

The Diabetes Foundation report on implementing national diabetes programmes in sub-Saharan Africa



Diabetes Foundation

International Insulin Foundation

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Acronyn	ns	MSF	Médecins sans Frontières (Doctors Without Borders)
AIDS	Acquired Immune Deficiency	NCD	Non Communicable Disease
	Syndrome	NGO	Non Governmental Organisation
AMLD	Association Malienne de Lutte	NIDDM	Non Insulin Dependent Diabetes
	contre le Diabète		Mellitus
AMODIA	Associação Moçambicana dos	RAPIA	Rapid Assessment Protocol for Insulin
	Diabéticos		Access
BMI	Body Mass Index	SDM	Santé Diabète Mali
DAZ	Diabetes Association of Zambia	SEMDSA	Society for Endocrinology, Metabolism
DOT	Directly Observed Therapy		and Diabetes of
HIV	Human Immunodeficiency Virus		South Africa
IDDM	Insulin Dependent Diabetes Mellitus	STEPS	STEPwise approach to surveillance
IDF	International Diabetes Federation	ТВ	Tuberculosis
IGT	Impaired Glucose Tolerance	TDA	Tanzanian Diabetes Association
lif	International Insulin Foundation	UNICEF	United Nations Children's Fund
MDGs	Millennium Development Goals	WHO	World Health Organization

Executive Summary

The International Insulin Foundation was established to study the barriers to access for people with Type 1 diabetes with regards to insulin and care. Through its work in Mali, Mozambique and Zambia it has been able to assess these barriers and propose in-country solutions.

This report was prepared using this field experience, discussions with key opinion leaders, a thorough review of the literature and the proceedings of an International Diabetes Federation Africa Region and a World Health Organization AFRO meeting held in Nairobi (2-3 March 2006) and in Bamako (29-30 June 2006). The aim of this report is to look at the 11 key elements needed to implement a national diabetes programme and propose concrete actions.

These 11 elements are:

- 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

Each section comprises an introduction, different examples and finally recommendations.

Based on the IIF's experience, **strong political** will is necessary in order for a national diabetes programme to be established. This political will can be generated through different means, but one of the necessities is **data** on the size and scope of the problem of diabetes. The role of a **diabetes association** is also essential in pushing this forward.

Once political will has been established, the development of **a national diabetes programme/policy** is needed in order to ensure continuity and guiding principles. This should help establish better organisation of the health system for care, medicines and other tools necessary for diabetes management. This should also include such elements as **prevention** and address the issues of **accessibility and affordability of medicines and care**.

In parallel, **education for healthcare workers** needs to be implemented, both for those in training and those already practising.

Healthcare workers need to work towards **patient education and empowerment** in conjunction with the diabetes association.

Different countries will be at various stages of organising care for diabetes. The aim of this report is to serve as a guide for a specific part of this implementation process or to serve as a recipe for countries with nothing in place.

Foreword

Why Diabetes in sub-Saharan Africa?

Leonard Thompson, a Canadian child, was given his first injection of insulin on 11 January 1922 (1). He was the first patient to be treated with insulin for Type 1 diabetes (also referred to as Insulin Dependent Diabetes Mellitus, IDDM). Having survived some 2¹/₂ years from his diagnosis, he had done better than most people with Type 1 diabetes in the pre-insulin era. As stated by Bliss (2), "Those who watched the first starved, sometimes comatose, diabetics receive insulin and return to life saw one of the genuine miracles of modern medicine."

Very little primary data exists on Type 1 diabetes in Africa and most information is based on anecdote. It appears, nevertheless, that three-quarters of a century after its discovery, insulin is still not available on an uninterrupted basis in many parts of the developing world (3-5). A survey in 25 countries in Africa found that in half of them insulin was often unavailable in the large city hospitals, while in only 5 countries was insulin regularly available in rural areas (6). Restricted access to insulin is not only due to lack of availability, but also to cost. Chale and McLarty (7) found that the annual direct cost for an insulin-requiring patient in sub-Saharan Africa was equivalent to US\$229, with almost 70% of this amount for the purchase of insulin.

In consequence, the life expectancy of a child with newly diagnosed Type 1 diabetes in much of sub-Saharan Africa may be as short as one year (8, 9). At present 98% of people with Type 1 diabetes in the USA survive 6 years after diagnosis, 15% of children in the pre-insulin era would survive for 6 years, but only 1% of children currently survive 6 years in sub-Saharan Africa (8). In Bamako, Mali after 8 years of follow-up 50% of deaths were reported in children with Type 1 diabetes (1990-1998) (10) and in 2004 none of the patients from this original cohort were alive (communication with author). Life expectancy after onset in rural Mozambique was found to be as low as 7 months (11). In addition, restricted access to insulin may result in debilitating complications such as amputation and blindness.

Bliss, in his book "The discovery of insulin" (2) relates the story of how the death of a little girl in April 1922 was the one time in Toronto that a patient who had been started with insulin extract died for want of it. Some 80 years after this tragic event, this is still unfortunately a common occurrence in sub-Saharan Africa.

The reason for these outcomes include socio-economic problems (lack of financial means and logistics), socio-cultural problems (illiteracy) and problems with adherence of young patients to treatment. These same barriers exist for people with Type 2 diabetes (also referred to as Non Insulin Dependent Diabetes Mellitus, NIDDM).

While good data on the epidemiology of Type 1 diabetes in Africa is lacking (12), it is clear that it is much less prevalent than in temperate countries, both because of a lower incidence and a poorer prognosis. It is estimated that in the 41 poorest nations in the world there are 19,000 people with Type 1 diabetes (13), almost all of whom find the availability or cost of insulin difficult. Even when insulin is available, its purchase may consume as much as half of the family's weekly income. A financial burden is also present for Ministries of Health in these countries where as little as US\$2 is spent per person, per year on medicines. Therefore, providing insulin for one child with Type 1 diabetes (at a cost of US\$100-\$150 per year) may mean not providing essential medicines to as many as 50 to 100 others (13).

This financial hurdle was was not present in insulin's early years. Frederic Banting, who together with Charles Best discovered insulin, was supposedly made an offer of over US\$100,000 and the opportunity to run private diabetes clinics, an offer he refused. He stated that, "... it was not even a temptation. It meant that the suffering diabetic would be exploited." With regards to the establishment of private diabetes clinics he stated "the indigent diabetic is our greatest problem. Every effort must be made to reduce the cost of insulin..." In 1922-1923 Krogh and Hagedorn started the non-profit Nordisk Insulin Laboratory in Denmark (2). Despite these valiant efforts in the early years of insulin's discovery and use, today price remains a major barrier for patient's adequate care in many situations in Africa.

It is with this in mind that leading academics and physicians in the field of diabetes created the International Insulin Foundation (IIF). The aim of the IIF is to propose concrete actions to solve problems of insulin access and diabetes care in the world's poorest countries in a sustainable way. The focus of the IIF's work has been insulin-requiring diabetes, however, the findings of it's work and experience can be extended to both types of diabetes.

In 2000 it was estimated that the prevalence of diabetes for all age groups worldwide was 2.8% and is projected to be 4.4% in 2030 (14). Most of this increase is due to obesity and its close link with Type 2 diabetes. However, the incidence of childhood diabetes is also increasing in many countries in the world with an estimated annual increase of around 3%. Incidence type 1 diabetesis rising more in low prevalence countries and increases in Europe are greatest in younger children (12).

Type 2 diabetes – a new public health problem in sub-Saharan Africa

The number of cases of Type 2 diabetes worldwide is estimated to be 150 million. This is however, is the minimum number, since it is estimated that for each person diagnosed there is one undiagnosed case in the developed world and 8 in the developing world (15).

The global trend of an increased prevalence of diabetes in African populations is closely linked to the increase in obesity. Indeed, Africa is experiencing one of the most rapid demographic and epidemiological transitions. It is characterised by a tremendous rise in the burden of non-communicable diseases and by the 'westernisation' of society (16). This is due to the "very advances for which modern societies strive—plentiful food, labour-saving machinery and longer lifespan foremost among them— [these] appear to enhance the risk of development of the diabetic state." (17) As the prevalence of diabetes continues to rise, the parallel increase in complications will put a strain on health care resources (18). In Tanzania, a study found that the treatment of complications was the second highest outpatient cost, representing 30.8% of total costs or US\$839,392 (7).

Much of the burden of disease that affects the population in sub-Saharan Africa can be prevented or cured with known and affordable technologies. The barrier to getting these treatments to patients is the lack of availability of staff, medicines, and information at the right time, in a reliable manner, and in sufficient, sustained and affordable quantities (19). The increase in Type 2 diabetes contributes to chronic conditions being the largest cause of death in the world, led by cardiovascular disease and followed by cancer, chronic lung diseases and diabetes mellitus, causing 29 million deaths worldwide (20). Worldwide, 3.2 million deaths are attributable to diabetes (21) every year compared to 3.1 million (2.8 – 3.5 million) that are caused by AIDS (22).

