Challenges in managing chronic disease in low resource settings: Type 1 diabetes in sub-Saharan Africa

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Abstract

Non-communicable chronic diseases are rapidly emerging as a new priority in developing countries due to urbanisation, lifestyle changes and improvements in health care. One of the major non-communicable diseases is diabetes mellitus and type 1 diabetes is one of the most common chronic diseases seen in children and young adults. Although accurate figures are scarce, it is clear from the limited literature that many individuals are diagnosed with type 1 diabetes across sub-Saharan Africa.

Management of type 1 diabetes in the low resource setting of sub-Saharan Africa is challenging and complicated by factors such as a lack of insulin, syringes and glucose testing equipment. Type 1 diabetes is an expensive disease to manage and its burden is magnified in resource-limited sub-Saharan Africa. A lack of specialist healthcare workers to provide diabetes education to individuals compounds the challenge. Consequently, sub-optimal management of type 1 diabetes is common and increases the risks of immediate dangers such as diabetic ketoacidosis, as well as amplifying the onset of long-term complications such as retinopathy and nephropathy.

Several projects have been initiated in sub-Saharan Africa to improve availability and access to insulin and the other supplies imperative to managing type 1 diabetes. Additionally, initiatives have been implemented to assist in educating healthcare professionals in diabetes management. Despite the initiation of such schemes, there is still a long road ahead to ensuring all people with type 1 diabetes in sub-Saharan Africa receive appropriate care and, consequently, do not face unnecessary premature mortality and long-term morbidity due to mismanagement of the condition. Challenges in managing chronic disease in low resource settings:

Non-communicable diseases are becoming increasingly important all over the world, particularly in developing countries. Traditionally, communicable diseases have dominated the health picture of low resource countries, especially that of sub-Saharan Africa. Today, with urbanisation, lifestyle changes and improvements in health care, non-communicable chronic diseases are rapidly emerging as a new priority, causing increasing numbers of morbidity and mortality and adding a huge financial burden to already stretched health care systems.

One of the major non-communicable diseases is diabetes mellitus. Present figures indicate that 14.7 million people in Africa have diabetes and the number is expected to increase dramatically over the next twenty years[1], mainly due to an increase in cases of type 2 diabetes. Of the current figure, estimates of the proportion of individuals with type 1 diabetes vary from 10%[2] to 25%.[3] The current diabetes epidemic is huge. On the contrary, the Millennium Development Goals, established by the United Nations in 2000, omit non-communicable disease from their objectives, instead focusing heavily on communicable disease such as HIV and malaria, child mortality and maternal health.

Worldwide, type 1 diabetes is one of the most com-mon chronic diseases seen in children and young adults.[4] Unfortunately, in sub-Saharan Africa, with limited resources and lack of expertise regarding type 1 diabetes, a diagnosis can still carry a death sentence.[5]

This article looks at type 1 diabetes in sub-Saharan Africa. Firstly, the scale of the problem is discussed, followed by examination of the barriers to the management of type 1 diabetes in sub-Saharan Africa such as the lack of resources and expertise in managing the condition. Finally, interventions being undertaken to improve the situation is discussed.

Type 1 diabetes appears to be less common in sub-Saharan Africa compared to Europe and North America.[6] Epidemiological data on type 1 diabetes in sub-Saharan Africa is very limited[1,7]; epidemiological studies are costly, labour intensive, and African populations often do not have accurate census data.[6] Additionally, the lower the incidence of a condition, the larger the surveyed population must be to obtain accurate figures.[8] In a systematic review by Hall *et al*,[9] only four studies estimating the prevalence and/or incidence of type 1 diabetes in sub-Saharan Africa were found to be published between 1990 and 2011. Type 1 diabetes prevalence was reported to be low, ranging from 4 per 100,000 in Mozambique to 12 per 100,000 in Zambia.[9] The large difference in rates in different sub-Saharan Africa countries could be due to differences in methodological collection, or due to true disparities in the ethnic composition of popula-tions.[7] A literature search revealed no new epidemiological studies since 2011 and the International Diabetes Federation (IDF) state there is *'an urgent need for further epidemiological research and improved data col-lection systems in the region'*.[1]

For unknown reasons,[6] the onset of type 1 diabetes is reported to be typically ten years later in people of native African origin compared to other populations, the average age of onset being 22 to 29 years.[7] Nonetheless, many children are diagnosed with type 1 diabetes in sub-Saharan Africa and the IDF estimate stands at 39,100 children under the age of 14 years liv-ing with type 1 diabetes.[1] Considering the average age of onset of type 1 diabetes in African individuals has been documented as 22 to 29 years and the IDF do not state the breakdown by type of diabetes

in their statistics for adults in their comprehensive Diabetes Atlas,[1] it is reasonable to presume this number to be only a small fraction of the total of individuals diagnosed with type 1 diabetes in sub-Saharan Africa.

