A POSITION PAPER

REFRAMING THE NATIONAL DIABETES RESPONSE; THE VOICE OF PATIENTS

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WORLD DIABETES FOUNDATION

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Background

Malawi is one of the countries hugely affected by diabetes and other Non Communicable Diseases (NCDs), taking into serious consideration the growing burden of diabetes, JournAIDS is generating this discussion paper as one way of stimulating debate and to help shape policy advocacy on addressing diabetes as one of the most costly NCDs to the economy. The 2009 Nationwide STEPS survey of the World Health Organization shows that Malawi has a diabetes prevalence of 6.5% this means that roughly 6 out of 100 people in the country have the disease. Based on reports from College of Medicine, Queen Elizabeth Central Hospital (QECH) receives a high number of referrals from across the country mostly cases with severe eye and foot complications and because these are late referrals, it is usually too late to help the patients.

Data collected from QECH operating theatre registers demonstrate that from 2007 to 2012 amputations in diabetic reduced. Most notably, in 2012 when there was a visiting doctor with skills in diabetic foot care, there were only 5 recorded amputations in diabetic patients. In the 2 years preceding there were 17 and 18 amputations respectively. Unfortunately in 2013 amputation rates were reportedly increasing again. This is a direct indication of the importance of local, specialist expertise at QECH. Patients present very late with foot sepsis, often being referred when it is too late to save the foot. There is poor communication between physicians managing diabetes and surgeons. In addition, patients are not properly educated on foot care and proper channels to follow once they have feet problems.

In September, 2011 at the United Nations General Assembly NCD Summit, global leaders agreed a Global NCDs Political Declaration that calls upon all member states to invest in NCDs, realizing that they are costly and have the potential to derail socio-economic development. Malawi's needs a robust response to tackle diabetes because it is one of diseases that kills faster than HIV and AIDS and Tuberculosis combined. The 2011-2021 Global Diabetes Plan of the International Diabetes Federation (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 2011, 366 million 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.

Policy Responses in tackling diabetes

In terms of policy formulation, diabetes as an NCD has not received enough attention, although in 2013 the Ministry of Health launched the 2013-2018 National Action Plan on the Prevention and Management of Non Communicable Diseases. At present diabetes and related NCDs are not clearly reflected in the national health budget as a result, diabetes and NCDs are one of the most neglected and underfunded in budgetary terms. Although the 2011-2016 Malawi Health Sector Strategic Plan recognizes NCDs as accounting for approximately 12% of the Total Disability Adjusted Life Years (DALYs) which is fourth behind HIV/AIDS, other infections, parasitic and respiratory diseases. Diabetes and other NCDs are not clearly focused in terms of financing. This has a serious implication on the quality of care and treatment received by diabetic patients across the country. The policy context is that at the moment it is not being responsive enough to tackle diabetes, this may also point to the lack of political will.

To respond to diabetes effectively there is a need of political commitment, for instance Kenya is the only African country to have developed a National Diabetes Strategy. Malawi can also do it if it is serious in terms of policy responsiveness.

For many people living with diabetes in Malawi such as 34 year old, Simon Mangulama, a father of three from Chiradzulu district in the southern region of the country. The truth is that diabetes is a chronic non communicable disease that places a huge strain of family income, it is worse when one's business comes to a standstill as the attention shifts towards diabetic care with more time invested in the management of the disease while the business suffers.

This is what exactly Simon faces, being a fish trader himself, living in the capital city of Lilongwe whose urban life is expensive requires a lot of investment towards the fish selling business to enable him provide all the family needs such as paying for kids school fees, house rent and food. However it was in 2011, when he was diagnosed with diabetes at Kamuzu Central Hospital.

" It was in 2011 when I discovered that my body was feeling weak and I had a lot of fatigue, it was worse because I had to go to the toilet frequently to urinate. Then i saw that my fish selling business was going down as I could no longer concentrate on the business because of the deteriorating physical condition", recalls Mangulama.

