of the DNA-binding protein, ZFP TFTM, protected nerve function, stimulated nerve growth and prevented tissue damage.

Colon cancer risk for women with type 2 diabetes
A US research team presented findings at the Digestive Disease Week in Los Angeles, USA, which indicate that women with type 2 diabetes have an 80% higher risk of developing colorectal cancer compared to women without the condition (Abstract S1245).

In the study, researchers selected 600 women undergoing screening colonoscopies – 100 with type 2 diabetes and 500 without diabetes. Both groups were similar in terms of build, age, and race, and all participants had a relative with colorectal cancer.

It was also found that women with diabetes who were obese had more than...
double the risk of colorectal adenomas, compared with non-obese women without diabetes. The researchers called for colorectal cancer screening in women with diabetes.

Cure in Chinese herbal remedy?
A team of US researchers recently took a surprising step towards the development of a potential treatment for the cause of diabetes using a traditional Chinese herbal remedy (*Cell Metab* 2006; 6: 417-27). A Gardenia fruit extract that is traditionally used in Chinese medicine to treat the symptoms of type 2 diabetes was found to contain a chemical that reverses some of the pancreatic dysfunctions that underlie diabetes.

The team discovered that Gardenia extract contains the chemical ‘genipin’. They found that the chemical blocks the function of the enzyme ‘uncoupling protein 2’ (UCP2). In both people and animals, high concentrations of UCP2 appear to inhibit the production of insulin in the pancreas and increase the risk of type 2 diabetes.

The researchers believe the increase in UCP2 activity is an important component of the pathogenesis of diabetes. When treated with the extract, pancreas cells taken from normal mice secreted insulin. But the cells of mice lacking UCP2 did not. The results suggested that the extract worked through its effects on the UCP2 enzyme. According to the researchers, this represents a useful starting point for new diabetes therapies. If successful in people, it would be the first drug to target the cause of diabetes in the insulin-producing cells.

Pre-eclampsia doubles women’s risk of type 2 diabetes
According to findings presented recently at the meeting of the American Diabetes Association (ADA), compared with women who had never had pre-eclampsia, women with a history of pre-eclampsia had a two-fold higher risk of developing type 2 diabetes (Abstract 80-OR, presented 10.06.2006).

Nearly 2% of women in the study who had pre-eclampsia went on to develop type 2 diabetes, compared with around 1% of women with no pre-eclampsia. When the data were adjusted for factors such as age, gestational diabetes, and high blood pressure, the link between pre-eclampsia and diabetes risk remained strong. The researchers suggested that since women with pre-eclampsia have a significant risk for developing type 2 diabetes – even in the absence of gestational diabetes – interventions aimed at improving overall metabolic and cardiovascular health should be considered.

Blood pressure drugs linked with diabetes risk
Recent findings indicate that diuretics and beta-blockers, which are used to treat high blood pressure, are associated with an increased risk of developing type 2 diabetes (*Diabetes Care* 2006; 3: 1065-70). The researchers examined the relation between the use of different types of antihypertensive drugs and the risk of type 2 diabetes using data from studies that followed three large groups of people: the Nurses’ Health Study I and II and the Health Professionals Follow-up Study.

All the people involved in the study had high blood pressure, but not diabetes initially, and were followed for between eight and 16 years. The risk of developing diabetes in people taking thiazide-type diuretics compared with those not taking a thiazide was increased by 20% in older women, 45% in younger women, and 36% in men. Compared to people who were not taking a beta-blocker, older women taking beta-blockers had a 32% increased risk of diabetes, while the risk for men was 20% higher.

Obituary

Lee Jong-wook
Dr Lee Jong-wook, Director-General of the World Health Organization (WHO), died recently following a sudden illness. Dr Lee worked for WHO for 23 years. The International Diabetes Federation recognizes Dr Lee’s tireless work in helping people attain the highest possible level of health and extends its sincere condolences to Dr Lee’s colleagues and family.
Society

IDF launches ‘Unite for Diabetes’ campaign

The ‘Unite for Diabetes’ campaign was launched recently by IDF at the meeting of the ADA in Washington DC, USA. The campaign aims to ‘bring diabetes out of the shadows’ for the global community to recognize the enormity of the diabetes pandemic and to encourage government support for a United Nations Resolution on diabetes. IDF is leading the global diabetes community in an effort to secure the UN Resolution on World Diabetes Day (14 November) 2007 (see the article by Martin Silink in this issue).

EU adopts declaration on diabetes

The European Parliament adopted by an absolute majority a written declaration on diabetes which urges the European Commission and the European Council to make diabetes care and prevention a priority and develop a Europe-wide strategy to tackle the condition. The Declaration urges the EU Commission and EU Council to prioritize diabetes in EU health policy, to encourage Member States to develop national diabetes plans and, crucially, calls on the Commission and Council to develop an EU diabetes strategy based on an EU Council Recommendation on diabetes prevention, diagnosis and control.

EU clamps down on food health claims

Under new EU legislation, food manufacturers will be prevented from making misleading declarations about the health value of their products. Under the new rules, any health claims – such as ‘low fat’ – will have to be checked by the European Food Safety Authority. European consumer groups hope that the new laws will ensure the reliability and accuracy of information on food labels. The legislation comes as part of a recent drive by the EU to combat obesity and ill-health in its Member States.

The Novo Nordisk DAWN Award 2006

To stimulate, acknowledge and reward outstanding efforts to improve health and quality of life for people with diabetes, Novo Nordisk will award a grant of 15 000 EUR to organizations or individuals whose projects and actions have helped address the people behind the condition. The initiatives should specifically address inequalities in health among disadvantaged populations with diabetes, such as low-income minorities, ethnic minority populations and special needs groups such as the elderly or people with a mental illness.

Projects should have demonstrably achieved one or more of the five goals that were developed based on needs identified in the global DAWN Study:

- enhance communications between people with diabetes and healthcare providers
- promote communication and coordination between healthcare providers
- promote active self-management
- reduce barriers to effective therapy
- enable better psychological care for people with diabetes.

Award submissions must reach the award panel no later than 15 September 2006. The recipient of the DAWN Award will be announced at a ceremony in December 2006 alongside the three best awards entries. These outstanding examples of best practice will be communicated through international publications to inspire others.

Visit www.dawnstudy.com for further details and to download the DAWN Award submission form.

For more information or to contribute News In Brief items to future issues of Diabetes Voice, please contact the Managing Editor, (fax: +32-2-5385114; catherine@idf.org).
Type 2 diabetes is at epidemic proportions among Aboriginal people in Canada – around 15% of the Aboriginal population from 15 years and older. During the 1980s, healthcare providers at the local hospital in Kahnawake Mohawk Territory near Montreal, Quebec, noticed high rates of diabetes among people with cardiovascular disorders. Around the same time, high rates of obesity were reported among elementary school children in the same area. When this information was brought to the Kahnawake community, the elders called for action to prevent the children from suffering life-long ill-health – particularly diabetes. The authors describe a programme through which activities at schools and in the community are designed and implemented with the objective of preventing type 2 diabetes through the promotion of healthy eating, physical activity and a positive attitude.
Health delivery

through close collaboration between the researchers and the community. Indeed, these recommendations became a guide for the development of other research codes at both the government and community levels.

Focus on children

The KSDPP intervention is centred on primary-school children. Approximately 600 children attend the two local primary schools – one an English language school, the other a Mohawk language immersion school. Community nurses and a dietician from the local hospital have delivered health education to Kahnawake schools for a number of years. In partnership with KSDPP, they created a curriculum for diabetes prevention specifically for the primary schools. The content of the curriculum is culturally appropriate and can be delivered by a school teacher. The focus of the material is on lifestyle, nutrition, fitness and diabetes issues.

KSDPP brings together healthcare providers, teachers and children to ensure the successful completion of 10 lessons during each child’s first six school years. Teachers receive support in implementing the curriculum and when working on specific curriculum-based class projects.

KSDPP also works to create and nurture a supportive environment within the schools, which reinforces the concepts encountered by children in the classroom. As part of the programme, the teachers receive help to create healthy-lifestyle activities for their students and themselves. Professional development activities are provided for teachers and parents to reinforce positive role-modelling behaviours.

Activities are provided for teachers and parents to reinforce positive role-modelling.

A key factor has been the ongoing reinforcement of the school nutrition policy permitting only healthy foods to be eaten for lunch, snacks and school events. Healthy breakfasts and snacks are organized for the children with the involvement of parents and teachers. Information booths on healthy eating and physical activity are set up at the schools on parents’ evenings. Large-scale activities have been organized, such as a treasure hunt and walk and a 1.5 km run for all children. The objective of these activities is to reinforce the children’s learning in the classroom with practical experiences and role models outside the formal teaching setting.

In the community, KSDPP has created extensive partnerships with other community organizations, such as the Kahnawake Youth Center, the Environment Office and the Community Health Unit. These collaborations have provided the people of Kahnawake with opportunities to learn about diabetes prevention and participate in activities to promote a healthy lifestyle, including nutrition-based activities developed jointly by KSDPP and local nutritionists. Partnerships between various local organizations resulted in the creation of a cycle path. Over the past 12 years, various Kahnawake organizations have increasingly incorporated opportunities for healthy eating and some physical activities into their own internal and external proceedings.

To ensure effective communication and the involvement of all members of the community in diabetes prevention activities, the Community Advisory Board was formed. The Board, which includes representatives from schools and the community, guides all aspects of KSDPP. At monthly meetings, information and reports from the research, training and intervention activities are presented and research issues are discussed. Plans are drawn up for the dissemination of information locally and to indigenous and scientific communities. Community Advisory Board members are also involved in other matters: reviewing abstracts and
articles, making presentations, revising the code of research ethics, and teaching visitors about Kanien’kehaka culture.

KSDPP has consistently seen good levels of participation in community activities; support for the promotion of healthy lifestyles is increasing among community organizations. The uptake of lifestyle changes themselves is slow, but the community is seeing positive changes among the people in Kahnawake. The key positive changes in the school children are those related to nutrition. A general reduction in the intake of fat and simple sugars was achieved through decreased intakes of high-fat snack foods and high-sugar soft drinks, and increased consumption of whole-wheat bread.

In order to better understand the reasons behind these mixed results, discussions were held with community members and local organizations. These dialogues provided opportunities for the intervention team to make recommendations to parents and the community in general to increase the consumption of certain healthy foods, reduce the time spent by the children and their families watching television or playing video games, and increase physical activity.

Feedback from community members was positive and encouraging regarding the reasons for the regression that followed the initial progress. Discussions were sparked in a number of key areas: the importance of creating new opportunities for regular physical activity; understanding the impact of television and computers; and the impact of economic factors – increased family incomes resulting from increased numbers of parents, especially mothers, in the local work-force.

