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Positive Voices

FOCUS ON DIABETES
& NON COMMUNICABLE DISEASES

WORLD DIABETIS FOUNDATION

NOT FOR SALE

FOCUS ON DIABETES

& Non Communicable Diseases

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Abbreviations

ABC	:	African Bible College
CHAM	:	Christian Health Association of Malawi
CCAP	:	Church of Central African Presbyterian
DAM	:	Diabetes Association of Malawi
IDF	:	International Diabetes Foundation
NCD	:	Non Communicable Diseases
JournAIDS	:	Journalists Association against AIDS
KCH	:	Kamuzu Central Hospital
MCC	:	Malawi Council of Churches
SDGs	:	Sustainable Development Goals
WDF	:	World Diabetes Foundation
WHO	:	World Health Organization

Commentary

Protecting the generation against chronic diseases begins with us

Malawi is on the epi-centre of the chronic disease burden, diabetes is one of the Non Communicable Diseases (NCDs) causing a lot of socio-economic challenges in the communities. Without urgent action, lives of productive citizens continue to be lost. Journalists Association against AIDS (JournAIDS) with funding from the World Diabetes Foundation of Denmark and its collaborating partners, is publishing this publication recognizing the disease burden in front of our eyes.

Through a team of our dedicated freelance and staff journalists, JournAIDS visited various communities in peri-urban areas such as Mtandile, Chinsapo, and Area 25 in Lilongwe, and Ekwendeni Mission Hospital in the Northern part of Malawi's Mzimba district. Malawi has a long way to go in tackling the burden of NCDs such as diabetes, blood pressure and other cardiovascular diseases.

Taking into serious consideration that the 2011-2016 Health Sector Strategic Plan recognizes NCDs as a key priority, there is a need for the country to invest in infrastructure and human resources for health without forgetting essential medicines and technol-

ogy. In a low middle income country like Malawi, NCDs such as diabetes account to 5.6% based on the 2009 STEPS survey of the World Health Organization (WHO) and the Ministry of Health. New reports reaching JournAIDS are more worrying that in one study in Karonga district prevalence has been found to be 9%. This is not only frightening but also a wakeup call for collective action to tackle the burden.

In September, 2015, Malawi joined the rest of the world in adopting 17 Sustainable Development Goals, whose Goal 3 has a target of reducing the NCD burden to 70 percent by the year 2030. A million dollar question is how can we meet this ambitious target if we cannot allocate adequate financial resources in the national health budget? The answer to this question is for all of us to consider.

Malawi cannot afford to watch when thousands of citizens are dying due to chronic disease. There are a lot of home grown solutions to these public health challenges. For many years, stakeholders in the NCD response have often faulted the private sector for failing to support various initiatives such as the World Diabetes Day. However, JournAIDS believes the blame should not be singled on one stakeholder, it is rather the responsibility of everyone starting from civil society, academia, private sector and government.

We remain very alarmed that even when NCDs are recognized in the Sustainable Development Goals, it seems development partners in the country who are key in providing resources are not showing interest to join the response. We would like to take this opportunity to remind all development partners to be responsive on their commitments made in the Paris Declaration on Aid Effectiveness and the Accra Agenda.

Malawi cannot afford to watch when thousands of citizens are dying due to chronic disease. There are a lot of home grown solutions to these public health challenges.

Exclusive Cover Story

Up North: Ekwendeni chronic care clinic excels

Situated some twenty kilometres away from the heart of the Northern city of Mzuzu, Ekwendeni Mission Hospital of the Church of Central African Presbyterian (CCAP) Livingstonia Synod, is now frequented by patients with diabetes and other chronic disease conditions, offering a glimmer of hope in reducing the chronic disease burden. It was established in 1819.

The chronic care clinic at the hospital started in 2013 by Anneke Snoep, a Dutch medical doctor who is cheerful as a group of journalists tour the hospital to hear one of the remarkable stories in a region where access to health services is compounded by perceived negligence from government headquarters at Capital Hill.

However, the one who tells this story is the hospital's principal clinical superintendent and head of medical department, Albert Nyirongo. He says that the idea to establish the clinic came due to the huge number of patients from the surrounding areas diagnosed with blood pressure, diabetes and other Non -Communicable Diseases such as cancer.

"We established the clinic because various conditions of diabetes, hypertension and cancer were on a huge increase. We also have some patients with cancer on palliative care. This special chronic care clinic is open at 8am every Tuesday," says Nyirongo who has worked at the hospital since 1990.

One of the key challenges in establishing the clinic was lack of Glucometres and their sticks. At present, the hospital procures the diabetes screening equipment from Central Medical Stores of the government. And they don't come that cheap.

"We always want to make sure we have the right amount of Glucometres which the hospital buys using its own resources generated from user fees. In the early stages of the clinic we had problems in attending to patients with hypertension. Now we have two BP machines functioning," explains Nyirongo.

Many patients with blood pressure and diabetes are served at the clinic which opens in the morning and closes at around 5pm - sometimes late until all patients have been attended to.

Nyirongo adds, the clinic is challenged in terms of health workers, as it requires highly trained health workers to deliver quality services at the clinic. At present the clinic is served by one doctor, one medi-

cal assistant, two nurses and one clinical officer. If the health workers are to perform to the optimum capacity they need refresher courses and other specialized trainings.

"The clinic has improved matters as many patients are provided with very good health services. We follow the clinical guidelines to ensure the best care is provided to the patients."

Nyirongo is disappointed that there is weak support from the private sector as companies that could help invest in infrastructure development. The clinic operates from improvised rooms and there is an urgent need for a specialized building to house it.

"Our dream is to have a separate clinic. That way we could expand access to chronic care services to more patients. We are looking for the private sector to invest in chronic care here and more especially in infrastructure development," stresses Nyirongo.

Although the 2011-2016 Health Sector Strategic Plan (HSSP) acknowledges the Ministry of Health as a major provider of health services, there are also other partners playing an important role, above all the private sector. In order to effectively implement the HSSP, partnerships need to be created and strengthened with the private sector, especially with Christian Health Association of Malawi (CHAM) - a faith based health affiliate of the Malawi Council of Churches (MCC), the private-for-profit sector, CSOs and other government agencies. Currently Malawi has no structures, policies or guidelines giving a framework in which the private sector can work with the public sector.