Linking poverty and the diabetes burden

It is very clear that diabetic patients who live on less than 1USD a day suffer a lot as they cannot access timely treatment due to lack of financial resources such as transport fares to enable them travel to health facilities which worse still are located at longer distances. According to the International NCD Alliance, diabetes is a cause of poverty due to lost income, lost jobs and high costs of treatment and complications (such as amputation, blindness, stroke, heart attack) which can push poor families into destitution. In a recent 2014 case study documented by JournAIDS, it was found that income levels were dropping rapidly in families whose breadwinners were men diagnosed with diabetes.

As evidence grows that diabetes and poverty are interlinked, Malawi cannot afford to ignore NCDs in poverty reduction interventions. Hence including diabetes in poverty reduction strategies such as Malawi Growth and Development Strategy (MGDS) is essential. The 2011-2016 MGDS II does not mention NCDs in its strategic responses. In the future the country's MGDS and other critical poverty reduction strategies must ensure that diabetes is strongly highlighted. Many diabetic patients living in urban areas such as Chinsapo, Mtandire are struggling with poverty, these urban communities have high poverty levels, characterized by lack of amenities such as piped water, while the living standards are very low. Diabetes is more common among slum dwellers. According to the International NCD Alliance, research has shown a diabetes prevalence of 10.3% in urban slums in India compared to the national average of 7.1%.

The plight of diabetic patients, access to drugs and treatment

Most diabetic patients across the country struggle to access timely treatment and drugs due to numerous factors such as weak dissemination of information and education to enable people access screening and other services. In addition the drug stock outs have been a huge challenge for many years. Diabetic patients interviewed in Lilongwe during focus group discussions reported sky rocketing prices of drugs to be one of the stumbling blocks towards effective diabetes treatment. On average a patient requires 3 bottles of insulin in a month, with each costing K8, 000 (USD18.40) and K24, 000 (USD 55) the whole month. In periods of serious stock outs patients reported that a single insulin bottle could cost K12, 000 (USD 28). Essential medicines for diabetes are often accessible nor affordable: In many low-income countries, insulin and other diabetes essential medicines are not affordable or accessible to the poor. **(Global Diabetes Plan 2011-2021).** In Malawi the Central Medical Stores is owed K4.4 billion in outstanding debts by public health facilities. The stores which is now a trust reported a 95% stock out rate in January, 2013 and continues to struggle with procurement which in turn affects access to drugs by patients.

Condition of health infrastructure in Malawi

As of 2010, the country had a total of 606 health facilities, out of these 361 were owned by Ministry of Health, 162 by the Christian Health Association of Malawi (CHAM), 31 of them belonged to Local Government, 51 jointly owned by Ministry of Health and Local Government and 1 was owned by CHAM and Ministry of Health. **(2011-2016 Health Sector Strategic Plan).**

Taking into consideration the growing burden of diabetes, related NCDs and Malawi's huge population the current number of health facilities can be rightly said not to be adequate. This is clearly demonstrated during diabetes clinics at Kamuzu Central Hospital and QECH where patients have to queue on long lines, while the central hospitals have no designated space for diabetic patients for the clinics. Calls have been growing for a national diabetes centre which could be a possible solution to deal with congestion problems faced by diabetic patients at various health facilities. In addition most of the health facilities in the country are poorly equipped and lack equipment for instance, the kidney dialysis machine at QECH breaks down frequently thereby affecting patients seeking urgent treatment.

The Ministry of Health has suggested various hospital reforms such as strengthening urban health centres in order to decongest central hospitals, Improve capital investment planning (offices, accommodation for staff, etc.) for central hospitals and developing a hospital reform policy amongst other strategies. However it is yet to be seen if these reforms will materialize.