Mixed results
During the first five years of the programme, these dietary changes were accompanied by increased levels of physical activity. However, over the next five years, physical activity returned to baseline; the time children spend in front of the television remains above the recommended levels. As a result, rates of child obesity in the community have in fact increased. These very mixed results – which are similar to those seen in many other health promotion projects – compelled the intervention team to promote increased physical activity and further nutritional changes, including the increased consumption of fruit and vegetables.

For 12 years, KSDPP has operated effectively in Kahnawake. The project has drawn strength from several factors, including an open and collaborative community-university partnership; the involvement of the community in the planning, implementation and evaluation stages, and research activities – particularly through the Community Advisory Board. The community is kept well informed about diabetes issues, research results, prevention, nutrition and physical activity. Furthermore, KSDPP represents a focus for people’s concerns over the future wellbeing of Kahnawake generations and their right to a healthy, preventive lifestyle.

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Answering the urgent need
for diabetes care personnel
in northern India

Sanjay Kalra and Bharti Kalra

Nobody can single-handedly manage the many and diverse aspects of diabetes. To be effective, diabetes care requires the coordinated input of people with diabetes and a range of healthcare providers, including a diabetes nurse, dietician, psychologist, pharmacist, physiotherapist or podiatrist, among others. Close collaboration between these professionals is central to providing optimum healthcare to people with diabetes. However, a lack of human resources is often an important limiting factor. Sanjay Kalra and Bharti Kalra report from northern India on an initiative which aims to meet the need for staff in the region to care for the growing number of people with diabetes.

As a result, already underserved areas of the world face growing obstacles in creating and maintaining committed diabetes care teams. Countries in Asia, Africa and the Caribbean are hit hardest by this lack of human resources. India, for example, has a nurse-to-population ratio of 1:2250, compared with the ratios of 1:10 to 1:150 seen in European countries.

Countries in Asia, Africa and the Caribbean suffer an acute lack of human resources.

Multipurpose diabetes workers
Understaffed countries with high levels of diabetes, such as those in the Indian sub-continent, are faced with a dual problem: a poor supply of trained manpower coupled with a high demand for diabetes care. In response, a healthcare centre specializing in endocrine conditions in a small city in northern India has trained local multipurpose diabetes workers to provide diabetes education, counselling, and clinical care.

Shortcomings in human resources are particularly pronounced in developing countries, where there is a shortage of qualified medical and nursing personnel. This leads to major gaps in the provision of general nursing and counselling as well as specialist diabetes care. These problems are compounded by a lack of diabetes training and an emphasis, in terms of funding and resources, on caring for people with communicable diseases, such as malaria and AIDS. An incessant brain-drain of skilled labour to the wealthy countries of North America, Europe and the Middle East exacerbates these problems in India.
These multipurpose diabetes workers constitute the first point of contact. They screen people, talk through immediate problems and refer people to the appropriate specialist. Young and highly motivated, their ages range from 20 to 35 years; the minimum educational requirement is upper-secondary level, with or without a paramedical diploma. All of them have a working knowledge of written English and are fluent in more than one local language.

The multipurpose diabetes workers are the first to see the people with diabetes who attend the hospital’s outpatient department. Trained in counselling skills, such as confidence-building and encouraging empathy, the multipurpose workers provide basic education and counselling, explaining the condition and offering emotional support to people with diabetes and their families.

Roles and responsibilities
The multipurpose diabetes workers are empowered to carry out blood glucose and urine ketone tests, initiate insulin treatment, and adjust insulin doses. They do so under the strict supervision of the endocrinologist; any dose adjustments are closely audited. They inform patients about the different insulin regimes and devices that are available. The workers are trained to use an approach that allows people to choose the most suitable option, thus shifting control to the people with diabetes and increasing their concordance with the suggested treatment.

Nutrition and lifestyle
The diabetes workers are able to provide basic nutrition management advice, including suggestions for a balanced diet, and offering tips on healthy cooking. They have knowledge of the seasonal availability and cost of foodstuffs, and can recommend local nutritional options.

People with diabetes are educated and motivated to exercise regularly. The multipurpose diabetes workers advise appropriate physical activities, such as walking and dancing, and create peer groups of people who are interested in a particular activity. They also offer practical tips on stress relief and making day-to-day adjustments in lifestyle, and work to infuse positive coping skills in people with diabetes and their relatives.

Special needs and substitutions
Children and adolescents with diabetes receive specific help in coping with the condition from the multipurpose diabetes workers, who foster a supportive community approach by creating a closely bonded network of families affected by diabetes.

Many aspects of foot care are handled by the workers. These include wound dressing and preventive foot-care education. As well as assisting, the workers are able, when required, to cover certain duties of the podiatrist.
or other specialists. The qualified hospital staff offer ongoing formal and informal training and support to the multipurpose diabetes workers.

Qualified staff offer ongoing training and support to the multipurpose diabetes workers.

Agents for change
Although their role has developed out of necessity, the multipurpose diabetes workers have become an integral part of the diabetes care team. If the health workers are unable to resolve a particular issue, people with diabetes are referred to a specialist, such as an endocrinologist or podiatrist, working in the same hospital. At times, the health workers’ feedback helps the specialist in modifying an approach to a particular problem.

Many people with diabetes feel more comfortable with the multipurpose workers than with the specialist medical staff; they often share the same ethnicity, dialect and socio-economic status. A wide range of communities, language groups and ethnic backgrounds are represented in the staff, reflecting the diversity of people who are seen at the hospital.

Perhaps the most important work done by multipurpose diabetes workers is in motivating people – convincing a reluctant person with diabetes to initiate insulin therapy, for example, or appealing to a school teacher to give a five-minute snack break for a child with type 1 diabetes. The multipurpose diabetes workers are proving to be effective agents for behaviour modification and health improvement.

A clash with tradition
Many physicians do not accept multipurpose diabetes workers as equal partners or colleagues in the fight against diabetes. While doctors have existed throughout human history, modern nursing is a younger profession – less than 300 years old. Traditional medical training and indeed the ancient Indian system of guru-shishya are based on hierarchies, emphasizing vertical rather than horizontal relationships between colleagues, as well as the superiority of doctor over patient. All responsibility traditionally lies in the hands of the treating doctor.

The concept of therapeutic patient education is slow to gain acceptance in most hospitals in India. Many doctors feel threatened by patients and health workers who profess to know about a condition that is being treated; the workers and patients are expected to play a subservient role.

The introduction of multipurpose diabetes workers requires time and commitment.

In this setting, the effective introduction of multipurpose diabetes workers as agents of change requires time and commitment. However, as the demand for diabetes counselling grows, the multipurpose diabetes workers increasingly play a key role in diabetes management, particularly in underserved communities.

An essential resource
The contribution of primary health workers is central to the efficacy of the Indian public health system. Indeed, multipurpose health workers have successfully taken primary healthcare to the doorstep of many millions of people in the Indian sub-continent, China and other countries. They prevent countless episodes of communicable disease, distribute tons of contraceptives, correct anaemia and dehydration, and immunize millions of children.

This approach has resulted in improvements in the health status and life expectancy of many people in the developing world. The independent nurse practitioner model in West Bengal, India, for example, uses qualified nurses with midwifery training as independent consultants in centres where gynaecologists are not available. A number of non-government organizations working with people with HIV/AIDS in India use trained non-medical counsellors to provide health-related advice and psychological support to high-risk communities in northern India. These same methods can be used, with good effect, in diabetes management.

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Optimal diabetes outcomes depend on a lifetime of appropriate care, including self-care, education and management. Health professionals require a body of knowledge and skills in order to provide effective diabetes care, education and management. In 2002, a step towards assisting healthcare professionals to gain that knowledge was taken by the International Diabetes Federation’s Consultative Section on Diabetes Education (DECS), when it published the International Curriculum for Diabetes Health Professional Education. This article reports on the next stage – building content and a programme based on the Curriculum for the education of multidisciplinary diabetes care teams.

With global usefulness and applicability in mind, the Curriculum was developed by people from all seven IDF Regions. Suitable for different health disciplines working at various levels, it can be adapted for delivery in a short workshop format or as part of a post-graduate diploma or master’s programme. The Curriculum covers the key topics and objectives for healthcare providers who plan to work in the field of diabetes. Further content includes information about the physical facilities that are necessary to provide diabetes education; sample three- or five-day programmes; examples of case studies; and advice on setting up a mentoring system. The Curriculum has been used as the framework for a number of diabetes health professional courses in different parts of the world.

Complementary material
Recent feedback indicates that the Curriculum is extremely useful and valuable, and its content is appropriate and relevant. However, feedback from some Regions reflected concerns that without content to support the Curriculum, the development and delivery of a diabetes health education programme was difficult. In response, DECS is currently completing a web- and CD-ROM-based resource that includes detailed complementary material. This resource will be launched at the IDF Congress in Cape Town in December 2006.

A working group of people with teaching and learning skills, as well as experience in diabetes care, education and management, met to develop the material. The working group was broadly representative of the seven IDF
Regions. Slides and speaker notes to accompany the outlines and objectives were developed by members of the group and a number of experts. Once completed, the slides, speaker notes and objectives were reviewed by independent healthcare professionals.

The material was developed by a group of people with teaching and learning skills and experience in diabetes care.

The Curriculum’s 19 modules encompass the basics of diabetes, self-care, nutrition, exercise, pharmacological therapies, and chronic complications. One of the modules is devoted to the role of the healthcare provider in diabetes care, education and management.

The evaluation process
Formal evaluation was carried out in two pilot programmes in India – in Chennai and Bangalore – and another in Eritrea, East Africa. The draft material was also used in other programmes; feedback on the appropriateness of the content and its design and ease of use was forwarded to the working group. While it is common practice in many parts of the world for physicians to offer education to non-medical healthcare professionals, the IDF programme can be taught by non-medical professionals. The pilot sites, which were provided with some funding, were expected to use non-medical facilitators.

In some places, junior physicians or primary care physicians took part in programmes that were facilitated by non-physician healthcare providers. In others, physicians used the slides and speaker notes to teach other physicians – and subsequently provided feedback.

In formal evaluations, the content was perceived as appropriate across a wide range of areas and settings. Overall, the level of satisfaction was high. Feedback from the physicians who took part in the pilots was no different in terms of satisfaction and perceived applicability and appropriateness from that of the other participants.