In order to reach out to more patients, the hospital is often challenged by the fact it charges a small user fee which poor patients cannot afford. However, with more support from the private sector, the fees could be reduced at a subsidy arrangement to make services more affordable.

Ekwendeni Mission Hospital also engages in awareness, although on a smaller scale, but faces lack of transportation. At present it only has two ambulances.

Despite the obstacles on the way, Nyirongo and his counterparts at the hospital is optimistic that the clinic has come to stay and will raise the bar higher to provide services to needy patients. As they say, a stitch in time saves nine.

"Our dream is to have a separate clinic. That way we could expand access to chronic care services to more patients. We are looking for the private sector to invest in chronic care here and more especially in infrastructure development."

Controlling blood pressure begins at home

Among many Malawians blood pressure is not a new phenomenon. It has been there for many years but as the chronic disease burden grows, a lot of people struggle to tackle blood pressure due to challenges in access to health care. The ray of hope over the horizon lies in the home...

Dolesi Nankwenya is a 48 year old woman from the peri-urban slum of Mtandile which lies on the outskirts of Lilongwe city near the newly constructed Bingu National Stadium. She was diagnosed with high blood pressure in 1992 at government's Bwaila Bottom Hospital. She has now taken the right decision to follow medical advice to live a normal life with the chronic disease.

"I was found with high blood pressure when I went to the hospital, It started with blurred vision, tiredness and breathlessness. The clinicians told me to stop taking salt completely. I think people out there should ensure to always have a healthy diet and reduce salt intake. It is dangerous," says Nankwenya.

She recalls before her husband passed away in 2013, he used to encourage her to take blood pressure medication and make regular health facility visits for checkups. Dolesi, who is now a proud member of the Mtandile Diabetes Club, is determined to look after her life in healthier way. The club uses Chimbalame CCAP Church as a weekly meeting point.

For a living, Nankwenya sells firewood and can make up to K5,000 (US$7) on a good day, which helps her to buy a few groceries and necessities for her home.

The 2014 World Health Organization Global NCDs status report notes that raised blood pressure is estimated to have caused 9.4 million deaths and 7% of disease burden - as measured in DALYs - in 2010 across the world. If left uncontrolled, hypertension causes stroke, myocardial infarction, cardiac failure, dementia, renal failure and blindness.

The reports also indicate there is strong scientific evidence of the health benefits of lowering blood pressure through population-wide and individual (behavioural and pharmacological) interventions. The global prevalence of raised blood pressure (defined as systolic and/or diastolic blood pressure equal to or above 140/90 mmHg) in adults aged 18 years and over was around 22% in 2014.

"Many modifiable factors contribute to the high prevalence rates of hypertension. They include eating food containing too much salt and fat, inadequate intake of fruits and vegetables, overweight and obesity, harmful use of alcohol, physical inactivity, psychological stress, socioeconomic determinants, and inadequate access to health care," reads part of the report.

Another blood pressure patient, 59 year old Emilida Toto from Piyasani in the same locality discloses to have been diagnosed with high blood pressure in 2011 at the Adventist Health Centre where her husband works. She recalls that when the BP rose prior to the diagnosis she lost consciousness only to be found in a hospital bed.

"I collapsed on the way to the health centre. I don't know what really happened and I was asking the clinical officers as to how I found myself on the hospital bed and how I entered into the health facility," she recalls.

From the day she was diagnosed with raised blood pressure, Emilida takes various drugs to control the disease but notes numerous challenges in accessing Felodipine which is a very scarce BP drug. She explains to have no challenges in accessing Aspirin, Atenolol and HCT at the government's main refer-

ral hospital, Kamuzu Central Hospital, which are provided free.

"Always I easily get these other blood pressure drugs, but it is very difficult to find Felodipine. At Kamuzu Central Hospital they keep telling me to buy the drug from the pharmacy," narrates Toto.

She says Felodipine costs K3,500 (US$4), which makes it hard for her to afford. She adds that most people in low income and poor slum dwellings cannot afford and urges government to put in place mechanism to ensure easy availability and access to this important blood pressure drug.

"The scarcity of blood pressure drugs such as Felodipine is a serious health threat because it's not many who can afford. We should remember that blood pressure is dangerous," she says.

She is not the only one facing the challenges. 64 year old Edna Nantimuni was diagnosed with raised blood pressure in 2013 and agrees that other drugs are not easily found at the hospital.

"I get most of my drugs from Kamuzu Central Hospital, but other drugs such as Felodipine are not available. Besides, it is difficult to reach the central hospital due to the long distances."

Mtandile is a huge peri-urban and slum settlement which has no health facility. The only nearby African Bible College (ABC) Clinic charges user fees for one to access services which makes life hard for people like Edna and Emilida.

"I am appealing to government to seriously consider building a specialized NCD health centre here in Mtandile which has a large population. It is very difficult for some of us to reach the Central Hospital because we are poor," laments Edna.

"Many modifiable factors contribute to the high prevalence rates of hypertension. They include eating food containing too much salt and fat, inadequate intake of fruits and vegetables, overweight and obesity, harmful use of alcohol, physical inactivity, psychological stress, socioeconomic determinants, and inadequate access to health care."

Living with diabetes for 28 years amid struggle to healthcare

In the diary of Zelina Mthumba, 1988 remains unforgettable because it was the year she was diagnosed with diabetes. 28 years later life goes on as she can be counted to be among the few lucky ones to have lived long. Diabetes can be conquered.

Zelina who is now 54, was diagnosed at Likuni Mission Hospital run by the Catholic Church. It is located some kilometres away from Lilongwe city and charges user fees. As she could not afford the user fees, she was referred to Kamuzu Central Hospital.

Since then Zelina strictly follows medical advice and takes her diabetic drugs consistently and has a proper diet. In 2004, she was again diagnosed with raised

The key strategy for successful National Diabetes Programs

- Comprehensive policy and delivery approaches enhance the organization, quality and reach of diabetes prevention and care. It is feasible and desirable for all countries to have a national diabetes program and successful models are already in place in some countries.