Type 1 diabetes is seen as a rare disease in sub-Saharan Africa, but this is likely related to the inevitable mortality if the condition is left untreated.[10] Another problem confounding the statistics could be misdiagnosis; patients presenting with symptoms such as weight loss, dehydration, polyuria, lethargy and sepsis, all of which can be seen in hyperglycemia and diabetic ketoacidosis, can be misinterpreted for more common conditions in sub-Saharan Africa such as HIV[11] or malaria.[12,13] Ultimately, this may lead to delays or omission of appropriate treatment and, when untreated, the life expectancy of type 1 diabetes is around one year.[14] Even when diagnosed with type 1 diabetes, few individuals have access to sufficient insulin, syringes and blood glucose monitoring equipment and die as a result.[1] Consequently, the low prevalence of type 1 diabetes in sub-Saharan African may be due to the fact that many individuals are dying very prematurely.

Even when a diagnosis of type 1 diabetes is made, in resource-poor settings, achieving good blood glucose control, which is essential to reduce the risk of long term complications such as retinopathy and nephropathy, is difficult. Again, recent analyses are limited. In a study carried out in Sudan,[15] glycaemic control was unsatisfactory in 86% of 147 children with type 1 diabetes, with the most frequent pre-meal blood glucose being 9mmol/L or higher. In Tanzania, only one type 1 diabetic from a cohort of 99 achieved 'good' glucose control (HbA1c <7.5%) and average HbA1c was 12.6% ± 3.5%, deemed to be 'very poor'.[4] Even in South Africa, it was shown that individuals had poor diabetic control with an average HbA1c of 10.62% in African natives.[16] Given that these studies were undertaken in urban regions and are representative of urban healthcare rather than the situation in resource-limited rural areas, it is reasonable to presume that the figures for rural sub-Saharan Africa may be even worse.

Poor glucose control in type 1 diabetes leads to an accelerated onset of the complications of diabetes and an overall negative impact on health. High rates of diabetic nephropathy[16] and diabetic retinopathy,[4] as well as detrimental effects on academic performance[15] have been reported in sub-Saharan type 1 diabetics. Hospital admissions are frequent[15] and diabetic ketoacidosis is a common diabetic emergency often leading to mortality, with death rates ranging from 25% in Tanzania to 33% in Kenya.[17] In a study undertaken in the DR Congo analysing mortality rates over a 10 year period, 17.4% of young diabetics died, most within five years of diagnosis, and over a third of the deaths were due to diabetic ketoacidosis.[18] It has been suggested that, in at least some countries in sub-Saharan Africa, life expectancy is improving,[17,19] however the trend is far from clear and evidence incredibly limited.

Why is managing type 1 diabetes in sub-Saharan Africa fraught with so much difficulty? Insulin is the drug vital to sustain life in type 1 diabetes. Relative to the total healthcare budget available in sub-Saharan Africa, insulin is expensive,[12,19] and a regular supply of insulin is unaffordable for many.[9] The insulin supply can also be erratic in sub-Saharan countries,[4] Lack of insulin due to availability and affordability is a major obstacle to individuals with type 1 diabetes in sub-Saharan Africa.[20]

In many countries, no medical insurance or free national health service is available and patients have to pay for all their medical care.[7] Elrayah *et al*[15] high-light, in their study in urban Sudan, that the costs of diabetes management constituted a large portion of the total household financial outgoings, and 65% of the family's health expenditure was required for the diabetic child. Of this, more than a third of the money was spent on insulin. In Tanzania, the monthly cost of an average insulin treated patient is equal to 25% of the minimum wage.[21] It has been estimated that in the world's 34 poorest countries, the direct cost of diabetes care per affected person is nearly 125% of the gross national income per head.[22] Type 1 diabetes is an expensive disease to manage and its burden is magnified in developing countries. Chronic self-underdosing with insulin occurs to economise and make supplies last for longer.[19] Underdosing of insulin leads to dangerous hyperglycaemia, and, if an individual is unable to pay for treatment, the untreated diabetes will be fatal.