Participants were asked to indicate two changes that they would make to their practice as a result of attending the course. Changes in the teaching of aspects of nutrition were mentioned frequently, together with the introduction of better teaching methods in general, and an increased emphasis on the promotion of self-management and patient empowerment. It appears that the programme increased awareness among participants of the holistic nature of diabetes care and management. As one respondent put it, “as a dietician, I thought my role was to give only dietary advice. After attending this course my opinion is that a focus on diet alone is insufficient.”
Facilitator evaluation

Evaluations were received from the facilitators in the pilot sites. The results of these indicate that most facilitators did not supplement, delete or alter the slides; most used the speaker notes provided. It was felt overall that the information provided was adequate and easy to comprehend. Many facilitators felt the slides could be adapted for their culture. However, the slides covering legal regulations, alcohol, diet, and devices were thought to be geographically and culturally specific and would require significant modification to be relevant to specific cultures.

The programme increased awareness of the holistic nature of diabetes care and management.

Both facilitators and participants indicated that they would recommend the programme to others. Many expressed the need for the programme to be conducted annually and delivered in professional schools and rural areas. Other suggestions included making available some form of recognition or certificate of attendance to participants who successfully complete the programme.

The next steps

The working group carefully considered the evaluations and suggestions and revised the slides and speaker notes in order to address the issues that were raised. To enhance the application of the modules in practice, activity slides have been incorporated; multiple-choice questions have been added to each module for use in self-testing or the group assessment of learning upon completion of the programme.

The resource, to be published on CD-ROM, will be accompanied by a hard-copy prospectus that will include tips on using the slides to prepare a programme. This material will be launched at the IDF Congress in Cape Town in December 2006 and after this will be available from the IDF Executive Office and website (www.idf.org).

The suggested programme consists of a basic-level five-day workshop; over the year following the workshop, participants complete course-work projects in their own countries; a three-day advanced workshop completes the course. This model has been used successfully for several years in the Caribbean.

Recognition

There is an important need for healthcare providers around the world to receive some form of recognition for their commitment to diabetes care and education. To this end, IDF will provide a certificate of attendance to participants who successfully complete the basic level and a certificate of recognition to those who complete the course-work and advanced programme.

It is hoped that access to a comprehensive health professional diabetes education programme will enable increased numbers of healthcare providers to establish programmes to enhance the knowledge and skills of their colleagues. Only then, backed by sufficiently large numbers of diabetes-aware skilled health professionals, will we be able to face the demands of the global diabetes epidemic.

Anne Belton, Trisha Dunning, Marg McGill

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Acknowledgement

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Further reading


Fruit and vegetables and the prevention of non-communicable diseases

Viviana Viviant

It is estimated that around 2 billion children and adolescents worldwide suffer from weight-related disorders. According to the World Health Organization (WHO), more than a billion people are overweight, at least 300 million of whom are obese. As societies continue to embrace unhealthy sedentary lifestyles, fuelled by high-fat, high-sugar processed foods, obesity-related disorders, including type 2 diabetes and cardiovascular disease, are affecting increasing numbers of people at all levels of society and in almost all the countries in the world. In this article, Viviana Viviant exposes some of the diet-related myths and misconceptions that might hinder effective nutritional education and backs calls for multi-sector societal solutions to the global obesity epidemic.

Although in recent years the number of fatalities has been dropping in developed countries, cardiovascular disease remains the principal cause of death worldwide. Increasing urbanization is driving up the prevalence of behaviour-related risk factors, such as a lack of physical activity and excessive consumption of animal fats. Soon, more than half of the world’s population will live in cities. This will compound a changing global disease profile that is complicated by increasing numbers of young smokers (particularly in the developing countries) and a dramatic rise in the number of people suffering from stress and depression.

Effective health education must form a key element of coordinated preventive strategies.

In short, many economies are in danger of being overwhelmed by spiralling healthcare demands. Before it is too late, it is essential that, as well as those at increased risk of obesity-related conditions – such as the metabolic syndrome or type 2 diabetes – the general population are made aware of the very serious threat to health and development that is posed by chronic non-communicable diseases. Effective public health education must form a key element of coordinated preventive strategies.
In their *Global Strategy on Diet, Physical Activity and Health*, WHO call for community involvement in modifying nutritional habits and the uptake of an active, preventive lifestyle. A large body of evidence supports the need for variety and balance in terms of the food groups that constitute our diets. Fresh fruit and vegetables are one of the most important of these. Yet despite confirmation in the findings of scientific research of the health benefits of regularly consuming fruit and vegetables, WHO estimates that in general we consume less than half of the daily 400 g that is recommended for preventive and therapeutic dietary interventions.

### Myths

Awareness-raising health education which communicates accurate and appropriate information on nutrition is the cornerstone of effective long-term lifestyle modification. However, a number of widely held misconceptions exist regarding the appropriateness – for people with diabetes as well as those without the condition – of consuming fruit and vegetables. The points below address some frequently reported myths.

**Two portions a day should be enough to ‘keep the doctor away’**

Two is not enough. A healthful diet contains five portions a day, consisting of two servings of vegetables (one raw and one cooked) and three fruits. As well as including fresh fruit and vegetables in regular meals, people should be encouraged to substitute high-sugar or high-fat snacks with fruit or raw vegetables.

**People with diabetes should avoid certain fruits and vegetables**

Although some fruits and vegetables contain more calories and carbohydrates than others, these can be consumed by people with diabetes – or indeed people with overweight or obesity. While carbohydrates make up between 12% and 15% of most fruits, grapes, figs and bananas are around 20% carbohydrate; potatoes, sweet potatoes and fresh sweet corn also contain around 20% carbohydrate, compared with the 5% to 10% contained in most vegetables.

**Beta carotene** is found in yellow, orange and green fruits and vegetables. The greater the intensity of the color of the fruit or vegetable, the more beta carotene it contains. Beta carotene is an anti-oxidant. Studies suggest that people who eat four or more daily servings of fruits and vegetables that are rich in beta carotene may have a reduced risk of developing heart disease or cancer. Other studies indicate that beta-carotene supplements do not have the same protective effects.

*Grapes are an important source of antioxidants and protect cardiovascular health.*

These foods have a number of health benefits for people with or without diabetes. Bananas, as well as being rich in potassium, contribute to the regulation of blood cholesterol; figs are an important source of fibre – a natural laxative; grapes, black grapes in particular, are a source of resveratrol, a
compound with antioxidant properties – which protect cardiovascular health.

Regarding the overall nutritional value of these vegetables, sweet corn tops the list as an important source of fibre and beta carotenes. Sweet potato also provides beta carotenes but contains less fibre; potato contains minimal amounts of either of these. It is important for people to be aware that the health benefits of potatoes (as with most food) depend on moderation and methods of preparation.

Frozen and canned foods are equally healthy
This is a common misconception. In the case of both the freezing and canning processes, nutritional value is lost and additives, such as sodium, damage the nutritional balance of the foods. Vitamin C and folic acid are usually the most affected nutrients. Fresh fruit and vegetables, on the other hand, as long as they are correctly handled and prepared, preserve their mineral and vitamin content. Frozen or canned fruit or vegetables can of course be consumed, although people ought to be aware of the possible loss of nutrients that may occur.

Dried fruits are not recommended
By removing their water content, the sugar concentration of fruits rises, as does their caloric content. Eaten dried, these fruits should be accompanied by liquid. When consumed in moderation and chewed thoroughly, dried fruits can benefit people with problems of overweight because these provoke a sensation of satiety (fullness), reducing the urge to continue eating.

People with high blood pressure should avoid certain fruits
Fresh fruit and vegetables are strong allies in the regulation of arterial blood pressure, particularly those that are high in potassium and magnesium. It is strongly recommended for people with high blood pressure to consume uncooked fruit and vegetables each day. Garlic, onions and leeks contain allicin, a phytochemical that protects vascular health.

Long-term investment in health
Clearly, people who are at risk of obesity-related conditions, as well as the general public, should be encouraged to follow the WHO nutritional recommendations, incorporating fresh fruit and vegetables into their daily diet. Healthcare providers can play an important role in enhancing people’s nutritional knowledge. Those working with people with diabetes clearly have a responsibility to ensure that their patients have access to information which may constitute a key preventive measure against diabetes-related complications.

The wider the variety of colours, the greater the benefits to people’s health.
There are two concepts that should be born in mind when offering either formal or informal health nutrition education. Firstly, we should stress the importance of colour. Regarding fresh fruit and vegetables, the wider the variety of colours, the higher the content of protective nutrients – and the greater the benefits to people’s health.

The other important point is the number of servings. People should be encouraged to include three portions of fruit and one of vegetables into both their midday and evening meals. However, one or two pieces of fruit and a helping of vegetables – cooked or raw – represent an improvement on none at all. Making these dietary modifications may require changing the eating habits of a lifetime; consuming the recommended number of servings should be seen as a long-term objective which can be reached progressively in manageable steps.

Further reading
The following documents are available from www.who.int/dietphysicalactivity


Health delivery

Diabetes care in Taiwan: a case-management initiative

Martin M-T Fuh, Cheng-Chieh Lin, Cheng-Shan Chiu

Diabetes, now a global epidemic, is the fourth leading cause of death in Taiwan. The most recent epidemiological data demonstrated that the prevalence of diabetes is approaching 5% and that the number of people with diabetes in Taiwan has reached 1.2 million. In order to comprehensively assess diabetes care in Taiwan, a nationally standardized programme has been in place since 2001, which includes performance measures that can evaluate accurately and reliably the quality of diabetes care. The authors describe the characteristics and achievements of the Diabetes Case Management Program 2001 (DCMP 2001).

DCMP 2001 is a patient-centred, evidence-based and clinically integrated care-delivery system. Its primary goal is to support diabetes care teams in medical centres, regional hospitals and local community clinics in their work to provide care for people with diabetes throughout Taiwan.

Performance measures

The programme has a set of integrated performance measures. These encompass multi-disciplinary diabetes care services, and include three-monthly physiological and biochemical data, lifestyle factors — such as smoking, exercise or physical activity, alcoholic intake, and working and sleeping hours. Individual dietary behaviours are recorded, including total daily energy intake, macronutrient consumption and dietary recommendations, as well as the results of annual foot examinations and eye care, urine analyses, and diabetes- and non-diabetes-related complications.

Access to data

The data collected through DCMP 2001 is stored on a database and provides enough information for cross-sectional and longitudinal assessments of the quality of diabetes care in Taiwan. As a result, the status, in terms of health and well-being, of the diabetes population in Taiwan can be assessed. Yearly figures can be made available relating to co-morbidities, complications, lifestyle interventions and dietary recommendations in diabetes care.

Through DCMP 2001, the health status of people with diabetes in Taiwan can be assessed.