- Strengthen UN and country-level leadership across multiple sectors to ensure coherent, innovative and effective global and national responses to diabetes, and achieve the best possible return on investment.

- Re-orient, equip and build capacity of health systems to respond effectively to the challenge of diabetes through training and workforce development, particularly at primary care level

- Optimize the provision of essential diabetes medicines and technologies through reliable and transparent procurement and distribution systems

- Develop a prioritized research agenda, build research capacity and apply evidence to policy and practice

- Use health information systems and robust monitoring and evaluation to assess progress

- Achieve innovative, sustained and predictable resourcing for diabetes, including Official Development Assistance (ODA) for low-and middle-income countries.

Source: *Global Diabetes Plan 2011-2021*

blood pressure which means she has to take a combination of different drugs to control the two chronic diseases.

"As a patient who has both diabetes and blood pressure, I have to take my drugs consistently and follow medical advice. Many people who see me don't understand that I have both diseases and I am still going stronger and live a healthier life," she shares.

Zelina has two daughters aged 22 and 25 respectively who monitor their mother's diet and help whenever the blood sugar levels get low. However, she still struggles financially and cannot afford healthier food which is getting expensive by the day.

To make ends meet, Zelina sells water at a nearby kiosk and earns a salary of K14, 000 (US$18), which she says is not adequate. Malawi's economy is one of the lowest in the world.

"Survival is very difficult with the current economic hardships. We survive by the grace of God. I should just thank my two daughters who are always escorting me to the hospital to get drugs and provide me with first aid when blood sugar is high or very low," admits Zelina.

She explains the importance of joining diabetic patients clubs is that it creates a platform for learning and information sharing to lead healthier lives.

Weak financing derailing response against diabetes and NCDs in Malawi

In a low middle income country like Malawi, diabetes emerges as one of the rapidly growing Non Communicable Diseases (NCDs). Coupled with weak financing, the situation threatens many lives and leaves many questions unanswered.

Diabetes accounts for more than 5.6% in prevalence in the country's population of about 16 million people - halting productivity and businesses as many patients cannot positively contribute to the ailing economy.

Febbe Mumba, a diabetic patient from Kabwabwa in Area 25, stresses on the need to have community or mobile clinics which might ease their access to medication. Such health facilities would accommodate many patients.

"We are given two days a month for medical check-ups and treatment at KCH. Due to congestion sometimes we don't get services and we run out of medi-

cation. We need our own clinics - either community based or mobile which can be at our disposal any time our condition worsens," suggests Mumba, diagnosed with diabetes in 2014.

The World Health Organization's (WHO) 2013-2020 Global Strategy on NCDs calls upon governments to strengthen governance and increasing revenues for prevention and control of NCDs through domestic resource mobilization, and improve budgetary allocations particularly for strengthening of primary health care systems and provision of universal health coverage.

Taxes and subsidies that create incentives for behaviours associated with improved health outcomes, as appropriate within the national context, are noted to be important in addressing the growing burden of NCDs.

Another diabetic patient, Govenara Fabiano from Chinsapo, a peri-urban area on the outskirts of Lilongwe city hinted the need to have nearby health facilities where many men could embrace its services as they tend to shun visiting referral hospital for screening unlike is the case with women.

"There are many men suffering from diabetes or Blood Pressure but the challenge comes over long distances to access such service. Many men would

rather spend more time for productive activities such as business or work. Once these clinics are available, many of our friends will come forthwith," stresses Fabiano.

Surprisingly, many of the patients were found to be women which shows big numbers of men shying away from health services for medical check-ups in which chronic diseases such as diabetes are screened.

Olive Kadzakumanja, a retired midwife nurse who is championing the fight around diabetes in Lilongwe, is a popular figure among patients. She is relentless and has established 17 diabetes clubs with over 50 registered members in each club.

She expresses sadness at the rate the chronic disease has hit communities, which needs urgent attention from government. Kadzakumanja also calls for financial investment in tackling diabetes and supports the idea of introducing mobile and community clinics in order to reduce the burden of chronic diseases.

Some of the diabetic patients visited are of old age, have low income levels, and face challenges to sustain proper diet which is essential in chronic disease care and treatment.

Catherine Maulana, a diabetic patient from the low income area of Mtandire also calls upon government to increase financing and invest in mobile clinics.

"Honestly, we are finding it hard to access medication due to long distances to reach Kamuzu Central Hospital where diabetes treatment and drugs are offered freely.

We need a nearby clinic whereby we can get medication without spending long hours walking to Kamuzu Central Hospital to get such services as traveling on minibus is costly due to our low income. Once these clinics are put in place, the situation can improve for us," says Maulana who has been living with diabetes and high blood pressure since 2010.

With funding from World Diabetes Foundation of Denmark, Journalists Association Against AIDS (JournAIDS) is currently implementing a diabetes prevention project, "Popularization Advocacy to Primary Diabetes Prevention", aimed at raising awareness amongst diabetic patients, NGOs, policy and decision makers and government in collaboration with College of Medicine, Diabetes Association of Malawi and the Ministry of Health.