Management of diabetes also requires syringes to administer insulin, blood glucose testing strips and meters, all of which also have intermittent availability in sub-Saharan Africa.[23] Majaliwa *et al*[4] report that no children in their study of 99 type 1 diabetics in Tanzania had capability to monitor glucose levels at home. Even in hospitals, especially in more remote settings, blood glucose measurements cannot be routinely performed due to a lack of facilities; in Mozambique, only 21% of health care facilities were found to have a blood glucose meter.[24]

In recent years the issue of access to medicine has emerged into the public spotlight, however much of this attention has focused on drugs to treat communicable diseases such as HIV, malaria and tuberculosis. The International Insulin Foundation (IIF), founded in 2002, has investigated the issues regarding the affordability and accessibility of insulin as well as the barriers to proper diabetes care in several countries in
sub-Saharan Africa including Mali, Mozambique and Zambia.[12,19,23,25] Multiple problems were found including inadequate assessment of needs, distribution diffi-ulties and poor knowledge in the health care system on insulin and how it should be utilised.[19] A single price for insulin was not set within each country and prices were found to be dependent on location of the purchase, the supply chain, and the method of purchase.[25] Syringes and glucose testing equipment also had varying prices and limited availability.[23]

Just as important as the availability and affordability of diabetes medication and equipment is the presence of specialist healthcare workers to provide diabetes education as well as multidisciplinary sup-port teams. In most African communities, the notion of a specific diabetes care team is uncommon.[7] Investment and research have been slow to respond to the burden of chronic diseases such as diabetes and health systems still remain heavily focused on

infectious diseases.[1] Correspondingly, Elrayah *et al*[15] point out that *'the present organisation of diabetes care does not give the patient empowerment, knowledge and self-care ability'.*

Despite the evitable challenges faced in improving the situation for type 1 diabetics in sub-Saharan Africa, small steps are being made and initiatives have been implemented. As aforementioned, insulin alone will not improve the lives of type 1 diabetics; instead, many factors are necessary which accumulate to build a 'positive diabetes environment'[23] (see appendix 1). The IIF, with it's focus as the *'universal availability of insulin for those with type 1 diabetes as a basic human right'*[19] has developed the 'Rapid Assessment Protocol for Insulin Access', a scheme which has analysed the situation for type 1 diabetes in three sub-Saharan countries. The resulting documentation has acted as a catalyst in driving better access to diabetes care, including the improved availability of insulin and diabetes equipment, and in bringing diabetes to the attention of health authorities.[26]

An equity pricing system by the world's two major pharmaceutical companies producing insulin (Novo Nordisk and Eli Lilly) has been implemented in the world's 50 least developed countries which has significantly lowered the price of insulin,[12] however, the scheme only applies to the limited amount of insulin purchased by governments and not that bought by private pharmacies.[19] Some countries, such as Mozambique and Mali, have systems in place for patients to receive free or subsidised insulin from government health facilities when available.[25]

The organisation 'Insulin for Life'[27] was founded in 1999[1] and is a not-for-profit organisation which obtains excess insulin, syringes, glucose testing equipment and other diabetic supplies (that would otherwise be wasted) from developed nations, and distributes these supplies to low income countries, saving the lives of significant numbers of individuals with type 1 diabetes. The International Diabetes Federation 'Life for a Child' initiative,[28] established in 2000, provides funding and support to established diabetes clinics across the developing world, including 17 countries in Africa. British charity Diabetes UK's twinning program with Mozambique has, amongst it's initiatives, improved insulin availability
at hospitals from 20% in 2003 to 100% in 2009, and
trained 265 healthcare professionals in diabetes over a three-year period.[29] Many other smaller scale projects within sub-Saharan countries are increasing aware-ness of diabetes among healthcare professionals and improving health care facilities.[13]

A steady rise in type 1 diabetes has been reported in many countries.[1,5] Whether the same is true for sub-Saharan Africa lacks a solid evidence base and further studies are imperative to determine the scale of the problem. Nonetheless, it is clear that people are dying and facing unnecessary morbidity due to unsatisfacto-ry care and treatment of type 1 diabetes. Improving access to insulin, syringes and blood glucose monitor-ing equipment is a vital step necessary to improve the lives of type 1 diabetics in sub-Saharan Africa, but this alone will not solve the dilemma. The omission of non-communicable disease from the Millennium Development Goals has caused difficulties in securing funding for non-communicable disease development programmes,[30] however, many promising initiatives are proving successful in facilitating improved dia-betes care in several sub-Saharan countries. Without a doubt, there is still a long road ahead to ensuring all people with type 1 diabetes in sub-Saharan Africa receive appropriate care and do not face unnecessary premature mortality and long term morbidity.

Appendix 1

Requirements for a 'positive' diabetes environment

1 organisation of the health system
2 Data collection
3 Prevention
4 Diagnostic tools and infrastructure
5 Drug procurement and supply
6 Accessibility and affordability of medicines and care
7 Healthcare workers
8 Adherence issues
9 Patient education and empowerment
10 Community involvement and diabetes associations
11 Positive policy environment

Table adapted from Beran & Yudkin (2010).

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Ron Raab, the founder and President of 'Insulin for Life', began collecting and distributing insulin himself in 1984, before the organisation was founded.