

African diabetes leadership forum calls for activism around non-communicable diseases

Contributions by: Prof WF Mollentze, Dr JMM Koning, University of the Free State, Bloemfontein, Peter Wagenaar

The Diabetes Leadership Forum Africa 2010, which took place in Johannesburg at the end of September, highlighted the urgent need to address the burden of diabetes and other non-communicable diseases (NCDs) in the developing world. To date, NCDs have been overshadowed by the perceived more urgent priority of addressing infectious diseases such as HIV/AIDS, tuberculosis (TB) and malaria. **Sir George Alleyne, director emeritus of the Pan American Health Organisation**, called for an activist mentality to be brought to the fight, as had been the case with HIV/AIDS as well as non-health-related issues such as the civil rights movement in the USA. 'We should introduce a "fear factor" to stimulate some much-needed public hysteria. We also need a surge of commitment to knock on political doors, especially now that those doors are open with the UN summit on non-communicable diseases due to take place next September', he said.

Prof Pierre Lefebvre, chairman of the World Diabetes Federation, warned that the current diabetes pandemic has been described in some quarters as a tsunami. 'The comparison is sound insofar as diabetes also has devastating effects in terms of death and disability. Unlike a tsunami, however, it is not sudden or unpredictable – and has been slowly developing for half a century. The wave is still growing and it's projected that by 2030, in the region of 910 000 000 people worldwide – more than 15% of the adult population – will be living with diabetes and impaired glucose tolerance (IGT). We need to join forces to contain the tsunami.' Prof Lefebvre proposed a 'new Einstein formula' to help achieve this: $e = m \times c^2$ – where e = excellence, m = money/manpower and c = commitment.

Lise Kingo, sponsors of the Forum, observed that it is estimated there are currently 12 million diabetics in sub-Saharan Africa – and only 15% of them are diagnosed. South African health minister, Dr Aaron Motsoaledi underscored that in Africa, most cases remain undetected, with the result that Africans die of diabetes and other NCDs at twice the rate of their counterparts in the developed world. 'Africa is set to experience the greatest increase in NCDs in the coming decade, with a projected rise as high as 24%', he said. 'A particular challenge is that when it comes to NCDs, we're not dealing with an infectious agent that responds to medication. Rather, we're dealing with a dangerous and very complex organism called the human being, which is highly resistant to the need to change diet and lifestyle to meaningfully impact on these conditions.'

Diabetes in sub-Saharan Africa: facts and figures

Prof Ayesha Motala from the Nelson Mandela School of Medicine of the University of KwaZulu-Natal quoted some alarming statistics. 'It's projected that diabetes will account for four million deaths in 2010, or 6.8% of all deaths in the region. This represents a 5% increase since 2007, at which time diabetes deaths already exceeded those from HIV/AIDS.'

By 2025, more than three-quarters of all diabetics will live in the developing world and the greatest increase will be seen in sub-Saharan Africa. 'The International Diabetes Federation anticipates a

54% increase in type 2 diabetes incidence for the world between 2010 and 2030, but the increase for Africa will be 98% – with the number of patients increasing from 12.1 million to 24 million. Where IGT is concerned, the increase for the world is 37%, but for Africa it's 76%.'

Data on diabetes in Africa are limited, and until the 1980s the few studies available showed a low prevalence. 'Contrary to this persistent popular belief, diabetes in Africa is no longer rare, even though the incidence is variable, with a higher prevalence in urban areas', said Prof Motala. 'South Africa is urbanising fast and by 2030, there will be more urban than rural dwellers. This makes urbanisation an important risk factor in its own right.'

Given sub-Saharan Africa's limited resources and failing health systems, diabetes is often only diagnosed when patients present with complications. 'Chronic complications are a major cause of morbidity and increased costs. Diabetes affects nearly all parts of the body, including the eyes, feet, heart and kidneys. In sub-Saharan Africa, 4.5 million diabetics have eye disease, 2.23 million require dialysis, 970 000 have cardiovascular disease and nearly 400 000 have a lost a foot.'

Progress on NCD risk factor management will depend on public-private partnerships. We need to draw on the experience of such partnerships in the infectious diseases area, such as GAVI, GAIN and Medicines for Malaria, which are making tangible gains
– *Dr Derek Yach, senior vice president: global health policy, PepsiCo*

Prof Motala reiterated the point made by others that infectious diseases tend to be given priority, pointing out that Africa had a double burden of both these and NCDs. 'There is a complex relationship between HIV and diabetes, with the antiretroviral treatments required by the former conferring a greater risk of metabolic syndrome and pre-diabetes. An integrated approach is therefore important and HIV facilities need to screen for and treat NCDs.'