During the planning and development phases of DCMP 2001, a great deal of preliminary data resulting from the implementation of the programme’s performance measures was presented and intensively reviewed by people in a variety of private and public healthcare settings. These people included:

- authorized decision makers from the Taiwan Department of Health and its Bureau of Health Promotion and Bureau of National Health Insurance — the sole healthcare
health delivery

insurance organization in Taiwan health administrators in regional governments delegates of the Chinese Diabetes Association and the Taiwan Association of Diabetes Educators members of diabetes care teams in Taiwan who are engaged in the Diabetes Education Clinical Path programme.

It is hoped that these measures will enhance the uptake of research into practice and might ultimately improve diabetes care and clinical outcomes. It has been recognized that a consensus on measures at national level can offer a method for assessing care within and across healthcare settings, while providing meaningful mechanisms for improvements in the delivery of quality care.

Improving diabetes care
The healthcare environment in Taiwan has some very particular characteristics, including a system involving a single purchaser of healthcare, and a medical community that is enthusiastic about computer-mediated modernization. It is in ideal conditions for reform, and has a culture of resistance to failure.

Through DCMP 2001, a range of essential diabetes-related data is collected.

Thus, the potential impact of DCMP 2001, with intensive collaboration between the healthcare services nationwide, is very strong. Recently, the payment mechanism of the Bureau of National Health Insurance was reviewed and specifically focused on the further enhancement of DCMP 2001 with a view to the continued improvement of diabetes care.

Martin M-T Fuh, Cheng-Chieh Lin, Cheng-Shan Chiu

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References
Diabetes is associated with numerous long-term complications. Many of these, like kidney failure and ischaemic heart disease, are life threatening. Others, such as eye damage and nerve damage, impact heavily on quality of life. But sexual difficulties, which affect both women and men with diabetes, often receive less attention than they deserve, despite the high levels of distress they generate. Mac Robertson looks at the risks for sexual dysfunction in men and women with diabetes and describes the current management options.

Sexual dysfunction is of major concern to people with diabetes. A survey of men with diabetes found that they were prepared to pay more for the treatment of their erectile dysfunction than for any other diabetes-related complication, except blindness and renal failure. The bulk of research on sexual function and diabetes has focused on men; the sexual functioning of women has received considerably less attention.

Diabetes-related sexual dysfunction in women has received relatively little attention.

Women with diabetes
A recent review of 25 years of research into diabetes and female sexuality indicated that women with diabetes faced a number of complications relating to sexual activity. While no increase was seen in the women’s problems reaching orgasm, there was an increased risk of reduced sexual arousal with slow and/or inadequate lubrication, a reduction in sexual desire, and an increased likelihood of pain during sexual intercourse.

Another recent study comparing women with type 1 diabetes with an age-matched comparison group of women without diabetes also found a higher incidence of sexual dysfunction and decreased lubrication. The women with diabetes complications reported significantly more problems with sexual functioning than those without complications. The women in the study with sexual problems — both those with diabetes and those without the condition — reported a lower quality of relationship with their partner.
Some women in the early undiagnosed phase of type 1 diabetes may experience problems with sexual arousal, the loss of sexual desire (libido) and even an inability to reach orgasm. However, this returns to normal once the women are diagnosed with diabetes and establish insulin therapy. Women with poorly controlled diabetes often have vaginal yeast infections or thrush. The pain associated with this disorder may make sex difficult or impossible.

There are other difficulties that may work against sexual joy in women with diabetes. Teenage girls with diabetes are particularly aware of the weight gain that can result from taking insulin. Problems of poor self-esteem or self-image and eating disorders are not uncommon in young women with diabetes.

Pregnancy

Due to the need for extremely tight diabetes control from the moment of conception through to birth, pregnancy in women with diabetes is not always the joyful experience it should be. A failure to achieve this control may result in either fetal abnormalities or babies with macrosomia and therefore a greater risk of death.

It is not surprising that the burden of the various potential hazards facing women with diabetes may contribute to a loss of sexual self-confidence and difficulty in achieving sexual satisfaction.

Risk factors for the more severe sexual difficulties in women with diabetes include poor blood glucose control, the presence of complications – especially sensory nerve damage – and certain drugs, such as tricyclic antidepressants, which are frequently used for pain in neuropathy.

Men with diabetes

Diabetes is one of the major risk factors for male sexual difficulties. This usually manifests itself as erectile dysfunction, in which men experience a persistent inability to achieve or maintain an erection that is sufficient for satisfactory sexual activity. This disorder is common in the general male population.

Figure 1 indicates the anticipated increase in the next 20 years.\textsuperscript{4}

In the USA, the Massachusetts Male Aging Study found that in men aged between 40 years and 70 years, between 39% and 67% suffered varying degrees of difficulty with erection.\textsuperscript{5} The severity of erectile dysfunction increased with advancing age.

Surveys of the incidence of erectile dysfunction in men with diabetes

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**Figure 1: The anticipated increase in erectile dysfunction over the next 20 years\textsuperscript{4}**

<table>
<thead>
<tr>
<th>Region</th>
<th>1995%</th>
<th>2025%</th>
</tr>
</thead>
<tbody>
<tr>
<td>North America</td>
<td>11.9</td>
<td>21.1</td>
</tr>
<tr>
<td>South &amp; Central America and the Caribbean</td>
<td>10.5</td>
<td>26.1</td>
</tr>
<tr>
<td>Europe</td>
<td>42.8</td>
<td>30.1</td>
</tr>
<tr>
<td>Africa</td>
<td>11.5</td>
<td>199.9</td>
</tr>
<tr>
<td>Asia</td>
<td>86.9</td>
<td>19.1</td>
</tr>
</tbody>
</table>

Worldwide prevalence will increase from 152 million men in 1995 to 322 million men in 2025.

**Figure 2: Risk factors for heart disease and erectile dysfunction**

- Coronary artery disease
  - Smoking
  - Hypertension
  - Dyslipidaemia
  - Diabetes

- Erectile dysfunction
  - Smoking
  - Hypertension
  - Dyslipidaemia
  - Diabetes

Endothelial dysfunction – the common denominator
are difficult to compare. Most do not differentiate between age, the type or duration of diabetes, or the presence or absence of complications.

The severity of erectile dysfunction is associated with increased levels of HbA1c.

This, however, was not the case with a recent Italian study. Over 1000 men with diabetes in Italy were followed for three years; 19% complained of erectile dysfunction. The incidence increased with age, the duration of diabetes and deteriorating metabolic control. Furthermore, the severity of erectile dysfunction was associated with increased levels of HbA1c – a long-term measure of blood glucose control. The incidence of erectile dysfunction was also high in men with type 2 diabetes and those with diabetes complications.

Endothelial damage
There has been a tendency to regard diabetes-related erectile dysfunction as being due mainly to nerve disease; but erection is essentially about blood flow. Sexual excitement results in increased blood flow into the vascular tissue of the penis, until a degree of stiffness blocks the outflow of blood by compressing penile veins – resulting in rigidity.

The current thinking is that the primary disorder in erectile dysfunction is endothelial dysfunction. Ultramicroscopic examination of penile smooth muscle in men with severe diabetes-related erectile dysfunction reveals a similar degree of destruction of this vascular endothelial tissue as that seen in non-diabetes-related erectile dysfunction.

Endothelial dysfunction is the basis of other vascular disorders seen in diabetes, including ischaemic heart disease. There is a great deal of evidence to indicate that we should regard erectile dysfunction as an early warning marker for this common and often fatal condition. Both are manifestations of atherosclerotic disease. In Figure 2, we can see that erectile dysfunction and ischaemic heart disease share other predisposing factors besides diabetes, such as tobacco smoking, high blood pressure and high cholesterol.

Management options
The key to the effective management of erectile dysfunction in men with diabetes lies in the proper control of blood glucose through lifestyle modification – exercise and diet – the avoidance of smoking, and the appropriate use of oral medication and insulin. As noted in the case of women with diabetes, it is not uncommon to see a reversible type of erectile dysfunction early on in men with type 1 diabetes, which improves once control is established.

Major advances
Once the erectile dysfunction is persistent and severe, it may respond to the same treatment as non-diabetes-related erectile dysfunction. The class of drugs known as phosphodiesterase 5 (PDE-5) inhibitors has enabled major advances in the non-invasive management of erectile dysfunction. The three PDE-5 inhibitors that are currently available are Viagra, Levitra and Cialis. All three have been associated with
Mac Robertson

Mac Robertson is Medical Director of the Dot Shuttleworth Centre for Diabetes and Institute for Human Sexuality, Parklands Medical Centre, Overport, Republic of South Africa.

Macrosomia, also known as ‘big baby syndrome’, is defined as a fetus that weighs above 4000 g. After birth, a person with macrosomia has an unusually large body. The extremities and head are also enlarged.

improvements in erectile dysfunction in over 50% of men with diabetes.

The quality of erection in men with the severe forms of diabetes-related erectile dysfunction is not as good as in men without diabetes. Furthermore, the high cost of these drugs, and the fact that most medical insurance schemes will not pay for them, puts them out of the reach of many who might benefit from their use.

The high cost of PDE-5 inhibitors puts them out of the reach of many.

Non-invasive treatments

Vacuum devices are non-invasive, inexpensive and effective. The flaccid penis is placed in a plastic cylinder. Negative pressure causes passive engorgement of the penis and an elastic tourniquet is slid onto the base when sufficient rigidity is obtained, trapping blood in the penile smooth muscle.

Men with impaired functioning of the testes (hypogonadism), who have low levels of the male sex hormone, testosterone, may benefit from testosterone replacement therapy; but care should be taken to ensure they do not have cancer of the prostate. If this is the case, there are various appropriate invasive therapies.

Penile injections

The most effective therapy when oral treatment fails is to inject into the penis medication to activate the blood vessels – either alprostadil alone or in combination with two or three other substances, such as phentolamine or papaverine. The onset of erection occurs within minutes and the injections are virtually painless. By the time men with diabetes-related erectile dysfunction seek treatment, many are using insulin injections. This form of treatment therefore often poses fewer problems than in men without diabetes. The cost of these injections is considerably lower than that of the oral drugs.

Other approaches

Intra-urethral alprostadil suppositories had a short life as they were not only less effective but required a tourniquet at the base of the penis for optimal results. Also, the suppositories often caused a burning sensation in the penis.

When all else fails, or when men with erectile dysfunction would rather avoid the constant need for on-demand treatment, surgical implants remain a successful, albeit expensive, form of therapy. The newer inflatable prostheses continue to be effective and reliable for many years.

Awareness and early referral

Diabetes healthcare professionals should maintain a constant awareness of the profound effect that diabetes may have on the sexual functioning of men and women, and the need for early and appropriate referral.