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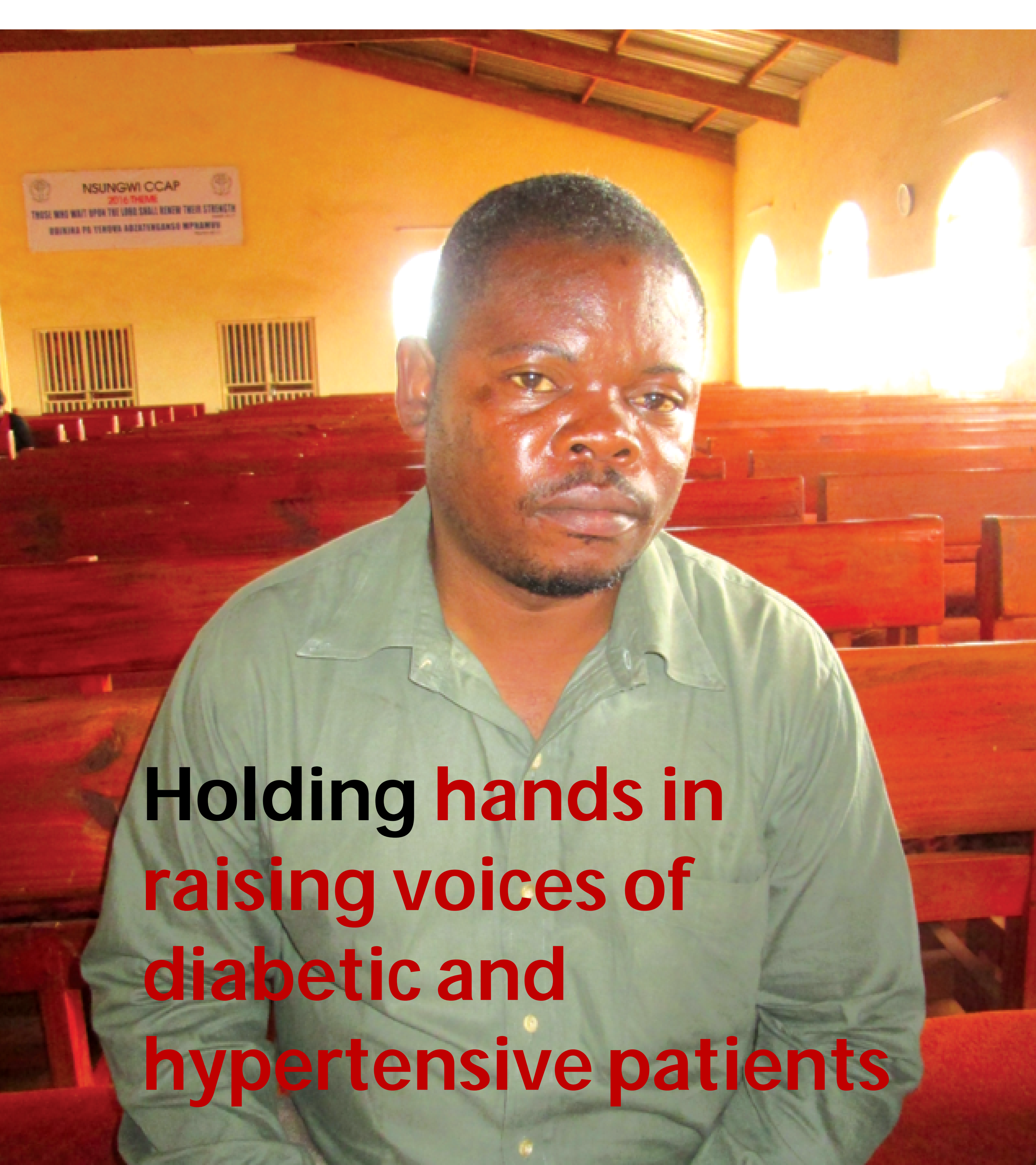


Holding hands in raising voices of diabetic and hypertensive patients

The chronic disease burden has penetrated the country and does not show signs of abating. With both the well to do and the poor affected there are many people, policy and decision makers who are working day and night to find lasting solutions. To make this work, more policy implementation has to happen.

The areas of Mtandire, Chinsapo and Area 25 are some of the peri-urban townships in the capital city of Lilongwe where communities have teamed up and formed groups that derives membership from patients suffering from diabetes, hypertension and other non-communicable diseases (NCDs).

The groups meet once in a month to share ideas and experiences on how patients cope with their day to day lives. A development which is making a big difference in that it has helped a lot of people to live positively and lessen the burden of NCDs.

In Area 25, one such grouping is chaired by McDonald Mpasuka, who is both diabetic and hypertensive. He speaks highly of the importance of the groups which has helped members to easily access counseling through trained volunteers who test and advise them accordingly on their dietary needs, medication and also facilitate the sharing of experiences.

"Through this group, I have been given the opportunity to have direct access to specialist doctors at the country's referral Kamuzu Central Hospital. We are given priority and special care when they learn that we are members of these groups," said Mpasuka.

He also said with the help of the volunteer health educator, patients are able to access testing on diabetes and hypertension and accordingly get advice on whether they should visit doctors at KCH if their lives are in danger.

The groups have helped in raising awareness on the danger of NCDs in that more and more people in the communities where these groups are based are coming to get screened, bringing out more new patients to help in lessening the burden.

However, there are challenges as most of the members come from poor backgrounds and fail to afford transport costs when referred to doctors at the central hospital. More can hardly afford foodstuffs that constitute diabetes patients dietary need.

"Patients need to eat frequently but most can't afford the recommended. We therefore call on government to consider subsidizing such food as many are sent to an early grave for lack of these," said Mpasuka.

He also asks government and well-wishers to consider introducing medical schemes for diabetic patients to enable them access drugs not found in public hospitals.

"With the current drug shortage in government hospitals, diabetic and hypertensive patients have not been spared. We feel this is the time to enable us access to the drugs from private establishments where costs are very high," he elaborated.

Olive Kadzakumanja, a volunteer nurse and diabetes educator, said: "These groups have also helped in reducing stigma to and amongst diabetic patients, improved couple counseling on sexually transmitted infections, HIV and AIDS and impotency. Diabetes affects a couples sexual life which drives them to seek comfort outside wedlock and consequently expose them to STIs,HIV and AIDS."

Stigma among diabetic women is real

Monica Mkandawire is a 40-year-old mother of three who hails from Chikwa village, Traditional Authority Chikulamayembe in Rumphi district. She has been living with diabetes for 21-years in Mtandire, a peri-urban area in Lilongwe city.

She vividly remembers of feeling dizziness, irritability, fatigue, excessive thirst, poor eyesight, insatiable hunger and excessive eating habits just a few a months before being diagnosed with diabetes.

"My husband divorced me and married another woman in August 2006 after being told that I am diabetic," says Monica. She never expected such action from her as he is a health worker as a Health Surveillance Assistant.

Monica cannot afford to buy 'special diabetic foodstuffs', but joining a diabetes club in her community initiated by a retired nurse volunteer has changed her life.