Shortages of health care workers

Acute shortages of health workers across Malawi's health facilities continues to hamper quality access to diabetes care and treatment. Although the Emergency Human Resource Plan (EHRP) has assisted in addressing the human resource crisis in Malawi, the country continues to experience critical shortages of key health technical cadres that can adequately respond to Malawi's disease burden. Diabetic patients across the country have reported cases of poor attitude and lack of observance of patients' rights by health workers. At QECH patients report being attended to by College of Medicine medical students who are not fully trained in diabetes management. The Ministry of Health recognizes that some training programs for health workers are outdated. The Health Sector Strategic Plan plans to revise curricula for training health workers to ensure that training programs address the health needs of modern Malawi in line with WHO recommendations on transformative education for health professionals.

Role of the media in highlighting diabetes

The media remains critical in raising awareness on diabetes prevention, treatment and care. However reporters and editors across the local print and electronic media houses have many knowledge gaps. A recent media baseline survey commissioned by JournAIDS found that reporters lack financial resources to adequately cover stories. In addition the lack of openness within the Ministry of Health to disclose information when requested by journalists is another point of concern and derails coverage on NCDs and diabetes in general. Many media houses still require capacity building which must be sustained to scale up coverage. It is also essential to note that editors in media houses have not been fully trained in handling NCDs related content in newsrooms and editorial desks. This is another area which needs to be carefully addressed as a matter of urgency.

Financial constraints derailing diabetes response

The NCD burden and diabetes continues to receive little attention as far as financing is concerned. The Health Sector Strategic Plan requires USD 3.2 billion to be fully financed and implemented over a period of 5 years. This is equivalent to an average per capita expenditure of $41.3 per annum. However with the current donor aid freeze, the country's health budget is constrained and is still below the 15% benchmark of the Abuja Declaration.

Diabetes screening alone requires USD 75,806 in a year with an estimated coverage of 50%, while diabetes case management requires an ideal budget of USD 51,160,806 in the 2015/2016 fiscal year. It is clear at the moment that financing for NCDs is little while the chronic disease burden continues to grow rapidly.

According to the Global Diabetes Plan 2011-2021, despite the evidence of the massive impact in low- and middle-income countries, less than 3% of the US $22 billion health-related Official Development Assistance is allocated to NCDs. Malawi which is now strengthening health financing should consider mobilizing domestic resources as an important strategy for assured and predictable funding .There are examples of some low- and middle-income countries using tobacco and alcohol taxes to fund hospital infrastructure and NCD prevention programs.

Key Recommendations

- **(To Malawi Government)** It should quickly implement the Health Sector Strategic Plan and meet the USD 3.2 billion budget by exploring innovative financing options such as alcohol and tobacco taxes amongst other measures to address diabetes and related NCDs. Additionally the government should seriously consider developing a National Diabetes Strategy and take diabetes an urgent matter.
- **(To development partners)** There is a need for donors in the health sector to seriously consider increasing financing towards diabetes and other NCDs. While chronic disease burden continues to grow, it is important to take urgent action. International donor countries should align aid to recipient country priorities, as agreed in the set of principles outlined in the Paris Declaration on Aid Effectiveness (2005). Most importantly, recipient countries such as Malawi need to prioritize requests for aid in line with the burden of disease in their countries.
- **(To Civil Society Organizations)** It is critical for CSOs across the country to join efforts to tackle diabetes and the growing NCD burden. There is a need to increase CSO coalitions that address NCDs such as diabetes. Apart from the Diabetes Association of Malawi, there is a need to create a Civil Society Diabetes Network which will scale up advocacy, awareness and strengthen CSO coordination. At the moment, there are only a few CSOs working in the field in Malawi.
- **(To the local media)** There is a need for the media in the country to take a leading role in raising awareness on diabetes and other NCDs. Hence radio programs, news articles and columns on diabetes if increased could make a huge contribution in the diabetes national response.

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One DALY can be thought of as one lost year of "healthy" life. The sum of these DALYS across the population, or the burden of disease, can be thought of as a measurement of the gap between current health status and an ideal health situation where the entire population lives to an advanced age, free of disease and disability. (WHO)

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