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How to get Diabetes Voice

Either

Become a member of the International Diabetes Federation (IDF)

As well as receiving Diabetes Voice four to six times a year in English, French or Spanish, IDF membership also entitles you to:

- become part of an international network of healthcare professionals and people who care about diabetes;
- a lower registration fee at the next IDF World Congress;
- receive other IDF materials containing the latest information on a wide range of diabetes-related issues;
- join a dedicated and proactive organization and add your voice to the millions concerned with diabetes.

Yes, I would like to become an IDF member. Please enrol me as:

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☐ Three-year member (195 EUR)

Please send me Diabetes Voice in:

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☐ French
☐ Spanish

Or

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☐ English
☐ French
☐ Spanish

YOUR CONTACT DETAILS

☐ MS  ☐ MR  ☐ DR  ☐ PR

FAMILY NAME(S):

FIRST NAME(S):

ORGANIZATION / COMPANY:

ADDRESS:

POSTAL CODE  TOWN:

COUNTRY:

PHONE  FAX:

E-MAIL:

OCCUPATION:

VAI:

Do you have diabetes?  ☐ Yes  ☐ No

PAYMENT DETAILS

☐ I will pay by credit card, to be billed in euros. Type of card:

☐ American Express  ☐ Mastercard
☐ Visa

Name of cardholder:

My card number is:

Exp. date:

Signature on card:

☐ I will pay by direct bank transfer to the IDF account

IBAN: BE03-6451-4103-3284; BIC: JVBABE22

VAI: BE433.674.528


Please return this form to: INTERNATIONAL DIABETES FEDERATION
Executive Office • Avenue Emile de Mot 19 • 1000 Brussels • Belgium • Phone: +32-2-5385511 • Fax: +32-2-5385114 • idf@idf.org
In 2003, a 16-year-old girl with diabetes had an idea which looks set to change the face of diabetes. Not long after his election as President-Elect of the International Diabetes Federation, Martin Silink was approached by Clare Rosenfeld, who spoke of her dream of a United Nations Resolution on diabetes. Inspired by Clare’s dream, Martin Silink spent the subsequent two years gauging the opinion of the diabetes stakeholders and garnering worldwide support for a UN Resolution. He approached senior figures from the diabetes world in more than 30 countries. The support was overwhelming and the feeling widespread – now is the time for the Resolution.

The outcome of a key stakeholder’s meeting in December 2005 was a decision that the concept was realistic and the campaign achievable. The author offers this update on the IDF campaign to bring diabetes out of the shadows and for the global community to recognize the enormity of the diabetes pandemic.

Diabetes is a global epidemic. Since the turn of the new millennium, the number of people with the condition has doubled. More than 230 million people worldwide are living with diabetes. Within 20 years, this number is expected to rise to a staggering 350 million. But despite the warning signs, governments have been slow to act. If steps are not taken to constrain the diabetes pandemic, the number of people living with the disease will soon be greater than the current populations of the USA, Canada and Australia combined. Left unchecked, this will bring devastating human and economic consequences. Each year, more than 3 million people die from diabetes-related causes – diabetes kills every 10 seconds.

Whilst the greatest rise is in type 2 diabetes, all types of diabetes are increasing. The diabetes burden is particularly harsh in the developing world, where poverty, environmental factors and the scarcity of services conspire to worsen access to healthcare. In low-income countries it
is depressingly common for children with diabetes to die because they lack access to life-saving insulin. Most families in developing regions pay for their healthcare out of the household budget. In many cases, the cost of caring for a loved one with diabetes drives families into poverty.

In low-income countries, many children die because they lack the insulin they need to live.

Indeed, diabetes threatens to undermine economic development worldwide as a consequence of the spiralling costs of medical care. In 2007, the world will spend an estimated 215 to 375 billion USD on care for people with diabetes and its complications. This figure is set to rise to between 234 and 411 billion USD over the next 20 years. It has been estimated that over the next 10 years China alone will lose 558 billion USD as a result of premature deaths from diabetes, heart disease and stroke.

Diabetes is growing fastest in low- and middle-income countries; soon, almost 80% of all people with diabetes will live in developing countries. These emerging economies will therefore bear the brunt of the rising costs. Already, seven out of the 10 countries with the highest number of people living with diabetes are in the developing world.

IDF believes that to do nothing in the face of the emerging crisis, to ignore its seriousness, or to dismiss its impact would be foolhardy and irresponsible. It is time for governmental, non-governmental and commercial agencies to tackle the educational, behavioural, nutritional and public-health issues that are driving the diabetes epidemic.

To dismiss the impact of the diabetes epidemic would be irresponsible.

The ‘Unite for Diabetes’ campaign seeks a UN Resolution on diabetes to be proclaimed on World Diabetes Day (November 14) 2007.

A UN Resolution on diabetes
An increased focus on diabetes by the global community has the potential to change the face of the disease. But reversing the current trend is not just a health issue. In order to tackle the global diabetes epidemic it will be necessary to take action that goes beyond the scope of national healthcare authorities or even single states. It will require a whole-of-government approach and the attention of the international community. A UN Resolution on diabetes will raise awareness among policy decision-makers of the global public health challenge at their door.

But the declaration of the Resolution itself will be ‘just the beginning’; the outcomes will include:
- increased global awareness of diabetes
- greater recognition of the human, social and economic
A UN Resolution on diabetes will help to improve access to life-saving insulin for children with diabetes in low-income countries.

- burden of diabetes
- the repositioning of diabetes as a health priority in individual nations
- the implementation of cost-effective strategies to prevent diabetes complications
- affordable public-health strategies for the prevention of diabetes itself
- recognition of ‘special needs’ groups (children, pregnant women, elderly people, indigenous groups, migrant populations from developing nations)
- increased research towards a cure.

**Working towards a Resolution**

A UN Resolution requires the support of at least one UN Member State as a sponsoring country. This country will draft the Resolution. The proposed Resolution then requires 45 supporting UN Member States to act as signatories. It will then be tabled as an agenda item for discussion at the UN General Assembly and dealt with by the Assembly’s Third Committee, which convenes to discuss matters related to humanitarian issues and health. If there is enough support for the Resolution at this point, it can be passed without the need for a vote in the General Assembly. Otherwise a formal majority vote of the UN’s 191 Member States would be required.

**A dual approach**

The strategy to ensure sufficient support for the Resolution combines a top-down approach and a bottom-up approach. The top-down approach seeks to use diplomatic means to address each UN Member State and secure a majority vote in the General Assembly or a consensus vote in the Third Committee.
The diplomatic efforts have already yielded results: support for attaining a UN Resolution on diabetes is widespread and a number of strategically important countries have expressed their interest in supporting the Resolution. One country recently translated its support into a commitment to act as sponsoring Member State for the Resolution. Appeals are being made to others to formally join the initiative.

We are engaged in an awareness-raising campaign that will reach one billion people worldwide.

The bottom-up approach consists of an awareness-raising campaign that will reach one billion people worldwide and draw attention to the seriousness of diabetes, its complications and the need for a UN Resolution to reverse the growing diabetes epidemic. This bottom-up approach will work through existing diabetes networks and the global media.

At international level, governments are urged to join the ‘Unite for Diabetes’ campaign by publicly declaring their support for the UN Resolution on diabetes, thereby recognizing the human, social and economic burden of the disease, particularly on low- and middle-income countries. At regional level, governments are encouraged to take concerted action with other like-minded states to build up strong regional alliances to combat the diabetes epidemic and improve diabetes care.

A blue circle of life
The ‘Unite for Diabetes’ campaign, the most significant global diabetes awareness campaign ever undertaken, will be represented by a simple blue circle. The icon, which is designed to be easily adapted and widely adopted, represents unity in diabetes and symbolizes support for the campaign for a UN Resolution.

The significance of the circle is overwhelmingly positive. Across cultures, the circle can symbolize life, mother earth and health. Most significantly for the campaign, the circle symbolizes unity. Our combined strength is the key element that makes this campaign so special.

The blue border of the circle reflects the colour of the flag of the UN – in itself a symbol of unity amongst nations. Indeed, the UN is the only organization that can signal to governments everywhere that it is time to fight diabetes and reverse the global trends that will impede economic development and cause so much suffering and premature death.

Our combined strength makes this campaign so special.

Inform, motivate, mobilize
A critical factor in our success will be communications. IDF will inform, motivate and mobilize the global diabetes community in the campaign for the UN Resolution itself, and target the general media soon thereafter. Press kits and advocacy kits have been produced and are available for organizations wishing to join the global campaign. Visit the IDF UN Resolution website, www.unitefordiabetes.org, and find out what you can do to support the campaign.

Through public debate, the media and educational campaigns, awareness of the seriousness of diabetes and its complications can be raised among civil society. IDF calls on everyone to unite for diabetes and join the campaign to secure a UN Resolution on diabetes that will provoke multi-governmental action to improve the prevention and treatment of diabetes and inspire medical science in its quest for a cure.

Martin Silink
Martin Silink is Professor of Paediatric Endocrinology at the University of Sydney and the Children’s Hospital Westmead, Australia. He is President-Elect of IDF and leads the campaign for a UN Resolution on diabetes.
Migration and diabetes: 

the emerging challenge

Manuel Carballo and Frederik Siem

Diabetes is affecting more and more people every year. In the last decade, the number of people diagnosed with diabetes of one kind or another increased by almost 50%. By the year 2025, more than 300 million people around the world could have been diagnosed with the condition. Many others who have diabetes will not have been diagnosed. Diabetes also represents a major threat to the health of the world’s millions of migrants, who appear to be at greater risk of developing diabetes than non-migrants. Manuel Carballo and Frederik Siem report.

Diabetes is a major health threat to people moving around the world.

Stress, sadness and immigration policies

Whether it is the forced movement of refugees and internally displaced people, or the movement of people looking for work and a better way of life, migration is always stressful. Some scientists believe that this is one of the key factors behind diabetes among migrants. Migration involves uprooting, leaving behind family and friends, moving under conditions that are psychosocially and physically difficult, and facing the realities of re-settlement in surroundings that may seem unwelcoming.

Part of the problem faced by migrants and refugees today is that migration

In the past, diabetes was considered a problem of developed countries; this is clearly no longer the case. People in developing countries and countries in transition are also very much at risk of developing diabetes. In 2003, 35.5 million were diagnosed with the condition in India – more than twice as many as in the USA in the same year. In China there were around 23.8 million people with diabetes. For the hundreds of millions of people moving around the world every year, diabetes also represents a major health threat. In Australia, the Netherlands, Norway, the UK, and the USA, studies suggest that migrants may often be more likely to develop diabetes than non-migrants. Why this should be so calls for more research; so do the questions as to whether and how migrants are able to get the care and treatment they need if they do develop diabetes.
policies are designed to make it difficult for couples and their children to move together. In the case of economic migrants, countries often insist that the person seeking work must migrate alone. This can oblige men to travel by themselves, leaving their partners and children behind. In other cases, women may be forced to leave their families behind.