"Medication is only one aspect of my care, but maintaining a healthy weight, increasing my physical activity, eating health foods with low fat, testing my blood sugar regularly, taking my medication as prescribed, are some of the ways that have greatly contributed to control my diabetes in the past 16-years," she says.

Stigma and discrimination in diabetic patients remains high in her community hence the need to increase awareness and improve quality of support services by making sure that diabetic drugs are available in all hospitals, including at community health centres.

"We are always advised not to eat anything before tests during hospital visits, yet we stay in long queues taking time to be attended to. Government and partners should do something to increase health workers in the diabetic section in order to speed up service provision," she stresses.

Monica's divorce story reflects the untold experiences that women living with diabetes pass through in their lives. Her husband stopped supporting the family financially, adding pressure in raising her daughters, Tawonga and Forget, 13 and 19 respectively.

The most common sexual problem associated with diabetes is erectile dysfunction in men but much less is known about sexual problems in women. Carbohydrates, when digested, change to glucose. Glucose is then transferred to the blood and is used by the cells for energy. In order for glucose to be transferred from the blood into the cells, the hormone-insulin is needed.

Diabetes develops when the pancreas fails to produce sufficient quantities of insulin-Type 1 diabetes or the insulin produced is defective and cannot move glucose into the cells-Type 2 diabetes. Either insulin is not produced or is defective and cannot move the glucose into the cells.

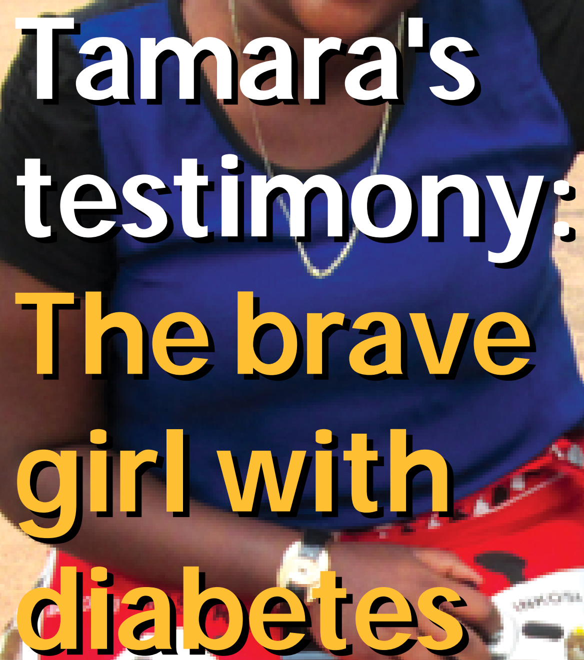
Type 1 diabetes occurs most frequently in children and young adults, although it can occur at any age while Type 2 diabetes is much more common and accounts for 90% to 95% of all diabetes.

The 2011-2021 Global Diabetes Plan of the International Diabetes Foundation (IDF) notes that diabetes is at crisis levels and escalating. Every seven seconds someone somewhere dies from diabetes, accounting for four million deaths globally each year.

In the year 2011, 366million people had diabetes, with another 280 million at high risk of developing it. If nothing is done, the number of people with diabetes will rise to 552 million in 20 years, with a further 398 million people at high risk.

Saidi Amini, 38, hails from Nkopi village, Traditional Authority Makanjira in Mangochi district but currently stays in Area 25 Township. He says that after being diagnosed with diabetes his wife has become very supportive.

"I encourage all men to love and support their wives especially when they are sick. Diabetes is not communicable so partners should not have fear when one is found with the disease. I am sexually active and my wife is four-months pregnant now as such it is not true that people with diabetes cannot perform sexually," shares Saidi, who uses the same hospital Monica does.



Tamara's testimony: The brave girl with diabetes

By just talking to Tamara Kanyamula, a 14 year old girl in Standard Six at Nkodola Primary School in the township of Mtandire, one hears a touching story. It is a reminder and a wakeup call to tackle the growing burden of diabetes among children in Malawi.

Tamara has since birth lived with Diabetes type 1, a condition in which the pancreas does not produce insulin. A first born in a family of three, diabetes was diagnosed when she turned 11.

Her mother, Florence Kanyamula, narrates how she gave birth to the girl only to realize her condition after the diagnosis.

"The girl grew just like any other child though she would get sick sometimes which I took as normal," she said. Tamara was born fat until in 2013 when she begun losing her weight and started showing strange signs like feeling thirsty, drinking too much

water and urinating frequently.

She began complaining about pain in her feet and her body temperature was always high, a condition which everybody thought was a sign of malaria," says Tamara's mother.

She was taken to several private and public health facilities including Kabudula and Mbwatalika but they were told that they could not diagnose any disease or malaria parasites, she adds.

"As a mother, I was very disturbed by her condition so much that I decided to visit a traditional herbalist as I thought she had been bewitched," Kanyamula says.

The little girl stayed at the herbalist for over a day where K7, 000 (US$ 6) was spent after selling a goat. She returned home unconscious.

"That evening, people in the community thought my daughter was dead. They gathered in the house and others started clearing our belongings to give room for mourning. Men were outside lighting bornfires using firewood," she recalled.

Meanwhile, some elders entered the house to examine if the girl was indeed dead.

"My uncle went out and hired a car to take Tamara to Kamuzu Central Hospital (KCH) where she was admitted for a week and some days," narrates the mother. She was later diagnosed with diabetes type 1 and was immediately put on injectable insulin. Her life bounced back and she is back in school.

As Tamara continues to take injectable insulin twice a day, she has also been advised to follow a diet of fat and sugar-free foods for the whole of her life. Tamara's mother said initially they found it difficult to follow the prescribed diet because during school break her friends would offer her sweets, chips, freezes and other foodstuffs which shot up her sugar levels.

The mother, however, said Tamara's sickness has affected her education since most of her school days were spent at home.

"Her friends have excelled to higher classes and are now in Form one while she was forced to repeat due to the sickness," she said adding that the ailment has also affected her small restaurant business and second hand clothes as she spends the money on transport to the central hospital for checkups and food.