It is interesting to note that in developed countries most people with diabetes are above the age of retirement, whereas in developing countries those most frequently affected are aged between 35 and 64 (21), therefore impacting people in their most economically productive years.

In most developing countries, inadequate financing and lack of manpower to address chronic diseases have been major barriers to chronic disease control. Other impediments are the failure to provide key decision makers with up-to-date evidence on the burden of chronic diseases; a lack of understanding of the economic factors that influence chronic disease risks; and the current orientation of health systems towards acute care. The chronic disease management model is more complex than that required for acute problems, such as many infectious diseases. It entails multiple causes over a lifetime and a more horizontal and integrated approach, with patient, family and the community being active participants (20).

An element of care within this integrated approach is the provision of insulin, which is vital for the survival of people suffering from Type 1 diabetes (and in some people suffering from Type 2 diabetes), as well as the provision of other medicines. Also of central importance are the means to administer the medication (syringes/needles), the means to monitor the response to insulin (blood/urine tests) and an understanding of how diabetes affects the life and work of an individual.

Diabetes in people in sub-Saharan Africa is a serious disease with poor prognosis. Most deaths are due to preventable causes and to address this, efforts are needed to increase public awareness of diabetes and to improve patient detection, management, and follow up (23). Part of the problem is that the International community does not recognise the problem of Non Communicable Diseases (NCD) and diabetes in sub-Saharan Africa. For example, over the last 5 years the World Bank has provided US\$4.25 billion in Ioans to countries for health sector work, about 2.5% of which was allocated to NCD prevention and control programmes, which were all in Eastern Europe (20).

Diabetes is not yet considered a major health problem in sub-Saharan Africa, even though it is already a major contributor to ill health and the overall burden placed on the health system. It is amenable to simple preventive measures and can be treated and managed with insulin and medicine, properly trained health workers and a health system, which is able to cope. Currently what is lacking is a sense of urgency from local, national and international actors. The African Declaration on Diabetes to be launched in the coming months aims to address this. It states that all people with diabetes should have the opportunity to access high quality and affordable services, medications, and supplies to optimise the outcomes of their diabetes.

In his 1901 notes on the diseases met in Africa Dr. Cook wrote "... diabetes is very uncommon, but very fatal..." (24). It should be everyone's wish that Type 1 diabetes become more common (meaning more cases are identified and treated), showing better diagnosis and prognosis for children in Africa. However, the worrying increase in Type 2 diabetes also needs to be addressed in a serious and effective manner. The warning signs of an emerging Public Health problem are evident. It is now up to various partners, both at a national and international level, to play an active role in tackling this epidemic in sub-Saharan Africa.

Introduction

Health systems in sub-Saharan Africa face an immense challenge in tackling HIV/AIDS, tuberculosis (TB) and malaria, the major contributors to ill health, loss of productivity and death among adults, as well as diarrhoeal disease and respiratory infections, which contribute substantially to mortality rates, particularly in under-5s (25).

In parallel many African countries are now facing a growing challenge from the increasing numbers of people with hypertension, stroke, coronary heart disease and diabetes (26). This has been called the 'double disease burden' and poses challenges to the healthcare of resource-poor countries, in part because of the demands it places on the need to invest in systems to provide both ongoing delivery of medicines and the knowledge and training of health care workers in managing chronic disease.

Problems identified by the World Health Organization (WHO) (27) in relation to healthcare organisation and NCDs are:

- Failure to organise care for chronic conditions;
- Health care workers lack tools and expertise;
- Practice is not informed by scientific evidence;
- Failure to address prevention;
- Information systems are not in place;
- Failure to connect with community resources

This report is based on the field experience of the IIF, a thorough review of the literature and the proceedings of an International Diabetes Federation (IDF) Africa Region and a WHO AFRO meeting held in Nairobi (2-3 March 2006) and in Bamako (29-30 June 2006). The aim of this document is to provide a guide to countries in sub-Saharan Africa wishing to implement a National Diabetes Programme.

Each section of this document highlights problems identified during the implementation of the IIF's Rapid Assessment Protocol for Insulin Access (RAPIA). Each part briefly introduces the problem, presents examples of how this particular issue has been tackled in different settings and finally proposes actions that countries can take to address these problems.

This work was made possible thanks to a generous grant from the Diabetes Foundation. More information about the Diabetes Foundation can be found in Appendix 1.

The views expressed in this report are those of the author alone and not necessarily those of the Diabetes Foundation or any of the IIF's other contributors or partners.

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Section 1: Organisation of Health Systems

"The health system encompasses all the organisations, institutions and resources that are devoted to producing health actions whose primary intent is to improve health."

World Health Organization (27)

Introduction

The following have been identified as constraints preventing health systems from achieving the Millennium Development Goals (MDGs) and as failings of the health system with regards to diabetes (28, 29):

- Inequitable access to services;
- Multiple providers: public, private and traditional;
- Provider behaviour towards patients;
- Poor patient attendance;
- Consultation times are too short leaving little or no time for patient education;
- Lack of physical infrastructure and equipment;
- Human resources need more training, better utilisation of existing resources and management including payment mechanisms, quality of care and supervision;
- Inadequate drug supplies and supply systems;
- Poor service management capacity;
- Complications are not monitored or evaluated in a systematic manner;
- Poor control of blood glucose and blood pressure;
- Inadequate referral systems;
- Lack of communication;
- Absence of patient education;
- Poor organisation of services;
- Deficient record keeping;
- Lack of preventive measures.

Health systems in sub-Saharan Africa are currently organised for the treatment of acute not chronic conditions (29). This presents a challenge since the management approach to a chronic disease differs significantly from the approach used for an acute condition in that the person with diabetes (or any other chronic disease) has to develop self-management skills as they are responsible for their day to day care (30). In parallel, people with diabetes need long-term follow-up and treatment, continuity of care and continuous access to medicines supplies and specialists and services.

The care for acute diseases is based on the 19th Century model of illness being a disruption of the normal state produced by a foreign presence or external trauma, e.g. infection or injury (31). This means that there are only two endpoints possible, either cure or death. The outcome of the treatment for a chronic condition is different. The aim of acute care is cure, whereas for chronic conditions it is the prevention of complications and death.

This section will highlight some examples of interventions that have taken place in different countries with regards to diabetes and chronic disease management, which may provide steps to improve care for diabetes in this region.

Examples

The necessary steps to address the problem of chronic respiratory disease, and these could also be used in relation to other NCDs, in sub-Saharan Africa are found to be (32):

- · Political engagement to mobilise human and financial resources
- A programme that is integrated within the health system
- Tools for diagnosis must be readily available
- Medicines need to be available
- A system of notification and follow-up
- Prevention policies
- Training of healthcare workers

In Jamaica (33) and in Tanzania (34), specialised clinics have been established for diabetes care. In Jamaica these clinics supplement the public health system in rural areas. The Tanzanian Diabetes Association (TDA) together with the Ministry of Health has established 44 clinics spread throughout the country. They are run by the district, regional and referral hospitals. Staff are provided by the Ministry of Health and their training and education is supported by international partners. These clinics are organised in the same way as the Tanzanian health system. For a more detailed description of the organisation of diabetes care in Tanzania please refer to Appendix 2.

The costs of consultations, medicines and laboratory tests in both Jamaica and Tanzania are covered by patient contributions and subsidies.

Interventions targeted at (35-37):

- Increasing professional's knowledge of diabetes
- · Improving the frequency of patient reviews
- Patient-oriented interventions
- More emphasis, responsibility and education for nurses

were shown to have a positive impact on patient outcomes. These reviews were targeted at interventions in developed countries and therefore their relevance to developing countries must be assessed appropriately.

A project dealing with epilepsy in rural Mali provides an example of how a chronic disease can be managed properly in difficult circumstances (38). This project included education for the individual, family, and village leaders as well as providing patients with an uninterrupted supply of medicines. People with epilepsy were followed up at home by a doctor with basic training in epilepsy.

The role of nurses is essential in chronic care in developing countries. This is shown for the care of asthma in rural South Africa (39) and diabetes in sub-Saharan Africa (40).

In Brazil (41) and Rwanda (42) auxiliary health workers and volunteers were trained to provide support for families. This was both for basic interventions and also how to cope with disease and death.

Referrals are also an essential part of the organisation of care. In looking at this issue with regards to eye care, barriers to proper referral in Mozambique were found to be (43):

- Cumbersome referral systems
- Problems with transport
- Problems related to the supply of medicines
- Insufficient knowledge of primary healthcare workers with regards to eye problems
- Overloaded specialist services
- Insufficient communication and coordination between services

Referral pathways were often non-existent or poorly used in Mozambique and Zambia (11). Three main problems related to referral identified in Zambia (44) are:

- Lack of information given to users about their diagnosis in general and specifically about the reasons for referral;
- Many of the patients referred were not given a letter which should have facilitated their entry into the hospital system;
- Lack of linkage from the hospital back to the urban health centres for follow-up.