Not surprisingly, research finds that one of the most common problems faced by migrants and refugees is chronic homesickness and sadness.\(^3\) Not only do they miss relatives and friends, but sometimes they are not even able to stay in contact with people in their home country. Refugees often do not know what has become of their families. Some studies report that migrants and refugees often feel that their health has worsened after arriving in a new country.\(^3\)

It is essential that the training of healthcare practitioners take into account the health of migrants.

Coping with the stress of migration and resettlement can take many forms. High consumption of alcohol and other addictive substances, such as tobacco, is one of the ways some people worldwide deal with difficult situations – migrants are no exception. The over-consumption of food is also a way in which many people deal with stress, and migrants who find themselves with a little more money than they were previously used to may be tempted to spend this on cheap food. Indeed, adapting to new eating habits and foodstuffs is always a problem for migrants and a potential risk factor for diabetes.

New eating habits and foodstuffs represent a potential risk factor for diabetes in migrants.

When migrants arrive in a country, they have to quickly become accustomed to new diets and new foods. Sometimes, the foods that are available and affordable contain more fat and less fibre than migrants were used to in their home countries – increasing the risk of obesity.

Another food-related problem is that when people move to other countries in search of work or safety from persecution, they often use food to prove to themselves and others that they are succeeding. This often means over-consuming poor quality food and over-feeding children. In situations like these, the potential for problems of obesity and diabetes is high.

Language and beliefs
No matter where people come from – or where they go – they take with them any inherited pre-disposing
disease factors. In some cases, people might come from backgrounds where the genetic risk of diabetes was high or where eating habits put people at risk of the condition.

Migrants also bring with them their traditional beliefs about health and disease. They may come from cultures and countries where most people never had access to good healthcare and where over the years they became used to not seeking care when they felt unwell; or believing that illness and disease are products of fate and not something that could be or should be prevented or mitigated.

Language represents an added problem for migrants, especially when they have health problems. People may have difficulty finding the words to express their symptoms and be unable to talk comfortably with healthcare providers. This is especially true if migrants come from cultures in which people do not easily discuss personal problems and – in the case of women – are not used to being examined by someone with whom they are unfamiliar.

Language difficulties and embarrassment at not being able to communicate effectively can lead to migrants choosing to ignore their problems. This can lead also to impatience on the part of healthcare personnel faced with migrants they cannot understand and who appear not to pay attention to what they are being asked or told.

In such situations, health problems are easily overlooked or misdiagnosed.

When the health problems of migrants are correctly diagnosed, problems related to cultural background and beliefs may persist. There may be different attitudes to chronic disorders and long-term care which can pose problems of adherence and effective follow-up. Particularly in the case of diabetes, it is important that people with the condition, their family and friends, and the healthcare team share a common understanding of the nature of the condition and its effective management.

**Migration is a key part of our collective social and economic development.**

**Planning, education and research**

Migration has become a key part of our collective social and economic development. It is essential that the design of healthcare services and the training of healthcare practitioners take into account the health of migrants and the challenges posed by conditions such as diabetes. It is also essential to work with migrants to ensure that they are aware of the types of care that are available and any other options open to them to protect their health.

Given the growing prevalence of diabetes worldwide, and the apparently high rate of diabetes in migrant populations, time should not be lost. At the International Centre for Migration and Health (ICMH), we are taking up this theme. This year, ICMH will begin a study of diabetes among migrants in 11 European countries and Canada. The study should provide new insights that healthcare planners, healthcare practitioners, migrants and the general public will be able to use in fighting diabetes and ensuring quality of life for all.

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Indigenous people are marginalized wherever they live. The holders of grim records as victims of discrimination and human rights violations, they fare poorly in assessments of economic, social, educational, or health status – whatever indicators are applied. For the most part, indigenous groups live without political influence or representation; they generally are unable to influence their overall economic situation, education or healthcare.

Diabetes: an invisible killer
Overall, the health of indigenous people is poor. Appropriate health services for indigenous communities are widely lacking – if available at all. As a result, large numbers of indigenous people all over the world are suffering disproportionately from diabetes. The severity of this situation has been repeatedly brought to the attention of governments and UN agencies.

Precise figures for the prevalence of diabetes among indigenous communities are not available; governments rarely possess – or in some cases are unwilling to provide – health statistics.
on indigenous groups. But the available data indicate that in most areas the numbers are alarming, and that, while it often goes undiagnosed, diabetes is a major killer among indigenous communities – and the threat is growing.

**Record levels**

The number of people with diabetes has reached record levels in many areas, including the Pacific. Among the Torres Strait Islanders of Australia, no less than 44% of the population has diabetes. On the Pacific island of Nauru, the latest figures indicate that 28% of people have diabetes – 22% on Tonga. The threat from diabetes looks to be equally severe among Native North Americans, Inuit people of the Canadian Arctic and Greenland, and indigenous people in the Philippines and elsewhere in Asia.

**Among the Torres Strait Islanders of Australia, 44% of the population has diabetes.**

Whenever new data become available, they confirm the seriousness of this situation. But most indigenous people around the world are never diagnosed; they never receive treatment for their diabetes and die from the condition without knowing the reason for their suffering. There is clearly an urgent need for the World Health Organization (WHO) and government bodies to address the health status of indigenous people. Programmes must be designed and implemented to stem the growth of the diabetes epidemic and prevent the consequent rise in death and disability among these already vulnerable communities.

**Indigenous initiatives**

Over the past 40 years, the Pacific Islanders have experienced a steady and consistent erosion of their food security. The resulting reliance on imported food has brought with it an alarming rise in rates of non-communicable diseases, especially diet-related conditions like obesity and type 2 diabetes.1

Tonga is a particularly extreme example. Over the past 20 years, the consumption of imported high-fat meats including sausage, mutton flaps (the loose piece of fatty meat from the end of a chop – previously processed into fertilizer), chicken parts and corned beef increased dramatically, amounting to some 56 kg per person per year by 1999.2 The story is the same throughout the Pacific.

In response, a number of indigenous groups are taking steps to change their situation. There are examples among Pacific Islanders of successful initiatives to return to traditional models for the cultivation and consumption of low-energy foods in order to reduce the obesity-driven diabetes epidemic. The government of the island of Vanuatu has made a commitment not to become a ‘dumping ground for food that has very low nutritional value’; Fiji has announced a ban on importing mutton flaps from New Zealand because of the proven links with obesity.

**Key to prevention – engaging the people**

It is vitally important that health organizations like IDF and WHO, governments, development agencies, health planners and healthcare professionals realize that the effective prevention of diabetes depends on the...
active participation of the indigenous people themselves. In order to achieve this, indigenous people must be engaged within the parameters of their own understanding of the cause and nature of the condition.

Synergies should be sought between the alternative understandings of health and illness held by indigenous communities. Traditional knowledge of the constitution and workings of the human body, and hence the ways in which these should be addressed and treated, are not entirely incompatible with modern approaches. Indigenous concepts of health are holistic. In this sense they reflect the approach to preventing diabetes that is promoted by many diabetologists and groups like IDF.

Indigenous concepts of health reflect the modern holistic approach to preventing diabetes.

But people’s perceptions of the workings of the body may differ greatly from that of modern medicine. These perceptions will influence the way in which explanations of appropriate treatments are received. It is necessary to take these traditional ideas and beliefs into account in order to develop practices that are culturally sensitive and thus acceptable. Too little is known, for example, of how diabetes – once people become aware of its impact on health – and the proper treatment of the condition are perceived by indigenous people.

Presumably, given that people with diabetes display a set of symptoms that do not easily gel into a single diagnosis, many groups do not have traditional terms for the condition. Without doubt though, indigenous people who are in contact with modern medical services are increasingly aware that diabetes is a major risk to the health of their community.

A common struggle
Indigenous people and their fight for basic human rights – such as adequate healthcare, decent living conditions, and education – in accordance with their cultural traditions and wishes should concern us all. In many parts of the world, the economic and health status of indigenous people is critically low. Indigenous communities are the object of systematic discrimination and exclusion from political and economic power. Indeed, according to all indicators, they are the poorest, the least educated, and have an appalling health record.

Indigenous communities are systematically excluded from political and economic power.

Indigenous communities continue to suffer displacement from their land, often evicted ‘legally’ by developers, or driven out of their homes by wars and environmental disasters. Generations of indigenous people have been forcibly prevented from continuing their centuries-old way of life and given little or no choice in terms of the lifestyle and diet currently available to them.

In response, the establishment of the UN Permanent Forum on Indigenous Issues was a major political achievement. The first meeting of the Permanent Forum in New York, USA, in May 2002 involved nearly 1000 delegates from indigenous communities from around the world. It represented a milestone in a century-long struggle for recognition. In a UN context, the Permanent Forum reports directly to the Economic and Social Council, and its wider mandate is to advise UN agencies and organizations like WHO and the World Bank on all issues concerning indigenous people – including health.

The support of groups like IDF will be important in persuading governments – and the societies they represent – to recognize the problem of diabetes among indigenous people and meet their responsibility to treat all citizens equally in terms of access to adequate healthcare and a preventive lifestyle.

Ida Nicolaisen
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References
Information bias:
why it happens and how to avoid it

As patients, many of us assume that we are receiving the best possible treatment for any medical condition we may have – people with diabetes are no exception. However, with an increasing emphasis on empowerment and choice, many of us are no longer prepared to simply assume that the treatment we are offered is the best available. For others, doubts arise when a treatment seems ineffective or there are adverse effects. Is the prescribed treatment the most suitable? Are there alternative treatments that might be more successful? Both patients and physicians need reliable sources of information. But how reliable is research as a source of information to inform our decision making? Jenny Hirst reports.

One trial does not provide sufficient information upon which to base treatment decisions. It is essential to look for systematic reviews of all the clinical trials of a particular treatment – hence the importance of the Cochrane Collaboration and the Cochrane reviews of many topics, including aspects of diabetes treatment. Protocols for Cochrane reviews and the completed reviews themselves are published in electronic form. These can be criticized publicly – and amended if necessary – and are regularly updated to take into account any new studies.