More optimistically, she feels all is not lost. Prevention works, with lifestyle modification alone having a 58% success rate in individuals with IGT. Even secondary prevention is cost effective, slowing the progression of the disease and delaying the complications. 'Health is an essential precursor of economic development, and NCDs such as diabetes have a major impact not only on individuals and their families but also on national economies. Despite the challenges in Africa, there are many examples of good practice in a number of countries. We're seeing increasing awareness among both communities and healthcare professionals, as well as a greater reach into remote areas.'

Scaling up NCD services in Africa: learning from HIV/AIDS

Dr Miriam Rabkin, associate clinical professor of medicine and epidemiology at the Centre for AIDS Care and Treatment Programs (ICAP), Columbia University, USA, feels that the

lessons learned from the astonishingly rapid scale-up of HIV services in sub-Saharan Africa can help strengthen systems for NCD treatment. Like those with HIV, patients with NCDs also need to interact with the health system regularly for life, need to take responsibility for their health and self-care, sustain healthy behaviour and access psychosocial support. Like those with HIV, they too require diagnosis, and enrolment and retention in treatment programmes, multidisciplinary care, longitudinal monitoring, and linkages and referrals.

Aspects to consider include civil society engagement, patient advocacy and a change of mindset from one of hopelessness to belief that treatment is viable. As with HIV/AIDS, simplified standardised diagnosis and management protocols are required, along with standardised first- and second-line drug regimens. Treatment needs to be decentralised to district level, task shifting from doctors to nurses needs to take place, the procurement and supply chain needs to be strengthened and there must be transparency in respect of record keeping, data use and target setting.

'Few, if any continuity care systems currently exist for diseases other than HIV/AIDS in resource-poor settings, however', said Dr Rabkin. She offered the following three suggestions:

- Use a public health approach, entailing simple, standardised protocols as well as a minimum treatment package.
- Adapt systems and tools that already exist for HIV/AIDS with a view to ensuring, *inter alia*, point-of-service diagnostics and co-location of services.
- Screen and treat. 'Think "systems" to enable a more holistic approach', she concluded.

Leveraging HIV services to address NCDs is indeed a viable option. **Dr Frank Mwangemi, deputy director of Family Health International (FHI) in Kenya**, gave an overview of a successful pilot project to integrate HIV and cardiovascular disease (CVD) services in that country. It was undertaken to monitor the cardiovascular complications of patients on HAART.

'Knowing that as time goes by, patients on ARVs experience increased CVD risk, we built the capacity of existing staff to deliver CVD prevention and care services in addition to those for HIV. We adapted our existing health information systems/tools and enhanced our laboratory capacity to incorporate CVD. The acceptability of this integration to both staff and patients was very high.'

He underscored the importance of partnerships, noting that while FHI had provided the seed funding for the project, the Kenya Cardiac Society had provided training and support and USAID had provided the funding for HIV services. 'Government buy-in was also essential', he said.

'HIV and CVD integration is indeed feasible in low- and middle-income countries', he concluded. 'The integration helped us to identify previously undetected risk factors so that we could implement prevention and management strategies. Routine blood pressure monitoring, particularly, given the risk of hypertension associated with ARVs, needs to be part of AIDS care and treatment. Prevention is cheaper and better than cure and I call on all policy makers to take into account the medical and socio-economic benefits thereof.'

In a similar vein, **Dr Knut Lonroth, medical officer in the Stop TB Department of the World Health Organisation**, posited a collaborative framework for the care and control of TB and diabetes. He described them as colliding epidemics, with each increasing the risk of the other. 'It's therefore important not to have colliding treatment programmes', he said.

The framework has yet to be piloted, but it aims to screen for

diabetes in TB patients, and where there is a high background prevalence of TB, to screen diabetics for the disease. The DOTS model of TB treatment, which has been used with great success since 1995, will be adapted to diabetes. 'TB programmes can help to advocate broad diabetes prevention and care efforts', he concluded, 'and can also contribute to broader healthcare system strengthening.'

Innovations in healthcare delivery: the use of mobile messaging

One billion people in Africa are underserved by conventional infrastructure, something that is a key barrier to healthcare provision. However, 45% have access to mobile phones and this is growing rapidly. **Gustav Praekelt, founder of the Praekelt Foundation**, gave an overview of two case studies, not specifically about diabetes, that spotlighted the success of an SMS programme called 'TxtAlert' in communicating with patients who would otherwise have been difficult to reach.