A diagram detailing the factors that can impact patient referrals can be found in Appendix 3.

In developing programmes for HIV/AIDS and the provision of ARVs, the following factors were identified as being vital (45-47):

- Provision of care and medicines close to the patient's home
- Establishing a close relationship between the patient and healthcare workers

Prevention and care need to be close to the individual in order to avoid, what has been described as distance decay (48). Distance decay is defined as the declining intensity of a given activity as the distance from its point of origin increases. This concept stresses the importance of having preventive and care services near the community and also good referral

systems in order to limit barriers to access that will mean that people who are far from health providers will not use services adequately.

Recommendations

In order to achieve lasting change for proper care for diabetes, political will needs to be present and sector wide changes need to be implemented. The Ministry of Health plays a vital role in establishing the appropriate environment for diabetes care. The Ministry is not only involved in the organisational aspects of health care provision, but also the social and economic. The WHO's Innovative Care for Chronic Conditions Framework (49) provides eight essential elements for taking action in order to shift the health system's focus from acute to chronic conditions:

1. Support a Paradigm Shift – Health systems in developing countries are now facing a "double burden" of disease, due to shifts in disease patterns and an ageing population. The paradigm shift needs to take systems that are currently organised around acute care and design them to manage diabetes and other chronic conditions. In order to tackle these chronic conditions, including HIV/AIDS and tuberculosis, it is going to be necessary to strengthen health care systems in sub-Saharan Africa. Chronic conditions need continued monitoring of the patient and a continuum of testing, medicines and care.

Treatment guidelines and algorithms need to be used for the management of diabetes. The IDF Africa has developed some of these guidelines and they are suited to the situation in sub-Saharan Africa. In addition, a personalised assessment of the patient is necessary taking into account their personal characteristics, diet and lifestyle.

Referral pathways need to be established and the role of each level of the health system in the provision of diabetes care needs to be determined. Each level of the health system will also need to have appropriate mechanisms established for the collection of data (Section 2: Data Collection).

For proper diabetes care private sector healthcare providers and traditional healers also need to be included in policies and programmes.

The organisation of diabetes care can have external support, international NGOs, local associations, etc., but should be fully integrated with the Ministry of Health's facilities and fit into the organisational structure of the health system. This organisation of care needs to optimise the use of resources available.

2. Manage the Political Environment – The RAPIA carried out by the IIF in Mali, Mozambique and Zambia (Section 2: Data Collection) provided a basis from which NCD policy documents could be formulated.

The Ministry will need to identify appropriate financing and funding for these diseases. For this purpose, studies to show the burden of disease and size of the problem are necessary (Section 11: Positive policy environment).

3. Build Integrated Health Care – Each level of the health system has a role to play in diabetes care, and thus needs certain materials and human resources to be available. Also, a certain level of organisation and coordination between different levels of the health system and different sectors within the same institution (inpatient and outpatient services, pharmacy, laboratory, etc.) need to be in place for patient management and referral.

The establishment of "parallel" diabetes clinics by international or national NGOs is a possible solution to addressing the lack of capability in the Public sector. However, these clinics should be fully integrated within the public sector provision of care in order to promote an integrated health system. The health system should provide basic diagnostic and patient education at different levels, including a national centre of excellence for referral and the treatment of complicated cases.

The WHO (50) has defined the general principles of good chronic care, as follows:

- Develop a treatment partnership with the patient;
- Focus on the patient's concerns and priorities;

- Use the 5 A's: Assess, Advise, Agree, Assist and Arrange;
- Support patient self-management;
- Organise proactive follow-up;
- Involve "expert patients", peer educators and support staff in each facility;
- Link the patient to community based resources and support;
- Use written information registers, treatment plans, treatment cards and written information for patients to document, monitor and remind ;
- Work as a clinical team;
- Assure continuity of care.

All these aspects should be included in the organisation of care and also be part of the training of healthcare workers (Section 7: Healthcare workers).

Based on discussions at the International Diabetes Federation Africa Region and World Health Organization AFRO meetings held in Nairobi (2-3 March 2006) and Bamako (29-30 June 2006) it was suggested to have the following organisation of care:

Primary healthcare level:

- Make presumptive diagnosis
- Refer to secondary level for initiation of treatment
- Routine care using the IDF clinical guidelines as a basis. The role of the Primary healthcare worker is to manage the person with diabetes. Any abnormal blood or urine glucose results or complications would mean the patient is referred to the Secondary care level.
- Patient education

Secondary healthcare level:

- Confirmation of diagnosis from Primary level
- Initiation of treatment and education
- Screening for complications
- Routine care, referral back to and support to Primary level

Tertiary healthcare level:

- Establish diabetes centres
- Diagnosis of complications
- Provision of care for complications
- Routine care, referral back to and support to Secondary level

Each level would monitor the level below it to ensure patients receive quality care. This would be done by using different tools for data collection (Section 2: Data Collection).

4. Align Sectoral Policies for Health – For effective management of chronic conditions, policies need to be aligned with others that impact on health. One such example of addressing the multi-sectoral approach to create a favourable policy environment for people with diabetes is to remove any taxes on materials used by people with diabetes, or change legislation on food.

Medicines are an important part of the patient's treatment, but also a major cost. Other costs include consultation and laboratory fees that the patient may need to pay as well as other indirect costs such as travel and loss of income due to attending diabetes clinics. Cost aspects of medicines will be dealt with in the section on accessibility and affordability (Section 6: Accessibility and affordability of medicines and care), but a clear policy statement from the government is needed on price controls, subsidies or special arrangements for patients.

As diabetes will place a life long financial burden on patients, the Ministry of Health should try to integrate health services with others such as social services.

5. Use Health Care Personnel More Effectively – Using healthcare workers effectively ensures that the patient benefits from a higher level of care.

Many countries are faced with staff shortages. Certain roles in diabetes care may therefore need to be passed on to different staff, for example nurses and clinical officers. In some instances roles may even be devolved to the community. Nursing staff or non-clinically qualified staff can take on major roles in the treatment programme of chronic conditions and reduce the workload of physicians. In addition new positions such as dieticians may need to be created or specialised nurses trained (47). (Section 10: Community involvement and diabetes associations)

Another player in the care of people with diabetes is the pharmacist. Most patients will need some form of medication during the course of their treatment. The pharmacist can play an additional role of explaining the treatment course to the patient and reiterating and supporting information the patient has been given by doctors or nurses.

For all these healthcare workers continued training is necessary in the clinical aspects of diabetes. However, just as important is training in other management and communication techniques that would help them deal with people with diabetes (Section 7: Healthcare workers).

6. Centre Care on the Patient and Family – Because the management of diabetes requires lifestyle and daily behaviour changes, care should be focused on the individual and his/her family.

Problems with transport (distance and cost) lead to problems for patients trying to access health facilities with the necessary infrastructure for diabetes care.

In addition, when patients are able to attend a specialised facility, they face long waiting times and short consultations. Two important factors for diabetes care are the continuity of care and the length of time that the carer spends with the patient during the consultation. Both allow the patient to build a trusting relationship with his/her carers and an exchange of vital information to take place. Once the individual has diabetes, they will have the condition permanently and so it will have a big impact on their everyday life. They will need to have a full understanding of this fact and learn how to deal with the new condition.

Regular follow-up is necessary to ensure no complications have developed, the patient is following their treatment and to answer any queries patients may have about their life with diabetes. Diabetes impacts all aspects of an individual's life and healthcare workers need to take this into account.

Follow-up visits and clinics should be organised around the patient and be close to their home in order to avoid conflicts with work and schooling as much as possible. This will increase attendance at these follow-up sessions and decrease any stigma attached to the condition.

An essential part of diabetes care is patient education with regards to treatment, diet and lifestyle. The IDF has developed guidelines for patient education, which can be used in order to empower the individual with regards to his/her treatment (Section 8: Adherence issues).

7. Support Patients in their Communities – The main community involvement in diabetes care is often through the diabetes associations. Involvement of other community members such as local government officials, village chiefs or elders, as well as traditional healers is also important. (Section 10: Community involvement and diabetes associations)

8. Emphasise Prevention – For Type 1 diabetes the only form of prevention possible in sub-Saharan Africa is tertiary prevention, the prevention of complications and death. Through improving the health system and increasing training this can be achieved. These improvements will also benefit people with Type 2 diabetes and other chronic conditions. This is discussed further in the Prevention section of this report (Section 3: Prevention).

Section 2: Data Collection

"An essential step towards improving health is to understand the distribution of disease, death and disability. This requires the systematic collection, analysis, and dissemination of timely, and accurate information on mortality, morbidity, and risk factors."

World Bank (51)

Introduction

This section of the report will look at different tools that can be used to collect basic information on the population with diabetes in a given area or country. It will also highlight different research tools and methodologies available to enable data collection and estimates of prevalence.