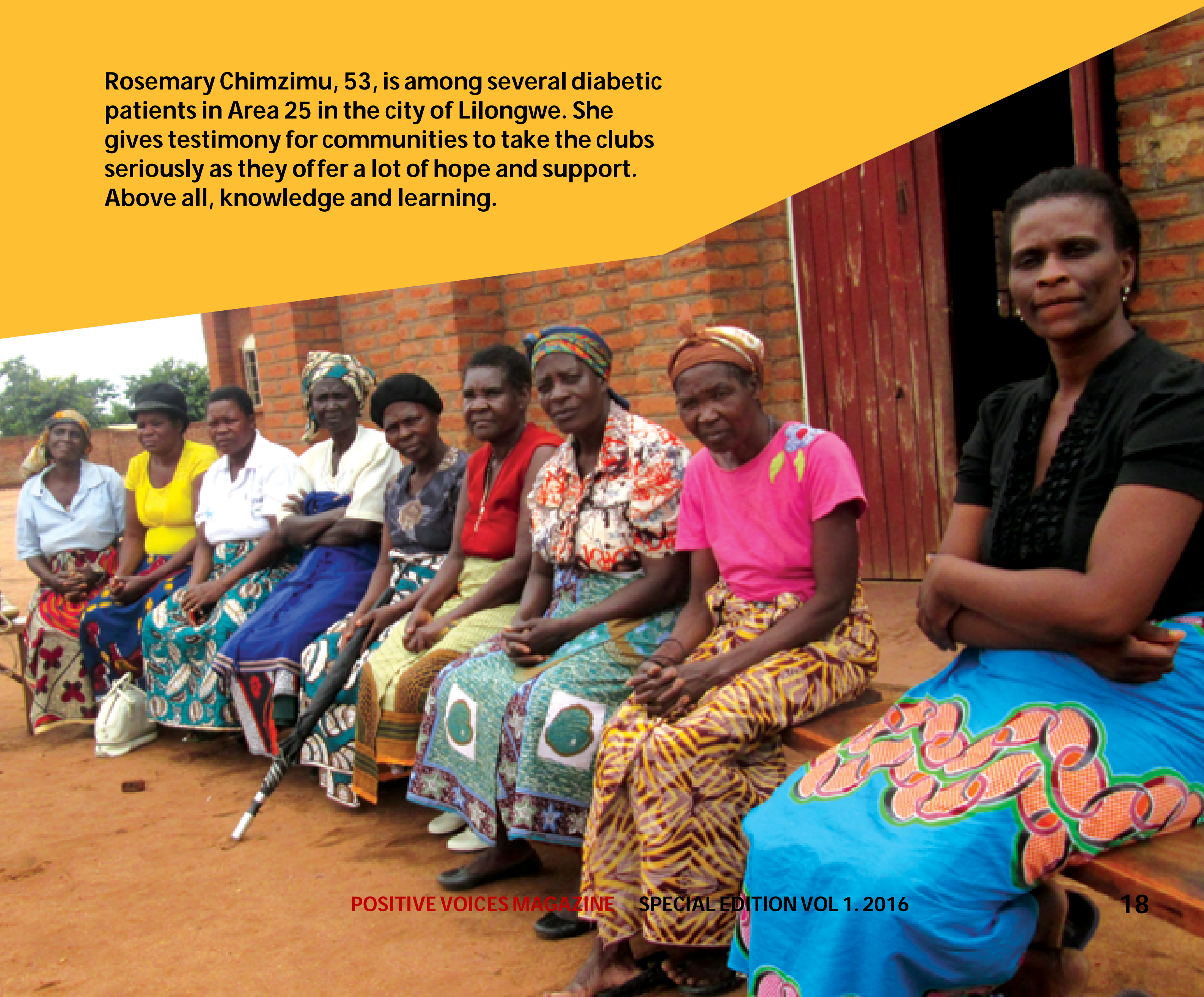
"We were privileged to receive support of K8, 000 (US$11) per month from Dr. Chiunda of Kamuzu Central Hospital, while a white doctor at the hospital donated a glucometer machine to check her sugar levels," she explains.

In 2014, Kanyamula and her ailing child joined the Mtandire Diabetes Club where the girl receives counseling and other management methods to control her diabetes condition.

"There is a great change in my child. She is now able to fully attend classes, follow her diet properly and is able to take her injection on time," Kanyamula observes.

When Diabetes Clubs turn into hubs of knowledge sharing

Rosemary Chimzimu, 53, is among several diabetic patients in Area 25 in the city of Lilongwe. She gives testimony for communities to take the clubs seriously as they offer a lot of hope and support. Above all, knowledge and learning.



Chimzimu was diagnosed with High Blood Pressure (BP) in 2004 then the following year she was found with diabetes following several signs such as body pains, fatigue, headache, thirst, and was urinating frequently.

"For the best part of the days, I was always bed ridden and left my farming business in Kasungu where I grew maize, tobacco and soya among others," she said.

She explains that she lost weight. "I reached a point of death because everything around me was not working," she says.

"My family took me to African Bible College (ABC) Clinic where they screened me and diagnosed BP and later the following year I was diagnosed with diabetes which was very high," she said.

Chimzimu continued receiving medication and was told to follow a strict diet of mgaiwa (whole grain maize flour) and local vegetables, roast meat, no fats, and little salt and sugar free drinks.

She joined Kabwabwa Diabetes Club where she is being encouraged and is learning and sharing experiences with friends who have the same disease.

"I am now a proud member of the club and I can mix with friends with whom we receive counseling on how to manage the disease. I have benefited a lot in this club. People who saw me in those years will be surprised to see the way I look now," she says.

At the same club, John Chirwa, 43, was diagnosed with diabetes at the age of 20 at Kamuzu Central Hospital (KCH) where he was put straight on insulin.

"They took me to the hospital when my situation was worse. I was admitted for a week but after receiving the treatment, I came back to normal and followed what I was told to do," he said.

He said he stopped school while in Form two because he could not see the letters on the blackboard due to blurred vision. Belonging to a club has helped him share and save more lives.