'SMS is a universal technology and its use to send patients reminders about their appointments and also to allow them to reschedule, made a significant impact on an HIV/AIDS adherence programme at Helen Joseph Hospital', he said. It reduced the percentage of patients lost to follow up significantly.

The second study looked at the impact of a free mobile portal called 'Young Africa Live', which aimed to engage young people pre-diagnosis in interactive conversations around sex and gender issues. Topics included dating tips, circumcision, what makes you gay, and multiple concurrent sexual partnerships. Topics have drawn as many as 452 000 comments, and 76 000 daily views have been logged.

'There is some very interesting work being done around mobile technology, which allows for large-scale patient engagement', he concluded.

The theme of the second day of the Diabetes Leadership Forum was 'Facing the future with hope for all ages'. **Dr Silver Bahendeka, chair, IDF African region**, introduced this session by stating that the time of 'testing urine with the tongue' is long gone. It was, however, a long walk to free people in Africa from the shackles of diabetes. New technology-based models of care are called for in Africa to manage diabetes and other NCDs without reinventing the wheel. In spite of the encompassing theme, NCDs in the elderly unfortunately did not receive any attention at this meeting.

Most countries in sub-Saharan Africa have introduced national NCD programmes and developed guidelines since 2001, said **Dr Kaushik Ramaiya from Tanzania**. This was followed by an increase of up to 50% in government funding in some countries over the following eight years. The key strategy used by healthcare workers to achieve this included advocacy, setting of priorities, mobilisation of resources and empowering people. Unfortunately, there are still some countries in sub-Saharan Africa where basic drugs are still unavailable. Scarce funding is still consumed by 'catastrophic spending' on the end result of NCDs, such as stroke and myocardial infarction. Dr Kaushik made a plea for the step-wise implementation of NCD programmes as well as to expand the list of traditional NCDs to include epilepsy and sickle cell disease among other chronic conditions.

'Medical doctors may not be great communicators but their opinions are respected when talking to politicians', said **Dr Mary Amuyunzu-Nyamongo, a social scientist and executive director of the African Institute for Health and Development**. Social scientists, however, have an important role to play in health

promotion as a vehicle to bring communities on board as partners and to assist people to take control to improve their own health. The social determinants of health include the environment in which people live and work, while cultural and societal values also play a role in some NCDs, for example, obesity. Social scientists are adept at determining the 'causes of causes of NCDs'. They also have an important role to play in the implementation of health policy, a serious challenge to the management of NCDs in most sub-Saharan African countries. 'Social scientists can assist healthcare workers and policy makers in strengthening communication and sensitising communities', said Dr Amuyunzu-Nyamongo. She also made a plea for a multidisciplinary research agenda that includes social anthropologists.

The formation of NCD alliances between stakeholders is critical in lobbying for the NCD cause, according to **Ms Susanne Volqartz, director of development, the Danish NCD Alliance**. NGOs have a tradition of working against each other in fund raising and promoting individual causes. By forming the Danish NCD alliance between the International Diabetes Federation, the World Heart Federation, the Union for International Cancer Control and the International Union Against Tuberculosis and Lung Disease, it was possible to form a massive lobbying group representing more than 600 000 people in Denmark with its small population of 5.5 million people.

'Disease prevention has no constituency', said Ms Volqartz, therefore disease prevention receives very little attention, while governments are forced to act when people are already sick. She also pointed out that many NCDs share the same social causes such as tobacco use, unhealthy diet, lack of physical activity and the harmful use of alcohol. It therefore makes sense for NGOs focusing on individual diseases or groups of diseases to form an alliance to convey powerful messages to the community and to persuade government to invest in disease-prevention strategies. Lobbying strategies must be supported by quality data, to be successful.

An increase in life expectancy of one year can lead to a 4% increase in GNP – *Prof Ayesha Motala*

The session 'National diabetes/NCD programmes' was somewhat disappointing with regard to the negative messages that came across during the panel discussion. **Dr Emmanuel Nomo from the Cameroon Ministry of Health** informed the meeting that the CVD risk-factor profile of people in the Cameroon is very similar to that of the South African black population. Although excellent plans were made on how to deal with NCDs between 2004 and 2006, little technical support and financing was forthcoming to implement these policies, a common phenomenon in sub-Saharan African countries.

'Mozambique has already formulated a national framework to deal with NCDs and is now looking at ways to incorporate the management of NCDs into primary healthcare and level-two services', according to **Dr Carla Matos from the Ministry of Health** in that country. Dr James Sekajugo, Uganda Ministry of Health, explained the relatively complex healthcare system in place in that country. 'The Department of Health only informs and it is expected of individuals to take care of their own health', said Dr Sekajugo. Another interesting aspect of healthcare management in Uganda is the inter-sectorial co-operation between the state departments of Health and Finance. Other sub-Saharan African countries are plagued by lack of basic data on NCDs, lack of funding for essential medication such as insulin, and inadequate infrastructure. It was heartening to learn, however, that these

deficiencies are recognised and confronted.