It has been shown that patient registers are needed when addressing NCDs in rural South Africa (52). These registers can be used to organise patient and population data to facilitate efficient and effective care by for example, providing reminders for providers and patients of appointments (53). Registers also allow for improved epidemiological surveillance (54).

The WHO AFRO Region calls for the establishment of a local database on the burden of morbidity, risk factors and principal determinants of NCDs (55). This would enable countries to address the emerging challenge of diabetes.

Besides providing information on mortality and morbidity, collection of data is also key in operationalising (56):

- Policy implementation
- Planning
- Monitoring
- Evaluation

Examples

In looking at Tanzania, routine data is collected in the following ways at different diabetes clinics established around the country:

- Attendance records (daily)
- Patient files (daily)
- Registers for Ministry of Health (daily)
- Numbers of patients attending education sessions including strong, weak points and areas for improvement for these sessions (weekly)
- Data on numbers of daily check-ups and education, clinic follow-ups, new cases at clinics (monthly)

This information is then used to inform different stakeholders with regards to numbers of patients, complications and quality of care.

In conjunction with these routine tools for data collection, districts, regions and countries may be interested in studying the prevalence of diabetes, risk factors for diabetes and other NCDs or the capacity of the health system to provide adequate care for people with diabetes. This has been done in Cameroon and Tanzania and was extremely helpful with the development of their diabetes policy and programmes. Examples of the types of studies are found in Appendix 4.

The WHO has developed the STEPwise approach to surveillance (STEPS) which focuses on the major risk factors that predict the most common NCDs (57).

The STEPS approach to surveillance provides a framework, which defines core variables for population-based surveys, hospital-based surveys, surveillance and monitoring instruments to achieve data comparability over time and between countries. STEPS is based on the concept that surveillance systems require standardised data collection as well as flexibility to be applicable in a variety of countries (58).

STEPS uses standardised questions and protocols. The protocol encourages the collection of small amounts of useful data information on a regular and continuing basis adopting standard methodology and sample size to detect trends in age and sex group (58) for epidemiological purposes.

STEPS is a sequential process, starting with gathering information on key risk factors by the use of questionnaires (Step 1), then moving to simple physical measurements (Step 2), and only then recommending the collection of blood samples for biochemical assessment (Step 3) (58).

The protocol calls for the surveillance of just eight selected risk factors, which may contribute a large part to the future NCD burden and can provide a measure of the success of interventions. These different risk factors are shown in Appendix 5.

The RAPIA developed by the IIF is a tool that can be used to assess the possible barriers to insulin access and diabetes care in a particular country (59). The questionnaires and the questions included in this protocol follow each level of the organisation of insulin supply from its arrival in the given country until it reaches/or fails to reach the patient. In parallel, the path of care was assessed from the highest levels of the health system, to regional/provincial organisations, hospitals, clinics and finally individual carers and people with diabetes. In addition, this tool is able to estimate the prevalence of diabetes.

The aim of RAPIA is to provide a practical field guide to assist teams in the collection, analysis and presentation of data and to evaluate and inform the development of health care services for diabetes management in resource poor settings. A detailed table of the questionnaires that comprise the RAPIA and the different areas that the RAPIA covers can be found in Appendix 6 and Appendix 7.

Recommendations

Data is needed at different levels for planning and organisational purposes. Data serves a different role at each level from reminding a healthcare worker about the last blood glucose a patient has had to calculating the number of people with diabetes in a given area.

The WHO STEPS and RAPIA tools can be used to provide background information that can assist in this process.

A combination of STEPS and the RAPIA can not only help in estimating the prevalence of diabetes and its related risk factors, but also assess the capabilities of the health system to care for people with diabetes and identify any barriers present.

Additional to larger scale data collection, information with regards to the individual patient needs to be collected. This can take the form of a patient file, kept at the health facility and/or a patient note book that the patient is required to keep and bring with them at every consultation. These should record the following information:

- Demographic and contact information
- Height and weight
- Date of diagnosis
- · Examinations and tests done at every visit
- Medicines prescribed

Registers should also be kept at each facility. These can then be regrouped on a district or regional level and then finally on a national level.

This collection of data should be standardised, either through paper or electronic registers.

Section 3: Prevention

"The only effective and equitable response to the global disease burden is to emphasise and strengthen preventive programmes."

Beaglehole and Bonita (60)

Introduction

Prevention of a disease can be tackled at three levels. Primary prevention is targeted at preventing the onset of the disease. Secondary prevention aims to detect the disease at an early stage and try to reverse its course. Finally, tertiary prevention aims to prevent and delay complications and death.

Figure 1 – Different levels of prevention



Adapted from Falkenberg (61)

The following diagram shows the course from the general population to a person having diabetes with complications and death.

Figure 2 – Different stages of diabetes

General	At risk	At risk	Undiagnosed	Diagnosed	Diabetes	Death	
Population	Overweight or obese	impaired glucose	diabetes	diabetes	complications		
Without diabete	es			With diabet	es		

Adapted from Epping-Jordan et al. (62)

Each change in level of colour shade is an opportunity for prevention.

Prevention is needed not only to avert much suffering of people with diabetes, but also to prevent increased use of and costs to the health system, engendered by complications. Data from Tunisia (63) and many other countries show that people with diabetes use the health system more than twice as frequently as people without diabetes, at over double the cost to the patient or to the system.

All prevention strategies need to take into account the person's "perceived threat" which is divided into two aspects. These are the "perceived susceptibility", the view the person has of how likely they are to get a certain condition and the "perceived severity" of the condition, which is the perception of how serious the illness is and the consequences of leaving it untreated (64). For example, it is important for people who have family members with diabetes to know that they are at greater risk, and also that left untreated diabetes can lead to serious complications. Cues for action also need to be on hand for patients. These are either the recognisable symptoms of diabetes (bodily events) or publicity (environmental). The perceived benefits of prevention and treatment need to be included in any media campaigns as well as community and healthcare worker information. In parallel, the perceived barriers that the proper prevention and treatment of diabetes may pose to the individual patient needs to be minimised through the same channels.

The diagram in Appendix 8 (65) shows how different levels of the health system need to work together in order to promote the prevention of Type 2 diabetes.

There is a certain "lag time effect" with NCDs, which means that present cases of diabetes are due to past exposure to risk factors (66). These are currently unknown for Type 1 diabetes, but an increase in obesity and a sedentary lifestyle are well known risk factors for Type 2 diabetes. Changes in food systems and patterns of work and leisure, and in diets and physical activity, are causing overweight, obesity, diabetes, high blood pressure, cardiovascular disease including stroke, and cancer even in the poorest countries (67).

Examples

Since "risk operates across a continuum for most variables", it has been suggested that "many more events arise from the 'moderate' middle of the distribution than from the 'high-risk' tail" (66). It is therefore best to avoid using a high risk approach and focus on a population based approach for the prevention of diabetes (60).

The triggers of autoimmunity that cause Type 1 diabetes are still unknown therefore for the time being the only form of prevention for Type 1 diabetes is Tertiary prevention. The 3 main risks for the increasing global prevalence of Type 2 diabetes are increasing life expectancy, urbanisation and obesity

In designing prevention strategies aimed at increasing exercise and modifying diet it is important to know the cultural aspects linked to these. For example, in many societies in sub-Saharan Africa it is difficult for women to exercise. In other cultures to be fat is to be wealthy and healthy and weight loss is associated with HIV/AIDS and other illnesses.

In a recent review, the following proposed preventive interventions are thought to be applicable to South Africa (68). Obesity prevention and treatment should be based on education, behaviour change, political support, intersectoral collaboration and community participation, local action, wide inclusion of the population, adequately resourced programmes, infiltration of existing initiatives, evidence-based planning, and proper monitoring and evaluation. Interventions should have the following components:

- Reasonable weight goals
- Healthy eating
- Physical activity
- Behavioural changes

Prevention should be managed in community services, identification of high-risk patients in primary healthcare services and treatment of co-morbid diseases in hospital services. A two-pronged approach has been advocated, with a health promotion programme directed at the whole population and interventions to encourage early diagnosis and management of persons at risk.

The means of doing this can be through:

- School and education
- Legislation
- Dietary guidelines
- Tax relief for companies providing occupational health and preventative services
- Media

In a review of 14 countries including South Africa and Tanzania the following types of interventions have been suggested (67):

- School meals
- Nutrition education
- Physical activity
- Work place programmes
- Screening
- Exercise
- Healthy menus in cafeterias
- Physical activity
- Community oriented programmes
- Promotion of exercise in culturally appropriate ways
- Health promotion policy
- Food, nutrition, physical activity and other risk factors
- Annual healthy lifestyles campaigns
- Television programmes
- Radio
- Promotion of healthy local diets
- Training of housewives for healthy cooking

Type 2 diabetes should be viewed as a complication of obesity and different measures have been implemented in developed countries to prevent obesity (69). These include:

- Diet
- Exercise
- Behaviour modification
- Drugs
- Surgery

It has been shown that two strategies have been successful in preventing diabetes (70, 71). One is a pharmacological intervention and the other a lifestyle intervention. The pharmacological intervention involves the use of glucose lowering drugs and the lifestyle intervention requires a high level of input from staff. Lifestyle interventions were able to achieve a significant enough weight reduction to lower the incidence of diabetes, while pharmacological interventions were not as efficacious (71). There have been numerous analyses of the problems of scaling up this type of approach to the total at-risk population and also the feasibility of using this type of approach in sub-Saharan Africa.