The Cochrane reviews
The reviews draw conclusions from clinical trials after the likely reliability of each has been assessed. For example, the Cochrane review comparing human and animal insulins did not find any clinically relevant differences in the effects of the two types, including the profiles of their adverse effects. However, the reviewers pointed out that the studies were of poor methodological quality. At first glance, this review may appear to be unhelpful in informing treatment decisions; in fact, it informs us that no important advantages of human insulins have been demonstrated which might justify their wide promotion by industry as superior to the animal insulins – with their long history of safety and efficacy.
Closing the information gaps

Systematic reviews such as those published by the Cochrane Collaboration help to identify important questions that are left unanswered – or unasked – by researchers, leaving gaps in evidence which bias the information received by patients and clinicians. The Cochrane Collaboration (www.cochrane.org) is an independent non-profit organization that works to make available worldwide up-to-date, accurate information about the effects of healthcare. It produces and disseminates systematic reviews of healthcare interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions. Founded in 1993, the Cochrane Collaboration was named after the British epidemiologist, Archie Cochrane.

Unfortunately, industry-funded research focuses on the short-term assessment of outcomes that will be adequate to secure the marketing licence necessary for a new drug. These outcome measures are not necessarily the same as those considered essential by patients and clinicians.

Vested interests

This situation has not improved over time. A later review of short-acting insulin analogues indicates that these have minor benefits in small numbers of people, but that their long-term effects have not been investigated. The need to investigate whether or not they might have an increased potential to promote cancer has been raised.

It has been estimated that the pharmaceutical industry spends over 10 billion USD per year on funding for around 90% of the 40 000 to 80 000 RCTs being conducted around the world at any given time. That such a high proportion of RCTs is funded by industry is of concern. Industry has a vested interest: the trials focus on patentable and therefore profitable drugs.

These concerns exist in the treatment of diabetes. Insulin analogues are an example. The Cochrane review of short-acting insulin analogues showed that 81% of the studies were sponsored by the manufacturers of insulin analogues. Furthermore, as sponsors were not declared for the remaining studies, the percentage could have been even higher. We simply do not know whether independent, methodologically sound studies – with the involvement of patients in the design and choice of outcome measures – would have come to the same conclusions.

Publication bias

While Cochrane and other systematic reviews are a trustworthy source of information, their reliability depends on the inclusion of all of the trials carried out into a specific topic. This includes both published and unpublished studies — not all are published. Those which remain unpublished are often the studies that yielded disappointing results: no benefits, adverse effects or poorer outcomes than with existing standard treatments.

Industry has much to gain by the selective publication of positive studies.

Clearly, this publication bias may distort the evidence that is available for review. Despite the importance of publishing all trials, industry-funded studies with negative results may not be submitted for publication because the industry has much to gain through the selective publication of positive data – presenting their new drugs in the best possible light.

Not publishing negative studies is the most obvious cause of publication bias. In 1980, the study reports that were submitted to the drug licensing
authorities by pharmaceutical companies were compared with subsequently published reports of the same studies. It was found that studies in which the pre-licensing records showed that researchers had looked for adverse effects were less likely to be published than studies in which adverse effects had not been sought.

In 2003, a study using similar methods described the over-reporting and under-reporting of industry studies of new drugs. It concluded that any attempt to develop treatment recommendations using analyses based only on publicly available data were likely to be derived from biased evidence.

**Recommendations based only on publicly available data are likely to be derived from biased evidence.**

In an important analysis of RCTs of treatments for ovarian cancer, published in 1986, an Australian oncologist demonstrated that the failure to make public all the data from clinical trials could lead to unwarranted inferences about the effects of treatments. It is essential that the problem of the under-reporting of clinical trials is addressed in order to provide greater openness and create opportunities for scientific debate – and thus prevent harm to patients.

**Misconduct and responsibility**

In 1990, an article was published with the provocative title 'Underreporting Research is Scientific Misconduct'. It suggested that failing to report clinical trials broke an implicit contract with the people who had participated in the trials, and reiterated the call for the registration of trials at inception.

Biased under-reporting of research can harm patients.

It is clear that the biased under-reporting of research may lead to harm, and sometimes death, as in the case of drugs to suppress heart rhythm abnormalities during heart attack. We now know that the adverse effects of these drugs killed tens of thousands of patients, and that warning of their lethal effects could have emerged many years before it did had the results of all clinical trials been published. How many unpublished clinical trials to which people with diabetes have contributed remain unpublished in spite of the fact that they contain relevant information?

The undoubted responsibility of researchers is to patients. Although clinicians are involved in the current preponderance of industry-sponsored research, their responsibility is to ensure that the information received by patients is as unbiased as possible. Thus, while acknowledging that part of the industry’s agenda is to keep their shareholders happy, it is vital that all trials are registered from inception, and that their results are published. All trials must contribute to the evidence upon which treatment decisions can confidently be based.

**Jenny Hirst**

Jenny Hirst is co-Chairman of the Insulin Dependent Diabetes Trust. UK.

**Acknowledgement**

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**Diabetes Voice**

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The International Alliance of Patients’ Organizations (IAPO) is a global coalition of patient groups, representing people of all nationalities and across all disease areas, which promotes patient-centred healthcare. The members of IAPO are organizations that at the local, national, regional and international levels support patients and their families and carers. Emma Rigby describes the objectives, work and achievements of IAPO, and focuses on the promotion of patient-centred healthcare – a central aspect of the Alliance’s mission and an example of the way in which IAPO makes international policy-makers aware of patient issues.

Increasingly, important healthcare issues are crossing geographical and disease boundaries. Non-communicable health conditions, such as obesity-driven type 2 diabetes – once considered a disease of the wealthy world – have reached epidemic levels in many developing countries. Around the world, research findings suggest links between diabetes and disorders like Alzheimer’s disease, celiac disease, stress and depression.

It is vital, therefore, that the various patient-representative organizations that cross these same boundaries work together for improvements in healthcare worldwide. When IAPO was formed in the mid-1990s, one of its founding principles was that messages that are broadcast by a chorus of united voices are more likely to effectively reach and influence healthcare policy-makers.

Messages from a chorus of united voices are likely to reach and influence healthcare policy-makers.

One voice – universal issues
During the 1990s, patient representatives from around the world met at a number of conferences. It emerged that people frequently face the same issues, no matter where they live or which health condition they are affected by. Most patient groups rightly focus their efforts on a specific disease area. But issues such as access to adequate treatment, and reliable and comprehensible information are basic rights that are universally relevant. In
order to create a strong voice that is capable of defending these basic rights across disease areas and continents, a number of organizations established a permanent international coalition. Since IAPO was officially registered as a non-profit organization – in the Netherlands – in 1999, the Alliance has gone from strength to strength – approximately 175 members representing an estimated 365 million people.

When organizations are linked, opportunities arise to share ideas, best practices, and resources. It is a principal belief of IAPO that patients throughout the world should be at the centre of healthcare. IAPO promotes this by building active partnerships with patient organizations, ensuring them a global voice, and bringing together like-minded medical and health professionals, policy-makers, academics, researchers and industry representatives.

IAPO’s current policy work includes drafting briefing papers on emerging issues. One of these – of particular relevance to people with diabetes – focuses on biosimilar medicines. Some companies have started manufacturing copies of biological medicines, including insulins, for which the duration of the initial patent is limited. IAPO looks at regulatory issues and discusses the role of patients in decision making – with a particular focus on safety and quality. The Alliance has a valuable role in the provision of information on emerging technologies to patient organizations so that these can participate in policy dialogues and share knowledge with the people they support and represent.

**The centre of care**

Working towards patient-centred healthcare is central to IAPO’s overall mission. In February 2006, following significant research and consultation, IAPO launched its Declaration on Patient-Centred Healthcare. Representing the first globally accepted definition of patient-centred healthcare,
**Biosimilar medicines** are follow-on versions of original biological medicines, which are produced using a living system or organism. Biosimilar medicines are independently developed after the patent protecting the original product has expired. Biosimilar medicines are intended to have the same action as the original biological medicines, and are designed to treat the same condition.

The Declaration was developed by the global patients’ movement. It is the firm belief of IAPO that advocacy of the five principles underpinning the Declaration will result in healthcare in which people are kept at the centre of decision making. These principles are:
- respect
- choice and empowerment
- involvement in health policy
- access and support
- information.

**Cost-effective healthcare**
Healthcare systems around the world are under considerable financial pressure. Many simply will not be able to cope if their focus is maintained on diseases rather than people. These systems require individuals to adhere to treatments, make behavioural changes and self-manage their health condition. There is growing evidence that a patient-centred approach leads to greater levels of individual responsibility and optimal usage of resources, which in turn lead to improvements in health outcomes and quality of care. These improvements reflect an optimal return for healthcare investment and suggest that patient-centred healthcare may be the most cost-effective way to improve health outcomes.

**A global remit**
The work of IAPO encompasses issues that are important in a range of socio-economic settings. In developing countries, there is a worrying lack of adequate information for healthcare providers and the people in their care. It is imperative that patient organizations make a constructive and meaningful contribution to global efforts to address this problem. Organizations such as the Community Health and Information Network (CHAIN) in Uganda continue to make this contribution; under the umbrella of IAPO, the work done by CHAIN is enhanced by input from groups outside Uganda facing the same issues, and vice-versa.

In developed countries, organizations such as Best Medicines Coalition in Canada have found a means through IAPO to pursue on a global stage their commitment to respect for people’s healthcare needs. The Coalition advocates patient-centred healthcare by empowering people to make informed choices based on relevant and adequate information about care and treatment options.

IAPO’s key tasks currently include publicizing the Declaration on Patient-Centred Healthcare and highlighting the importance of its messages. IAPO is calling for the support and collaboration of patients, policy-makers, healthcare providers, and health-related industries to endorse the principles outlined above and make these the centre of their policies and practice.

**An open invitation**
The Alliance welcomes examples from individuals and organizations of effective patient-centred healthcare. In this way, the patient’s voice can be brought directly to the individuals and organizations that take decisions on our behalf (see website details below).

IAPO has developed a number of communications tools in order to support the global drive to raise awareness of patients’ rights. A website provides information about patient issues and the objectives and achievements of IAPO; a monthly e-newsletter updates stakeholders on key initiatives. Membership is open to organizations — not individuals. But any group that is led by patients and meets our membership requirements can become an IAPO member.

**Emma Rigby**
Emma Rigby is IAPO Capacity-building Director.

For more information about IAPO, visit [www.patientsorganizations.org](http://www.patientsorganizations.org)

The Declaration on Patient-Centred Healthcare can be read in full at [www.patientsorganizations.org/pchreview](http://www.patientsorganizations.org/pchreview)

**Reference**
From practice and research
to large-scale implementation:
the 3rd DAWN summit

The Diabetes Attitudes Wishes and Needs (DAWN) programme was launched in 2001 with the global DAWN study. Initiated by Novo Nordisk in partnership with the International Diabetes Federation (IDF) and an international expert advisory board, the DAWN programme aims to respond to shortcomings in diabetes care; less than half of the people who are diagnosed with diabetes worldwide reach optimal health and quality of life. The 3rd DAWN summit, which was held recently in Florence, Italy, gathered 900 experts, people with diabetes, policy-makers and professionals from 64 countries to set the stage for large-scale initiatives to improve treatment outcomes through patient-centred self-management and psychosocial support strategies.