At the end of this session a delegate from the floor remarked that 'the voices from the panel are very passive. Will we ever manage (to deal with the burden of NCDs) if our policy makers are lukewarm?'

The session 'Transitioning from concept to implementation' was introduced by **Dr Anil Kapur, managing director, International Diabetes Federation**. The WDF is currently funding 236 projects in 93 countries and Africa is receiving more than its fair share of this funding: 90 projects (69 ongoing) were funded in 34 African countries. This initiative has since its inception placed 4 700 doctors and 7 125 nurses in Africa; 990 diabetes clinics were established on the continent, some of these are 'container clinics' and these clinics could form a nidus for NCD clinics. The focus areas for these projects include the diabetic foot, screening for eye disease, mothers and children with diabetes, and the co-occurrence of diabetes and TB.

Dr Eva Njenga reported on the success of a WDF diabetes project in Kenya. Successful partnerships were formed between the Ministry of Health and diabetes organisations, resulting in the provision of 3 900 healthcare workers and 400 lay community workers, the opening of 45 diabetes clinics and the strengthening of 109 additional healthcare facilities over a 10-year period. A great premium is placed on public awareness, diabetes education and involvement of the youth.

Dr Abbas from Tanzania discussed the 'step-by-step' WDF foot-care project in that country. In this programme, emphasis is placed on creating awareness and the provision of educational material and foot-care starter packs. Data are continuously collected from 15 foot-care centres in 14 regions. The main aim of this initiative is to reduce the amputation rate in Tanzania.

Dr Nelia Steyn from the MRC, South Africa, discussed a WDF funded interventional project 'Health Kick' aimed at developing healthy lifestyle programmes in schools, mainly by promoting healthy eating habits. In the **Cameroon, Dr Eugene Sobngwe** initiated a WDF-funded study to establish the most cost-effective and practical method to diagnose gestational diabetes, while **Prof Bob Mash from the Western Cape** discussed the successful WDF-funded project on the improvement of the quality of diabetes care at primary healthcare level in that province.

Dr Silver Bahendeka introduced the session 'The Africa Diabetes Care Initiative (ADCI) 2010–2012'. He highlighted the fact that diabetes mellitus is a major health threat in the developing world. It is confounded by the double burden of disease. Many African countries do not have national diabetes care programmes. There is also a widespread lack of essential medicines. He made the comment that 'Talk does not cook rice – it is time to act'. Barriers to achieve optimal diabetes care have to be identified and addressed. Africa needs a programme that will maximise key resources, support self-management and push forward viable and sustained management programmes. This need led to the development of the African Diabetes Care Initiative by the IDF. The ADCI will focus on three main areas: education, diabetes in children and the diabetic foot. A task force was established for each of these focus areas.

'Africa is a continent of great contrasts, immense potential and great challenges', said **Ms Grace J'Alango from Kenya**. There are more than 12 million people in Africa with diabetes. Prevention is paramount to stop the rapid increase. The answer lies in diabetes education. The ADCI plans to roll out diabetes conversation maps in all sub-Saharan African countries. There are several barriers in the field of diabetes education, including the lack of career pathways and a lack of resources.

Dr Ali Mohamed Gaman from Kenya, a diabetologist and himself suffering from type 1 diabetes since childhood, shared his experience of being a patient for 36 years, with the audience in a talk on 'Care of Children with Diabetes'. A child diagnosed with type 1 diabetes in Africa has a life expectancy of seven months to seven years! Healthcare facilities do not exist or are inaccessible, there are many socio-economic constraints and families often live from hand to mouth. Day-to-day survival is much more important than worrying about the long-term complications of the disease.

There is a high prevalence of acute and chronic complications; 25 to 90% of children with diabetes will develop keto-acidosis. The prevalence of severe hypoglycaemia is also very high. Most patients do not have access to home blood glucose monitoring. The lack of insulin is the biggest cause of death in children with diabetes. He then gave an insight into his own experience – living with diabetes. He found that the doctors had minimal knowledge of this condition. His diet consisted mostly of beans and cabbage. Follow-up appointments were erratic and unstructured. Access to insulin was problematic, especially when there was a coup in the country. He experienced a lot of anxiety.