In Mali, Santé Diabète Mali (SDM) is implementing and assessing the efficacy of an education programme for the general population. This project includes information about diabetes and its prevention. It has been implemented in 2 areas of Bamako using peer educators and different drawings explaining different aspects of diabetes and its risk factors. It is closely linked with the health system in these areas to facilitate diagnosis for people who think they may be at risk.

In Mauritius, the government was able to establish a programme that substituted the use of palm oil for the healthier alternative of soya bean oil (72), which was shown to lead to an observed decrease in serum cholesterol.

There is a need for research to be carried out to find appropriate means for prevention in sub-Saharan Africa and this is verified by the lack of existing literature on the subject (73). In looking at the prevention of Type 2 diabetes in children different methods have been used to address this:

- Use of family practitioners (74)
- Summer camps (75)
- Decrease television viewing (76)
- Diet (77)
- Family based (78)
- Physical activity (79-82)
- School based programmes (83-87)

The studies for the prevention of Type 2 diabetes in children are taken from developed country settings. Therefore, their adaptability for use in sub-Saharan Africa must be investigated. Also, many of these studies fail to address changes in the environment and lack long-term follow-up. The main conclusions are that:

- A mix of interventions is probably necessary for prevention of Type 2 diabetes
- Families play an important role
- There is a lack of adequate studies in this area, particularly for sub-Saharan Africa

The interventions detailed in Appendix 9 from other countries may be applicable to African settings with some adaptation. These studies show measures that can be taken to prevent the onset of Type 2 diabetes (Primary Prevention). Secondary and Tertiary prevention of Type 2 diabetes is done through proper treatment (blood glucose control) and follow-up of patients and assessing any complications they may have. These are addressed in the organisation of health system section (Section 1: Organisation of Health System).

Without proper care for their feet people with diabetes can develop foot problems. In a study in Dar es Salaam (88), it was found that 15% of people with diabetes had foot ulcers. Of these, 15% needed minor amputations and 33% major amputations. Other complications, such as retinopathy, also need preventative measures such as proper adherence to treatment and monitoring. Any complications will need to be treated accordingly and treatment for the person's diabetes adapted accordingly.

Recommendations

For Type 2 diabetes, Primary prevention should be focused on weight loss and exercise. Culturally sensitive programmes need to be developed and the changes brought about need to be lasting changes to the individual's behaviour. Cultural issues such as the belief that to have a fat wife is a sign of wealth or that weight loss is a sign of being ill or having HIV/AIDS (68, 89), need to be incorporated into any specific programme. Primary prevention should take place within the community.

Population based approaches should be chosen in order to decrease the emergence of risk factors by promoting healthy life-styles. In combination with early diagnosis and cost effective management (90) these are the best ways to tackle diabetes in developing countries.

Early diagnosis, the improvement of care and constant monitoring of patients should be the focus of Secondary and Tertiary prevention. These levels of prevention should take place in the appropriate health facilities depending on the organisation of care within the country.

A three step approach has been proposed by the WHO for the prevention of chronic conditions (91, 92). The first step is a planning step, which includes the collection of data and looking at the burden of and risk factors for disease. This is described in more depth in the Data section of this report (Section 2: Data Collection). The next step is to formulate a 5-10 year plan for action on prevention and control of major chronic diseases (Section 11: Positive policy environment). Identifying the most effective means for implementing these policies forms the third step in this model.

Section 4: Diagnostic tools and infrastructure

"More than two thirds of patients with diabetes surveyed at hospitals in 2004 were unaware that their problems were related to high or low concentrations of glucose in their blood and did not know that they could or should monitor those concentrations."

Ramaiya (34)

Introduction

Urine and blood glucose measurements are the means for diagnosis and follow-up of diabetes. Monitoring of these is necessary in order to adapt and optimise treatment.

Urine test strips, glucometers and laboratory tests are therefore essential for diagnosis and treatment. The cost of testing equipment to the health system and the patient may be an important constraint on diabetes care.

Examples

In Mozambique there is some resistance to blood testing, possibly for fear that the blood will be tested for HIV/AIDS. This might be overcome by the application of urine testing (personal communication). In the Gambia, glycosuria was found to be specific but only moderately sensitive as a screening test for diabetes (93).

The positive predictive value of glycosuria for a diagnosis of diabetes was 48%. Overall sensitivity was 64% (probability of a positive test for a person with diabetes) and was higher among overweight and/or hypertensive subjects, among elderly people in an urban area, and among subjects with higher blood glucose levels. Extrapolated specificity (probability of a negative test result for someone without the disease) was 99.7% (93).

In Mozambique and Zambia (11) only some patients have their glucose concentrations monitored without charge in public health facilities. Others, depending on whether they have one or more tests per month or if they have their own glucometer, pay anywhere from US\$0.20 to US\$50 per month for their monitoring. Only 6% of health centres visited in Mozambique had facilities to test blood glucose compared with 25% in Zambia (11) (see Appendix 10). There was also a shortage of trained staff.

In addition to monitoring equipment, other 'tools' such as fridges, stethoscopes, sphygnamometers, etc. are needed in the "toolkit" for proper diabetes care (see Appendix 11). Other items such as opthalmoscopes and neurological pins are needed to test patients for complications.

Recommendations

Ideally, each level of the health system needs some means of measuring glucose levels at a location that is close to the patient. Urine glucose strips are appropriate at a primary healthcare level, being easy to use, interpret and cost-effective. At the secondary care level a glucometer should be available. Finally at a tertiary level precise laboratory assessments and HbA1c measures should be provided.

The government agency responsible for purchasing monitoring equipment should standardise the types of glucometers present in order to reduce the price of strips (since they can be bulk-purchased). Staff will need to be trained on how to use these tests and interpret the results.

The Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) (94) have come up with the following list of equipment required for diabetes care. This list has been modified to show the lowest level each tool should be present at:

- Scale and tape measure (height and waist measurements) Primary
- Sphygmomanometer with different cuff sizes Primary
- Blood glucose strips and blood glucose meters Secondary
- Urine strips for glucose, glucose and ketones and multi-item testing Primary
- Opthalmoscope and Snellen Chart Tertiary
- Tuning fork Secondary
- Patella hammer Secondary
- Cotton wool and disposable pins Secondary
- Diabetes education materials Primary

This list can be modified and adapted according to how diabetes clinics are organised and also the level of the health system.

Section 5: Drug procurement and supply

"Access to essential medicines depends on a nucleus of key factors: rational selection, affordable prices, sustainable financing and reliable supply systems. [...] Access to essential medicines is part of the progressive fulfilment of the fundamental right to health."

Brundtland (95)

Introduction

Medicines play an essential part in the provision of health care. For chronic conditions, such as diabetes, medicines need to be present at all times to ensure proper care and prevent complications and death. On the WHO's Essential Drug List (96) Glibenclamide, Metformin and various insulin formulations are present highlighting the importance of these medicines.

The WHO identifies four factors necessary for proper access (97):

- Rational use;
- Affordable pricing;
- Sustainable financing;
- Reliable health and supply systems.

Twenty to fifty percent of the recurrent government health budget in developing countries is used to procure drugs. Drugs are among the most important and cost-effective elements of health care and often a key factor for the success of a health sector reform. However, pharmaceuticals are frequently being used irrationally (98).

The graph below (99) shows some of these levels at which misuse of these resources occurs.



Figure 3 – Drug funding and supply: cumulative effects of system failure at various levels

Only 5% of the total pharmaceutical sector lending is committed to components such as drug policy work and rational use of drugs. It has been suggested that the World Bank should improve its pharmaceutical sector involvement by promoting drug policy research and development including national and international dialogue on pharmaceutical issues to ensure rational use of both drugs and loans (98).

In Mali, Mozambique and Zambia the quantity of insulin needed is determined based on historical consumption. In looking at regional distribution of insulin, capital cities receive a higher proportion of insulin relative to their population. For example in Mozambique 77% of the country's total insulin is supplied to institutions in the capital (40). This may be due to many people coming from other areas of the country to the capital city to get their insulin, or having family members in the capital city purchase their insulin, but is mainly due to mismanagement.

Examples

The WHO has started prequalifying medicines for HIV/AIDS (97). No such system exists for insulin or other medicines for diabetes care.

Different regions have come to various agreements with regards to the approval of medicines (100) and also procurement (101).

Some countries have achieved savings from 40 to 60 percent in pharmaceutical expenditure by improving selection and by competitive purchasing (51, 101) by reducing the variety of pack size, dosage and strengths and generic bidding.