The objective of the DAWN study in 2001 was to explore the many non-medical barriers to improving the health and quality of life of people with diabetes. The findings exposed the gap that exists between the psychosocial and self-management challenges of living with the condition and the available healthcare resources – even in advanced and well resourced settings.

The first two DAWN summits, held in 2002 and 2003 in the UK, were key components in the programme’s role as catalyst for a practical worldwide response. At the 2nd DAWN summit, which brought together leaders in the field of diabetes and organizations from 31 countries, the worldwide DAWN call to action was made: to put the people behind the condition at the centre of care (see Diabetes Voice Special Issue 2004).

The 3rd DAWN summit
The focus of the 3rd DAWN summit, held in Florence, Italy, in April 2006, was on setting the stage for the implementation of practical and research-oriented initiatives. The aim of the meeting was to review the progress to date in implementing the DAWN call to action, share best practices, build networks and partnerships, showcase practical solutions and strategies and present new initiatives.

The meeting opened with the announcement of a national Novo Nordisk DAWN initiative in Italy, which will be overseen by the Italian Ministry of Health. Novo Nordisk also
announced its commitment to a new global DAWN initiative in partnership with IDF and the International Society for Pediatric and Adolescent Diabetes to be focused on youth worldwide with all types of diabetes.

A panel of experts from around the world discussed regional progress, successful models and future priorities for improving patient-centred diabetes care. The results of a 2006 DAWN Expert Survey covering 18 countries revealed that despite positive developments in many countries, the majority of people with diabetes do not receive optimal care. There was wide agreement on the need to call for further international support for the large-scale implementation of the DAWN call to action and further definition of the elements of patient-centred care.

Communication, dialogue and advocacy — central to improving the treatment and quality of life of people with diabetes — were highlighted throughout the meeting. For healthcare providers, self-reflection and coaching by peers was considered key elements in adopting new and effective ways of facilitating patient autonomy. People with the condition were encouraged to act as diabetes ‘ambassadors’ and active agents for change, sharing their experiences with peers, healthcare providers and the community at large to the benefit of all. Several initiatives to enhance communication, dialogue and advocacy were introduced during the event.

Tools for supporting action
A number of tools and systems have been developed to facilitate the delivery of therapeutic diabetes education and psychosocial care. Tools to facilitate patient self-determination and the quick identification of individual treatment needs were among those presented, as well as integrated satellite, internet, and mobile phone systems.

The DAWN Monitoring Individual Needs of People with Diabetes (MIND) research programme was introduced in Florence. The DAWN MIND protocol supports people with diabetes and their carers in addressing the psychosocial obstacles that arise in the development of individual care plans and promotes personal involvement in the care process.

In communities where there are high levels of illiteracy, the use of illustrations in didactic material can support the education and thus the empowerment of people with diabetes. The winner of the 2005 DAWN International Award is a fine example. Assistance to Youngsters with Diabetes in Egypt enhances the health and quality of life of children with diabetes through the provision of structured therapeutic health education and carefully developed illustrated booklets (see Diabetes Voice, June 2005).

Several IT systems and computer programs were displayed at the conference, which aim to facilitate the systematic use of DAWN questionnaires in daily diabetes care. The inclusion of DAWN tools in diabetes ‘passports’ was another example of various country-wide initiatives. The successful tools that were submitted by conference delegates will be disseminated through future DAWN events and publications.
Enhancing communication
About half of the 900 delegates reported receiving training in patient-centred care. However, few had received feedback on their own consultation techniques. Such feedback is effective in promoting self-awareness and reflection – essential for sustained behaviour change. Team workshops were proposed as a key way to implement the DAWN call to action locally.

Coaching in counselling skills for healthcare providers should begin already in medical school and examples of use of the DAWN study in curricula in medical schools were highlighted. Coaching in self-management for people with diabetes is perhaps one of the most critical aspects of diabetes education. A new DAWN initiative in the USA was introduced where people with diabetes are trained to coach other people with diabetes to maximize outcome of their visits with their doctors.

Influencing the decision-makers
In a world of competing healthcare agendas and contrasting social and economic priorities, convincing governments to address diabetes is a major challenge. Of the 200 or so countries in the world, less than 10 have national guidelines with clear recommendations on psychosocial diabetes care. Even where these guidelines exist, there is no guarantee that practice reflects theory; political support and investment in resources are essential.

Initiatives are underway in the EU, Eastern Europe and globally – at the UN – which provide an opportunity to highlight the human burden of the disease. A practical framework was described in Florence to raise the political profile of an issue such as the need for changing how we care for diabetes:

- clearly define the urgency of the problem
- demonstrate a feasible, valid policy solution
- scan the broad political environment to effectively address the politics of the issue.

The UK and Germany were two examples of countries that have adopted patient-centred evidence-based guidelines. The continued involvement of all stakeholders through a common vision is vital to the successful implementation of such national guidelines.

Teamwork
The importance of partnership was stressed throughout the conference. Effective partnerships should be sought at all levels: from the unions of people with diabetes and their care teams, to the concerted efforts of a wide range of stakeholders in developing evidence-based, appropriate and updated guidelines.

Disparities affecting health
There is a growing focus on the health disparities that exist between regions and countries. In some parts of Africa, insulin is available only 22% of the time; in the Eastern Mediterranean and the Middle East, 33% of the population accounts for 85% of health expenditure. These discrepancies also exist within national boarders – among minority populations, such as elderly people or immigrant groups.

Financial restraints represent only one of the core problems. But disparities in care do not arise due to economics alone; factors such as illiteracy, stress and a lack of access to culturally sensitive support often conspire to interfere with people’s ability to self-manage their diabetes.

The DAWN Award 2006 was announced to reward new promising initiatives to support people in disadvantaged minority populations to better manage their condition with available resources (see News in brief page 7).

Global problems, local solutions
The IDF-led campaign for a UN Resolution on diabetes, which is supported by key organizations around the world, aims to send a clear signal that diabetes affects around a billion people worldwide – a situation that will deteriorate unless appropriate steps are taken. Delegates at the DAWN summit saw many examples of effective advocacy resulting from the gathering of stakeholders from all parts of the world and from all walks of life.

The DAWN journey towards better health and quality of life for all people with diabetes has just begun; we have a long road ahead. The majority of the summit delegates concurred that the level of self-management support and psychosocial care received by people in their region was on average ‘minimal’. But major progress is being made. There was agreement on the need to include well-being as an additional indicator of the quality of care, and the importance of improving self-management and psychosocial support to reduce the economic and human burden of the condition.

The DAWN International Expert Advisory Board
According to the International Diabetes Federation (IDF), Pakistan had 6.2 million people with diabetes in 2003. By 2025 this number is expected to reach 11.6 million. Another 6 million or more people currently suffer from impaired glucose tolerance. This makes the diabetes population in Pakistan the seventh largest in the world and, if the predictions are accurate, it will take fourth place by 2025. In Pakistan, deaths from diabetes alone are projected to increase by 51% over the next 10 years. These figures make diabetes an epidemic – one which places an enormous burden on our healthcare systems and societies.

The above situation is compounded by socio-economic factors: 30% of Pakistan’s population lives below the poverty line and half of the population is deprived of basic living necessities. Furthermore, low government investment in healthcare (0.7% of GDP) and the scarcity of healthcare services (one doctor per 1450 people, one nurse for 3300) conspire to worsen access to healthcare. The enormous direct and indirect economic burden of diabetes pushes into poverty families that were not initially poor.

These alarming circumstances call for immediate action. According to the World Health Organization, an annual reduction of 2% in chronic disease death rates in Pakistan would give rise to an economic gain of 1 billion USD over the next 10 years.

In order to explore new possibilities in diabetes management and provide a platform for the exchange of information on recent diabetes-related advances and research, an international conference was held recently in Karachi, Pakistan.

An annual 2% reduction in chronic disease deaths in Pakistan would save 1 billion USD over 10 years.

The meeting aimed to provide an innovative and comprehensive overview...
of the latest developments in the field, and to share practical information on diabetes care, advocacy and awareness. The scientific programme was kept to the highest standards in order to give all delegates the opportunity to exchange opinions with experts and scientists from all over the world.

The conference concentrated on two of the IDF World Diabetes Day themes: diabetes and foot care (2005), and the current theme, diabetes in the vulnerable and the disadvantaged. The 2006 campaign was officially launched at a press conference during the meeting in Karachi.

The meeting aimed to share practical information on diabetes care, advocacy and awareness.

Further aims of the conference included:
- to discuss strategies and measures to cope with the very high and rapidly increasing incidence of diabetes in low-resource and underserved communities
- to work out strategies for developing a country-wide network of diabetes centers
- to develop and evaluate measures to prevent and reduce foot complications in people with diabetes and thus curtail the high incidence of amputations
- to highlight the significance of primary prevention programmes and discuss their design and implementation
- to review the status of diabetes care in Pakistan
- to engage national and international media in order to enhance public awareness of diabetes.

The conference attracted international experts in diabetes. Speakers included leading figures in diabetes care from various countries; 40 national speakers participated in the conference. More than 1000 delegates from Pakistan and abroad were in attendance.

World Diabetes Day campaign material was extensively reported by the local, national and international media.

This meeting was an important event, not only for the advancement of diabetes care in Pakistan, but also as the launch pad for this year’s World Diabetes Day campaign. The material delivered at the press conference launch was extensively reported by the local, national and international media. The national and international significance of the theme was fully recognized in the press.

Those concerned with diabetes prevention and care in Pakistan and the international contributors to the conference are indebted to the organizers for a landmark event.

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At Novo Nordisk, we’re proud of the insulin therapies and delivery systems we’ve developed — and continue to develop — because those innovations make life better for millions of people around the world. But people with diabetes need more than medicine and needles. They need the guidance and support to take control of their own care.

That’s why we pioneered DAWN, an initiative to promote the treatment of psychosocial issues and empower people with diabetes in the management of their own care. We also sponsor Nurse Dialogue events worldwide, where tools, therapies and education are shared in open forums. Addressing the needs of the person behind the disease, combined with proper medicines, support and education, are the cornerstones of effective diabetes treatment. By taking a leadership role in all these areas, we hope to change the way we all care for diabetes.