Over time he and his family realised that effective management of diabetes could only be achieved if they understood the disease and made necessary changes and adjustments. He concluded that it is possible for someone who lives in a resource-poor setting with diabetes to live a normal life if he has the tools and support. It is important to enable patients to take control of their diabetes. In order to improve the lives of children with diabetes, the following aspects are important: improve availability and accessibility of insulin; education; diagnostic tools must be made available; improvement in drug procurements and supplies; training of healthcare workers; positive policy environment; reduction in the gap between the standards that we accept and what we deliver at primary-care level. Several initiatives are now available in sub-Saharan Africa to improve the care of children with diabetes, e.g. ISPAD.

No patient should die because of a lack of awareness of diabetes
– *First lady Bongive Ngema Zuma*

Dr Mesmin Deyamen Yefou discussed some issues relating to diabetes foot care in sub-Saharan Africa. Three main factors contribute to the development of the diabetic foot, namely neuropathy, peripheral arterial disease and infection. In the developed world, it is mostly due to peripheral arterial disease, but in the developing world, the diabetic foot is due to peripheral neuropathy. Many countries have a very high rate of amputations due to diabetes. In Burkina Faso it is estimated to be 48%.

There is a very high financial burden due to the diabetic foot and foot ulcers. In Africa, patients have amputations to reduce the cost of ulcers! In order to improve this, diabetes has to be prevented, patients must be educated, lesions should be detected at an early stage, and management of the diabetic foot must be improved. In order to improve the organisation of care, the political will is very important, especially in locating the necessary resources. There is a need for structures for education, screening, treatment and auditing, and healthcare workers must be trained.

The topic of the following session was 'Improving patient care – targeting the right patient with the right treatment' **Dr Alieu Gaye, vice president of the IDF**, introduced this theme with a talk 'Providing access to Medicines and essential technologies: The Essential Medicine Box'. He defined essential medicines as

those medicines that satisfy the priority healthcare needs of the population. They are selected with due regard to public health relevance, evidence on efficacy and safety, and comparative cost-effectiveness. Essential medicines are intended to be available within the context of functioning health systems at all times, in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at a price the individual and the community can afford. Medicines regarded as essential remain a national responsibility. Access to healthcare, and, therefore, to essential medicines is a part of the fulfillment of the fundamental right to health. The global number of people with access to essential medicines has increased from 2.1 billion in 1977 to 3.8 billion in 1997. Essential medicines are only one element in the continuum of healthcare provision but they are a vital element.

The major challenges that can be obstacles to health improvements are:

- Inequitable access: 30% of the world's population lack regular access to essential drugs. In the poorest parts of Africa and Asia it can be as high as 50%.
- Health reforms: in many low- and middle-income countries, health-sector reforms have led to insufficient funding for health.
- Medicine financing: In many poor countries 50–90% of the medicines are paid for by the patients themselves.

Dr Gaye went on to discuss the Access Framework intended to optimise access to essential drugs. This framework hinges on rational drug selection, affordability, sustainable financing, and reliable health and supply systems.

Dr Mapoko Ilondo, senior advisor, Global Health Partnerships, Novo Nordisk addressed the meeting with the 'Changing Diabetes in Children initiative'. Childhood diabetes has a high mortality rate in poor countries. The IDF estimates that there are 280 000 children under the age of 14 living with type 1 diabetes in developing countries. The annual cost of insulin and diabetes care may easily exceed a family's total income. Urgent action is needed to improve conditions. There are several barriers to care, including poverty, lack of diagnosis, lack of proper treatment and inadequate infrastructure.

The Changing Diabetes in Children programme is designed to provide long-term solutions to sustainable diabetes care for children in developing countries. Components of the programme include patient education, setting up a diabetes registry, monitoring and control, providing infrastructure and equipment, training healthcare workers and providing free or low-cost insulin. Novo Nordisk has a long-term commitment to improve the outcomes of children with diabetes. Under this initiative young people were trained to become diabetes ambassadors.

The Changing Diabetes in Children programme is a partnership initiative with Ministries of Health, civil society, WDF, Roche and ISPAD. The ultimate goal is to change the outlook for children with diabetes from hopeless to hopeful. The programme has already been rolled out in six countries, namely Bangladesh, Cameroon, the DRC, Guinea, Tanzania and Uganda; 1 100 children have been enrolled to date. The ambition is to have 10 000 children enrolled in the programme by 2015.

This very successful meeting was closed by Silver Bahendeka, chair, IDF African Region by quoting Ms Grace Atieno Jalong'o: 'Let's stop the wave of diabetes before it turns into a tsunami.'

Contributions by: Prof WF Mollentze, Dr JMM Koning, University of the Free State, Bloemfontein, and Peter Wagenaar, correspondent