Poor quantification and distribution can lead to unequal distribution of medicines throughout a given country. For example in Mozambique 77% of total insulin ordered remained in the capital city. See Appendix 12 for a more detailed analysis.

Another approach is to negotiate with suppliers of medicines and other supplies to lower prices. For example Novo Nordisk's LEAD initiative (Leadership for Education and Access to Diabetes care) (102) has established a new "best pricing" policy which offered insulin to public health systems in the 50 poorest countries at prices not exceeding 20% of the average price in North America, Europe and Japan.

The implication of this Initiative for Mozambique was a drop in price from US\$9.00 per 10ml vial of IU100 human insulin in 2001 to around US\$4.50 in 2002 (40).

Appendix 13 shows how cost improvements could be made with improved quantification and tendering, this being as applicable to syringes and testing materials as to medicine.

Recommendations

Referring back to Figure 4 different measures can be taken to lessen the effect of the cumulative losses incurred throughout the process of drug supply.

Budget allocation of drugs – Selection of which medicines to buy should be done based on the WHO Essential Medicines List. These medicines should then be purchased through tenders or pooled procurement and in a way that would minimise total cost.

Inadequate buying procedures – Tendering needs to be improved with grouped tendering and other such approaches, which should be being investigated where possible. Other possibilities such as the Novo Nordisk LEAD Initiative should be explored with manufacturers.

Quantification problems – These problems are closely linked to lack of data, which is addressed in the data collection section (Section 2: Data Collection).

Inefficient procurement – Custom regulations and infrastructure at ports of entry need to be adapted for the receipt of medicines.

Inefficient distribution – This is also linked to the lack of data (Section 2: Data Collection) and to the poor infrastructure present. On a case by case basis, distribution networks need to be developed to minimise delays, exposure of medicines to the elements and poor storage.

Irrational prescription – Adequate training for both prescribers and dispensers (Pharmacists) will solve part of this problem (Section 7: Healthcare workers). Therapeutic guidelines can also be developed and if followed correctly will promote good prescribing practice.

Non-compliance by patients – This is addressed in Section 8. Healthcare workers, pharmacists and patients have a role to play in solving this problem through better training, diagnosis and follow-up.

Section 6: Accessibility and affordability of medicines and care

"Access to essential drugs [and appropriate care] should not be a luxury of the privileged few. It is a matter of social equity and justice."

Perez-Casas et al. (103)

Introduction

In 2000 alone, treatment with insulin lengthened the life of an estimated 5.1 million people worldwide with Type 1 diabetes (104). Yet despite this and the fact that insulin has been available since 1922 many people in sub-Saharan Africa still cannot access insulin when they need it (3-5).

In Sudan the total median cost for diabetes care was US\$283, of which one third was spent on insulin (105). In 2001 in Cameroon average direct medical costs for diabetes were about US\$489, of which 56% was hospital admissions, 33.5% on drugs, 5.5% on lab tests and 4.5% on consultation fees (106).

Due to this financial burden diabetes and other chronic diseases may lead households into poverty in many countries, with consequences for extended family as well (107). Ways need to be found to alleviate the overall financial burden on patients, so as to ensure that adherence is not affected by financial barriers.

Examples

One example of a way to get medicines cheaper to the individual patient has been the use of revolving funds. The initial medicines are purchased using donations or are directly donated. The money from the sale of these is "recycled" into the "fund" to purchase more medicines. Part of the fund can also be set aside for providing medicines for free to certain categories of patients. This can also be done with syringes and testing.

However, problems with revolving funds are that (108):

- Administration is problematic
- They are not sustainable
- There is insufficient revenue compared to expenditure

Another possibility is establishing differential pricing schemes for medicines and medical care dependent on age, income, employment status, etc. However, many problems exist with such measures:

- Difficulties with providing the required documentation.
- High levels of bureaucracy may mean extremely long procedures for situations that may be an emergency.
- Lack of knowledge from staff and patients about pricing
- Inconsistent pricing

Different means have been established in different countries to address the problem of payment and charges to indigent patients. In Ethiopia, for example, village chiefs are responsible for distributing vouchers and certificates giving people access to free healthcare (109). Other countries have measure for the elderly, handicapped, children under 5 and even people with chronic conditions (40).

An example from Rwanda shows how a prepayment scheme combined with external aid is able to cover the costs of HIV/AIDS services for patients. Each family pays US\$7.80, which allows a family of up to seven members access to care, essential drugs, ambulance transport to the district hospital and a limited package of services from the district hospital for one year. These prepayment schemes have:

- Increased the use of health services including prevention
- Improved financial accessibility to health services
- Improved the quality of care

Prepayment schemes such as these can be used to address the issue of access and cost (49, 110). In Guinea Bissau, one such scheme provides people with access to primary care at the village level, a package of essential drugs and some free services at higher levels of referral (110).

An example of a risk-sharing mechanism from Ethiopia is a scheme comprised of indigenous arrangements used mainly for assisting victims in death and for funerals. These associations are also called upon in various self-help activities and sometimes provide health insurance, even though mostly in an informal manner (111).

Most community financing schemes have become necessary because of severe economic constraints, political instability, and lack of good governance. Their success may, however, depend on subsidies to pay the premiums of low-income populations, and integration with the government system to provide better protection against small risk pools (112).

A way to address this has been developed in Cambodia with an NGO established to manage a Health Equity Fund (financed by MSF and UNICEF) identifies the poor and pays user fees on their behalf. Patients are referred to this NGO once they arrive at the hospital and staff see that they are unable to pay their admission fee. In parallel, staff from the NGO actively seek poor patients on the wards. The target patients are those who fall into the categories of "extremely poor" and also those, who due to their illness, risk falling into poverty. Payments are determined on a case by case basis. The importance of this type of fund is that it does not mean any loss of income for the individual facility and it has been shown to increase access to care for the poorest patients (113).

Recommendations

Medicines for diabetes care should be accessible at the proper public facilities. It should be clear to patients where they are able to get their medication and other supplies. In addition, sustainable financing systems need to be in place to ensure that cost is not a barrier to care.

Depending on resources and policy considerations, each government should ensure that clearly defined and applied exemption criteria for patients are in place for consultation fees, laboratory tests and medicines, based on age, income, type of disease and employment status. It is also important that the criteria can be easily verifiable and that they do not cause delays in the treatment of the patient. Community financing should be investigated if and where it might be appropriate.

Section 7: Healthcare workers

"Capacity-building in countries in greatest need must remain a priority issue for the international community. We need a quantum leap in capacity building".

Brundtland (114)

Introduction

Healthcare workers play a key role in the management of diabetes, but there is a relative lack of knowledge of staff with regards to diabetes in sub-Saharan Africa (115). Besides coordinating treatment, staff must be part of the process to educate the patients on how to care for themselves. Additionally, healthcare workers need to play an active role in prevention, prescribe lifestyle changes and be willing and able to care for an individual with a chronic condition.

Other challenges include the need for a team approach to care, for an elaboration of treatment and for the patient to be an integral part of this team. Motivation, retention and training of new healthcare workers are challenges in sub-Saharan Africa.

Examples

In Tanzania a survey in early 2004 showed that a training programme, based on training modules created by IDF Africa, increased awareness of diabetes from around one-third to around two-thirds (34). The training programmes in Tanzania also included laboratory technicians.

The following tools are a necessary part of healthcare worker training (116):

- · Move from reactive care to proactive, planned, and preventive care
- Be able to negotiate individualised care plans with patients, taking into account their needs, values, and preferences
- Be supportive of patients' efforts at self management
- Organise and implement specific clinics or group sessions for patients who share common diseases
- Care for a defined group of patients over a long period of time
- Work as a member of a healthcare team
- Work in a community based setting
- Design and participate in quality improvement projects
- Develop information systems (for example, patient registries) and use available technology and communication systems to exchange information on patients
- · Learn to think beyond caring for one patient at a time to a "population" perspective
- Develop a broad perspective of care of patients across the continuum from clinical prevention to palliative care

Observations in Mali, Mozambique and Zambia showed that healthcare workers are often unfamiliar with the management of uncommon diseases like diabetes. In one study in Tanzania, 21 of 199 patients diagnosed as having cerebral malaria actually had diabetes mellitus (117).

Healthcare workers need to acquire increased theoretical knowledge (different types of diabetes, modes of presentation, etc.), but also practical aspects of caring for people with diabetes and chronic conditions such as general clinical skills (118).

Another essential element is the provision of treatment protocols. In Tanzania, for instance, specialised protocols exist for the treatment of diabetic ketoacidosis in adults. These are distributed to different wards where such patients may be treated.

IDF Africa has developed treatment guidelines for diabetes, which are ready to use.