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The power of advocacy in increasing access to care for patients

Since its establishment in 2002, the World Diabetes Foundation has funded 370 partnership projects in 110 countries, focusing on awareness, education and capacity building at the local, regional and global level. Advocacy is one of the components driving change on the ground.

By the end of 2014, the total project portfolio had reached US$ 323.3 million, of which US$ 110.7 million was donated by the World Diabetes Foundation (WDF). The largest proportion of the WDF's funding (38%) is spent on access to care, strengthening healthcare system and building healthcare capacity, followed by creating awareness and primary prevention.

The relatively high share of funding to Africa illustrates the WDF's poverty focus, which targets those countries least able to withstand the burden of diabetes and its complications. The Non Communicable Diseases burden and diabetes continue to receive little attention as far as financing is concerned.

In Malawi; Journalists Association against AIDS (JournAIDS) is implementing a diabetes prevention project, "Popularizing Advocacy to Primary Prevention" under a project partnership agreement WDF 14-858 with funding from World Diabetes Foundation of Denmark. The organization through the project is working to raising awareness amongst diabetic patients, NGO's, policy makers, decision makers and government.

Lesina Grivin, born in the 1950's was diagnosed with blood pressure in 2012. It all started when her husband died in the year 2009, the same year his brother-in-law died and left 6 children, within few months in the same year her daughter died and left two children.

"I was thinking too much especially on how I can raise 8 orphans. My husband left a small house which I do get rentals from monthly but it is a small house and it is not enough as a source of income for my upkeep and the orphans," says Grivin whose origin is Kandeu village, Traditional Authority Ganya in Ntcheu district.

She left her village in 1975, settled at Piyasani Township and affiliated herself to a nearby Mtandire Diabetes Club.

"Since joining my health is better now because I have been following medical expert advice," says Grivin whose health passport indicates that her last check up on 1st February, 2016 was 143 over 99 compared to her last check up on 2nd November, 2015 which was 152 over 100.

Annie Matewere, born on 29th October 1966, married with seven children is another patient who is benefiting from the JournAIDS advocacy project. However, her only concern is the shortage of syringes in public hospitals. In most cases, she does not inject herself with insulin as recommended by doctors because of scarcity of syringes.

A week before, during a JournAIDS media tour, Olive Kadzakumanja who is a nurse midwife volunteer confirmed that the referral hospital, Kamuzu Central, had run out of syringes as such patients were asked to purchase their own from private pharmacies.

Type 2 Diabetes is a condition which occurs when the body is no longer able to deal with the increasing level of glucose (sugar) in the blood. Normally, when we eat food, in particular carbohydrates (starches and sugar) the level of glucose in the body increases.

In a person with Type 2 Diabetes the body may not produce enough insulin or the insulin produced may not work as effectively as it should. This is referred to as insulin resistance and being overweight increases insulin resistance.

Using advocacy JournAIDS hopes that in the next few decades, diabetes and other NCDs will be high on the health agenda, whereby sustainable domestic and overseas development assistance will bring change in the lives of many patients.

A leg amputee with a chilling tale of diabetes

As the time is approaching midday, a small group of journalists are in a vehicle going to visit a diabetic patient with an amputated leg. As the road path is too narrow they decide to drop from the vehicle and take a 15 minute walk to meet Francis Phiri, a 64 year-old retired social worker and teacher. His amazing story is not for the faint-hearted.

A Husband and father of seven, Phiri has re covered from a horrible wound after months of excruciating pain and suffering. His leg was amputated at Mzuzu Central Hospital in Malawi's northern region city at the recommendation of medical authorities. He has advanced diabetes.

"It started as a small wound on my large toe mid last year. It kept growing with blisters and never healed until August 2015 when the leg was amputated," says Phiri, wearing a blue short sleeved shirt.

Phiri who largely depends on farming, says the leg loss has reduced him to a wheelchair and has lost partial eye sight, also referred to as diabetes retinopathy, which occurs when nerves in the human eye are damaged by high levels of glucose.

"I still have several of my children and grandchildren to educate. But life is no longer the same," he explains from the open veranda of his house in Efalanja village in the area of Traditional Authority Mtwalo, Ekwendeni, in Mzimba.

Anneke Snoep, a medical doctor at the nearby Ekwendeni Mission Hospital in the district notes that blurred vision and wounds that are slow to heal are among the symptoms of diabetes. Snoep who heads the chronic care clinic at the hospital says the weekly clinic was established to help provide adequate care to the rising number of such patients at the facility.

The Principal Superintendent for the hospital, Albert Nyirongo, agrees with Snoep.

"The number of people who attend our weekly clinic has since soared to an average of 30. For a mission hospital like this one, whatever health services we provide one has to pay. For patients on insulin, a [bottle] of insulin which lasts for a period of at least three weeks costs MK 9,000 (US$ 12). Even the tablets we are using for diabetes, they are expensive", says Nyirongo.

The majority of NCD patients are productive citizens below the age of 60, which is a setback to the Sustainable Development Goals on eliminating poverty and reducing the burden of Non Communicable Diseases by 70 percent in the year 2030.
The Diabetes Association of Malawi (DAM) is advocating for a subsidy for diabetes drugs to be made available for free. Diabetic patients take the drugs for their lifetime just as is the case with those suffering from HIV.

According to the 2011-2021 Global Diabetes Plan, adequate access to essential medicines, diagnostic technologies and supplies for diabetes reduces complications and improves health outcomes.

The plan notes that such access requires a reliable and transparent system of procurement and distribution of essential diabetes medicines and technologies to all relevant health facilities. The considerable savings made by stopping the loss and leakage of medicines that come as a result of corruption and poor planning need to be given more attention.

Executive Director for Journalists Association against AIDS (JournAIDS), Christopher Bauti, calls upon stakeholders in the health sector to invest resources towards research on NCDs in Malawi to generate latest information on the chronic disease burden.

"If you look into the data on the NCD burden, we are referring into a survey that was conducted by World Health Organisation in 2009. That time the prevalence rate was 5.6 percent. This is now 2016, do you think the statistics are still the same," he wonders.