The SEMDSA guidelines on Type 2 diabetes include details on the provision of information for early detection, effective management and the integration of clinical services into a multidisciplinary chronic disease programme within the existing and evolving national health care system. There is an emphasis on lifestyle modification, appropriate education and medication, the prevention and treatment of complications and timely referrals to a higher level of health care, as well as the concept of the patient charter of rights and responsibilities (94).

Recommendations

Disease specific training is needed for all healthcare workers. This training needs to be adapted to different workers and their roles in providing care. IDF Africa has developed training modules that can be used for this and the IDF also provides various training courses.

Two different aspects need to be addressed, namely training for future healthcare workers and training/updating for healthcare workers in practice.

Such training should include the different types of diabetes and their mode of presentation, and how to manage chronic conditions. A team approach to diabetes care should be fostered including the patient's family and community as well as healthcare workers and ancillary staff. Pharmacists, laboratory technicians and other ancillary staff should receive the appropriate training with regards to their designated role in the provision of diabetes care.

The treatment protocols developed by IDF Africa are useful in this training and for treating patients and are applicable to most settings in sub-Saharan Africa, with little or no need for adaptation for specific countries.

In addition to this disease specific education, healthcare workers should receive training in the management of people with diabetes and other chronic conditions.

Section 8: Adherence issues

"Health care that provides appropriate information, support, and ongoing surveillance can improve adherence, which will in turn reduce the burden of chronic conditions and enhance patients' quality of life."

World Health Organization (49)

Introduction

The goal for diabetes treatment is to keep blood glucose levels as near normal as possible. Therefore, people with diabetes must carefully balance food intake, insulin/medication and physical activity in order to prevent complications. Adherence to diabetes self-care is an active, responsible and flexible process of self-management, in which the person strives to achieve good health by working in close collaboration with healthcare staff, instead of simply following rigidly prescribed rules. Self-care implies that the individual actively responds to changing environmental and biological conditions by making adaptive adjustments in the different aspects of diabetes treatment in order to maintain control over their blood glucose and reduce the probability of complications (119).

Many factors previously considered in this report, such as health service organisation and accessibility of care, will impact adherence. Barriers to proper care in South Africa included long travelling distances, complicated drug regimens and long waiting times (32). As well as a reduction of these barriers, proper adherence requires patients to have enough appropriate information about their treatment.

Examples

For chronic conditions, medication, lifestyle and emotional aspects need to be taken into account with regards to adherence to self-care (120). Interventions should be focused on what patients perceive as problems and not what health professionals think patients should know and do. Healthcare workers need to do a needs assessment of what their patient views as problems with their care.

Some measures that have been used to increase adherence are:

- The use of mobile phones to send reminders for taking medication and/or to make appointments with physicians. The text message can include a reminder to the patient to take their medicine as well as tips on healthy living (49).
- Directly Observed Therapy (DOT) has been used for TB. It was found that health centres and community guardians were effective in increasing patient adherence to their treatment for TB and therefore decreasing the number of bed-days patients used (121).

In trying to improve adherence, besides general information about their condition, healthcare workers also need to provide patients with five core self-management skills (120):

- Problem solving
- Decision making
- Resource utilisation
- Forming a patient/health care provider partnership
- Taking action

It has been suggested that individual education needs to be delivered in an environment closest to the daily life of the patient (outside of wards and clinics) and that this education should be continual. It is also important to see the results of patients acquiring new knowledge and how it is put into practice (122).

Recommendations

Proper adherence requires individuals to have enough appropriate information. Patients need to be able to know when their condition worsens and when they need to use the health system.

Adherence is impacted by the following four factors (123):

- 1. Health care team and system-related factors
- 2. Condition-related factors
- 3. Characteristics of therapies
- 4. Patient related factors

The role of the healthcare provider should become that of teacher and partner, in order to help the patient learn the skills that are necessary to enable behaviour changes. In assessing a patient's adherence, the level of adherence to each sub-component of treatment, e.g. diet, exercise, administration of medicines, etc. must be considered as these can each have a negative and cumulative effect on a patient's overall outcome. Healthcare workers should be careful not to appear to judge a person who has not adhered to his/her treatment, but should analyse the situation and listen to why the patient has not followed instructions to address these factors specifically (119). Aspects of diabetes such as different types of food and their impact on blood glucose levels also need to be addressed.

Many studies have shown that cost of treatment is often the main barrier for adherence to care (124). This is considered in Section 6: Accessibility and affordability of medicines and care.

Section 9: Patient education and empowerment

"Educational initiatives aimed at promoting self-management in chronic diseases such as diabetes need to be designed with an awareness of the complexity of social and cultural experiences and attitudes in target communities."

Stone et al. (125)

Introduction

The WHO defines empowerment of patients as the process of enabling people to increase control over, and to improve their health (126). People are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives (127).

For adherence to be successful the patient has to have the desire to avoid illness/or to get better and needs to be aware of the specific health action that will lead to success. Behavioural changes require knowledge, skill and motivation (128) and these need to be taught to patients. This may be more problematic in cultures where one's fate is considered to be held by a supernatural force.

Examples

Examples of how to increase education in culturally sensitive ways are:

- The combination of written information and drama (129)
- The use of drama and singing as a means of providing the community with information about HIV/AIDS (personal observation)

In Tanzania and Zambia, camps for children have been organised. This allows children the opportunity to interact with other children with diabetes and also learn about different aspects of their diabetes care.

The IDF Africa Region and SDM have also developed culturally sensitive material combining written material and drawings enabling healthcare workers and peer educators to explain different aspects of diabetes care to patients. Experience suggests that the contribution of visual aids to improved outcomes in European and US settings is very limited and there is little to suggest that they will provide significant impact in Africa. There is, however, some benefit in the production of these aids to those that produce them, as the process becomes a learning tool for them (personal communication).

Verifying that the individual has understood the education received and continued education are also important aspects (130). Effective self-management support strategies that include assessment, goal setting, action planning, problem solving and follow up are also skills that need to be taught in order to empower the patient (53).

Recommendations

Patient education should focus on prevention as well as treatment. For a person with diabetes, the healthcare worker should discuss the severity of the condition, what needs to be done to control it, the health system, the different roles of staff, and where to get assistance should they need it. Perceived and actual barriers need to be addressed by both the patient and the team of healthcare workers. The use of pamphlets and oral explanations from healthcare workers may not always be appropriate, and education needs to be adapted for children and for patients who cannot read. Drama may be a culturally appropriate way to provide even illiterate members of the public with clear prevention messages. Education should be continuous, with verification that information has been taken on board and that it is being applied correctly.

Emphasis needs to be placed on attitude change, improved communication skills, and skills in cognitive behaviour modification for healthcare workers in order to increase patient education and empowerment.

Section 10: Community involvement and diabetes associations

Article 1: That a not for profit diabetic association be organised and established for diabetics and those interested in diabetes for material aid and benefit and to promote the study, the diffusion of precise knowledge and the better treatment of diabetics in this country.

Articles guiding the role of the British Diabetic Association co-founded by R.D. Lawrence and H.G. Wells in 1934 (131)

Introduction

Illness causes loss of family income due to the loss of a productive member and also the fact that more of the family income goes towards caring for that person (51). In many countries in sub-Saharan Africa the family extends to the community at large and therefore the suffering of one member of the community can have an impact on all members.

The healthcare system, the provider and the community need to be integrated for proper care of chronic conditions (53). One of the components of the chronic care model is to mobilise community resources to meet the needs of patients, for example, by encouraging patients to participate in effective community programmes.

Examples

The World Health Organization (132) outlines the importance of community involvement as including the provision of access to emotional support, to community funds for destitute people, as well as reducing the family's burden and stigma. This approach has been successfully used in Canadian aboriginal communities (133), and is the principle behind the project in Mali (134).

It is important to take into account traditional healers, who play an important role in the provision of care (135). The WHO defines a traditional healer as "someone who is recognised by the community ... as competent to provide health care ... based on the social, cultural and religious background ... and beliefs that are prevalent in the community regarding ... causation of disease and disability." (136) Traditional healers have important social and cultural positions in many communities in sub-Saharan Africa and are often the first port of call for patients. They share ideas and concepts about disease and illness with the patients they treat. In Tanzania it was found that 35% of people with diabetes have sought traditional treatment (137). The inclusion of traditional healers into health programmes, with proper training, may be valuable when there is a shortage of medical personnel especially in rural areas (138).

In Mali, Mozambique and Zambia, an important community contribution to diabetes care was the presence of a diabetes association (40). This was an organisation initially established by physicians and now incorporates patients, giving them a larger role. These organisations, in a similar way to the organisations in Europe and the USA, were established to assist people with diabetes both through direct personal support and through collective work to improve conditions for the community as a whole (139).

The diabetes association in Zambia has a purely advocacy and support role, whereas the associations in Mali and Mozambique also provide care. In Tanzania, the TDA also offers two-week training programmes to teams of healthcare workers from each regional hospital, in addition to this advocacy and care role. After training, each team is given a starter kit containing diagnostic and educational tools for continuing diabetes care where they work (34).