Some of the major challenges dogging the response against NCDs in Malawi include long distances to health facilities, shortage of human resources for health service delivery, including essential medicines and technology. There is a need for collective action to tackle the NCD burden urgently recognizing the 17 Sustainable Development Goals agreed in New York in 2015.

Demystifying diabetes: a recipe for success in tackling the burden

More often there are a lot of misconceptions associated with chronic diseases such as diabetes. Others still think it is for the rich in society yet the truth points out to a different picture; the burden does not choose class or levels of income, it is here on the doorsteps of everybody.

For the Malawian society to successfully tackle NCDs like hypertension, diabetes and can cer, people have to change their thinking - that the chronic diseases are for the affluent alone. Similarly, it is not true that diabetes is only for older people and that there is a cure.

"We have a number of diabetic patients from distant rural areas who come for treatment here. It is important to note that unhealthy diet is a risk factor for diseases like diabetes.

Taking too much sugar, a lot of salt and heavy meals eaten hours after a previous meal like [nsima yoyera] fully milled maize flour is not a healthy eating habit. What we eat really matters," says Anneke Snoep, the founder of the chronic care clinic at Ekwendeni Mission Hospital

Snoep appeals to government and other partners to mount robust awareness campaigns on NCDs. The health authorities at Ekwendeni estimate that 1 in every 3 patients who attend the chronic care clinic at the facility are poor people and come from distant rural areas.

"Often times many diabetic patients go for medical check-ups when their health has already deteriorated due to lack of knowledge. It is a very big challenge for poor people when they have been diagnosed with such diseases because the kind of diet which they are supposed to follow is expensive.

Furthermore, to come frequently for check-ups remains a challenge because of long distances to health facilities and low income levels," narrates Anneke who is like an icon at Ekwendeni.

According to the 2014 Global NCDs Status Report, obesity has been increasing in all countries. In 2014, 39 percent of adults aged 18 years and older (38 percent of men and 40 percent of women) were overweight. The worldwide prevalence in obesity nearly doubled between 1980 and 2014. In 2014, 11 percent of men and 15 percent of women worldwide were obese. Thus, more than half a billion adults worldwide are classed as obese.

One of the diabetic patients at the hospital, Samuel Tchetche, agrees with Snoep - that the disease is difficult to manage for the rural poor.

"I was diagnosed with diabetes in 2011 at Ekwendeni Mission Hospital but soon after getting better I travelled to South Africa to look for greener pastures. I also took my drugs whilst in South Africa but later my condition worsened," explains Tchetche, a father of four who was admitted at the hospital upon his return to Malawi in December, 2015.

Although Tchetche is now getting better it is still difficult for him to properly adhere to a healthy diet as he is not working and cannot generate sufficient income to meet the dietary needs.

"I live in Enukweni in Mzimba district. With my current condition I am supposed to come to Ekwendeni regularly for check-ups which is expensive for me. And it is a journey of 15 kilometres one way," he laments.

The key is adherence: take diabetes drugs regularly

Taking diabetes drugs strictly is the best way for patients with diabetes to live a healthier life. In common cases dropping medication has led to loss of lives. With the increase in adverts about false drugs and religious leaders confusing patients, the need for adherence to scientifically proven drugs is the real deal.

Malawi is one of the countries in Southern Africa hit hard by the chronic burden of Non Communicable Diseases (NCDs). With this in mind, there are now more traditional herbalists who peddle drugs they claim can cure diabetes and often use radio to float misleading advertisements.

Lesley Matimba is a clinician at Ekwendeni Mission Hospital's Chronic Care Clinic where diabetic patients tell many stories of failing to adhere to drugs which have scientific proof. Many have been misled. He observes that diabetic patients who do not commit themselves to taking drugs as advised by physicians risk worsening their condition and, in extreme cases, court their own death.

"Usually when a patient has stopped taking drugs, [they] come back to the hospital very sick. It [diabetes] is a condition whereby one needs to be taking drugs regularly. A person cannot survive without drugs. Even if a patient stops taking drugs just for two days, he comes back to the hospital very sick," notes Matimba

The 2011-2021 Global Diabetes Plan states essential medicines for treating hyperglycaemia and the blood pressure and lipid disorders that characterize diabetes and lead to its complications are available in low cost generic forms that are affordable to all countries. These medications not only help prevent complications, such as heart attack and stroke, occurring in the first instance but are equally or even more effective in preventing subsequent complications.

"So the best preventive way is for the patient to take drugs as advised by the clinician and should avoid walking barefooted or avoid sustaining injuries," Matimba advised.

But in separate media interviews some diabetic patients attributed non-compliance to medication due to poverty as patients from poor rural settings have difficulties to pay for the medication and travel costs to the mission hospital.

"Since Ekwendeni is a paying hospital, there are times when one needs to get drugs but they don't have money to pay for them. So they just opt to stay home," said Samuel Tchetche of Enukweni.

In rural clinics such as the one at Enukweni, a distance of about 15 kilometres from Ekwendeni and 35 kilometres from Mzuzu city, usually there are no drugs and screening equipment for diabetes.

"It would be good if government would ensure that drugs and other medical supplies for the treatment of diabetes are made available in the rural hospitals and clinics. Government has a special HIV program on nutrition whereby those living with the virus are given special foods. I wish the same gesture would be extended to us who have diabetes," Tchetche says.

The sentiments are echoed by Elizabeth Jere of Euthini in Mzimba, some 80 km from the hospital. She spends about K3,000 (US$ 4) on transport and K1,550 (US$ 2) on her medical bill each trip.

"I was diagnosed with diabetes four days ago and have been advised to stop eating certain foods. But some of the foods they have recommended to me need money so I'll struggle to access them," reveals Jere who is a subsistence farmer.

"I wish authorities would introduce mobile clinics so that I should be getting medication right at Euthini. Otherwise it will be difficult for me to be coming here to Ekwendeni every month for medication," she laments.

The 2014 World Health Organization (WHO) Global NCD Status Report recommends the need for routine monitoring systems to be established, in order to provide regular facility-based assessments of the availability of key medicines and health technologies. These systems need to provide information from the public and private sectors and from urban and rural locations, so that equity of access to these essential commodities can be assessed.

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