Recommendations

The local community and families of people with diabetes need to be educated with regards to diabetes and how to care and support for people with this condition. Communities can also be organised to provide monetary support for patients or ways of lessening the financial burden. Local beliefs, such as diabetes being a curse and issues around marrying a sick person need to be addressed within the community.

Traditional healers need to be integrated into the formal system of care. They should be trained appropriately to cooperate with, and provide appropriate referral to the formal health sector.

The role of the Diabetes Association can be to facilitate care, but also to provide advocacy on issues such as cost and availability of treatment. Diabetes Associations have a role in bringing to the Ministry's agenda the growing epidemic of diabetes in most developing countries. When Diabetes Associations also provide care, it is important that this is fully integrated with and supplements the role of the formal health sector.

World Diabetes Day, (14 November each year) can be used to organise events to bring the issue of diabetes to the attention of the public and the authorities in a given country. This is a good opportunity for advocacy by the Diabetes Association to influence the Ministry of Health and other local stakeholders.

Section 11: Positive policy environment

"Decision-makers can take actions that will reduce the threats chronic conditions pose to the health of their citizens, their health care systems, and their economies. Their actions regarding financing, resource allocation, and health care planning can significantly diminish negative effects. Armed with essential elements for improvement, informed decision-makers can make a difference."

World Health Organization (49)

Introduction

Many countries in sub-Saharan Africa lack a policy framework with regards to NCDs and diabetes. Such a framework needs to incorporate a variety of factors including prevention, organisation of care, subsidies for medicines and care and allocating appropriate resources to diabetes care.

The World Health Report in 2000 (27) emphasises the need for policies on NCDs in developing countries to include proper financing and the development of intersectoral links, improved monitoring and continuing education. It is also vital that the bilateral and multilateral donors recognise the growing burden of NCDs in developing countries. Raising the profile of diabetes will require collaboration from health professionals, academics and people with diabetes, both at a national and an international level.

Examples

In looking at policy formulation in sub-Saharan Africa one needs to consider donors, international organisations and global influences and the role they play in influencing policies within countries (140). Poor coordination of external resources and donor projects combined with the fragmentation of donor's aims lead to many problems (141). An improvement in this situation requires international diabetes and public health communities to lobby and mobilise politicians and other international agencies (142).

In order to improve policy on prevention it is necessary to incorporate healthy public policies into population level approaches in combination with individual lifestyle approaches (143).

A key to the success of the policies and work in place in Tanzania was the early collection of good epidemiological data (personal communication) (Section 2: Data Collection).

Botswana provides an interesting example of the measures a country can take to address an increase in chronic conditions. The Ministry of Health has established a team responsible for NCD surveillance, prevention and control (49). In addition, Mali and Mozambique have NCD groups within their Ministries of Health. Mali, Mozambique and Zambia are also at different stages of developing an NCD policy (40). While national strategies may be very ambitious, it is important that they recognise regional disparities within countries (40).

Recommendations

Better coordination of donors and NGO programmes within countries is important to allow them to build on each other and not compete.

Data is also needed in order to show the scope of the problem of diabetes (Section 2: Data Collection).

The environment in many sub-Saharan countries is changing and this needs to be addressed by policy makers. A high level of political commitment is necessary in order to address the multiple challenges that diabetes places on a country and its health system. Wider issues that may affect the prevalence of diabetes also need to be addressed. Examples of these issues include the types of food people are able to afford, the promotion of cash-crops that have detrimental effects on what foods are available and affordable and increasing levels of urbanisation and urban sprawl that impact the ability of people to walk and exercise safely.

The African Declaration on Diabetes calls on governments, NGOs, international donor agencies, industry, health care providers and all partners and stakeholders in diabetes to ensure:

- Adequate, appropriate and affordable medications and supplies for people with diabetes
- Earlier detection and optimal quality of care of people with diabetes
- Effective efforts to create healthier environments and prevent diabetes

Medicines will be part of the largest expense that patients and their families will face. (Section 5: Drug procurement and supply) Government action to control prices, additional to the benefits of generic tendering outlined in Section 5: Drug procurement and supply, include abolishing import duties and introducing price controls. (144)

With regards to the organisation of health, the inclusion and regulation of traditional healers and the private sector is necessary. A clear plan of what is available for diabetes care at each level of the health system is needed. This may entail new rules being put into place that enable nurses to perform certain roles, e.g. prescribing medicines.

Policies need to be developed with specific and feasible measures and in the form of an agreed policy document. A specific person or group should take charge of moving this document forward. A sample of what a policy document can contain is included in Appendix 14. This policy document should also have a wide range of support and ownership. Having a designated focal person within the Ministry of Health working on NCDs and diabetes is a way to ensure that this policy is then implemented.

The United Nations Resolution on diabetes will also be an opportunity to raise the global profile of diabetes and ensure that diabetes receives the attention and funding it deserves from multilateral partners and donor agencies.

Conclusion

Examples from countries such as Tanzania and Cameroon, show that diabetes in sub-Saharan Africa can be tackled. The different ingredients needed to do this, including strong political will and local champions, are highlighted in this report. As stated by Olusegun Obasanjo, President of the Federal Republic of Nigeria (92): "Governments have a responsibility to support their citizens in their pursuit of a healthy, long life. ... I believe, and the evidence supports me, that there are clear links between health, economic development and poverty alleviation. If my government and I are to build a strong Nigeria, and if my brothers and sisters throughout Africa are to create a strong continent, then we must include chronic diseases in our thinking."

Building on this the African Declaration on Diabetes envisages a future for diabetes in Africa in which:

- Diabetes and the associated risk of related NCDs are widely recognised as a health priority and resources are allocated accordingly
- Politicians, donors, planners and providers of healthcare along with all government sectors, industry, businesses, NGOs, professional associations and patient organisations unite and co-ordinate to prevent diabetes
- The capacity of health systems and the health workforce is equal to the task of treating and managing diabetes to prevent complications and achieve optimal health and well being for people with diabetes

Based on the IIF's experience, strong political will is necessary for a national diabetes programme to be established. This political will can be generated through different means, but one of the necessities is data on the size and scope of the problem of diabetes. The role of a diabetes association is also essential in pushing this forward. The development of a national diabetes programme/policy is necessary to improve the organisation of the health system to provide care, medicines and other tools necessary for diabetes management. The programme/policy should also address prevention and issues of accessibility and affordability of care. In parallel, education for healthcare workers needs to be implemented, both for those in training and those already practising. Finally, healthcare workers and the diabetes association need to work towards patient education and empowerment.

Different countries are at various stages of organising care for diabetes. The aim of this report is to serve as a recipe for countries embarking or proceeding along this path. This report aspires to address some of the barriers that contribute to the complexity of diabetes care in sub-Saharan Africa, leading to excess mortality. In 1995 Huddle said "Because of poverty, ignorance, lack of healthcare facilities and personnel the diagnosis of diabetes in some Africans is equivalent to a death sentence." (145) In 2006 this is unfortunately still the case. It is hoped that the IIF's work, and this document, will positively contribute to ending this scenario in Africa, so that the diagnosis of diabetes is no longer a death sentence.

Appendices

Appendix 1 – The Diabetes Foundation

The Diabetes Foundation is a UK registered charity (Registered Charity No.292317). Its aims are to support and advance research in the field of diabetes and particularly juvenile (insulindependent) diabetes in the United Kingdom and throughout the world and to provide material of an educational and informational nature to persons who are interested in and affected by diabetes.

Appendix 2 – Description of Diabetes Care in Tanzania

In Tanzania there is a network of diabetes clinics providing access to the approximately 100,000 people with diabetes. The TDA, together with the Ministry of Health, have established 44 clinics spread throughout the country. These clinics provide consultations for diabetes and hypertension. They are run by the district, regional and referral hospitals. At these facilities consultations are free of charge. Medicines and tests are subsidised and for patients who still cannot afford charges, they are free. Staff are provided by the Ministry of Health and their training and education supported by international partners. These clinics are organised in the same way as the Tanzanian health system. The lowest level these clinics currently serve is the District level (11 clinics). Above these there are Regional (21 clinics) and Referral clinics (5 clinics). The National Hospital, in the capital, has become the national centre of excellence for diabetes care. It includes specialised services for laboratory work, a foot clinic, and a diabetes information centre to train doctors, nurses, and people with diabetes ((34) and personal observations).

These clinics run different specialised clinics or education sessions on different days of the week. For example at Muhimbili National Hospital in Dar es Salaam:

- Monday: children's clinic
- Thursday: general clinic
- Tuesday, Wednesday, Friday information/education sessions

In addition, the diabetes nurse goes on ward rounds and since the diabetes team is known on different wards they are informed about new patients.

Pregnant women, with gestational diabetes or mothers with diabetes, are followed up twice a week until delivery at both the antenatal and diabetes clinics.

Any inpatient with diabetes will be discharged through the diabetes clinic. For example when a person with diabetes is discharged from the general medical ward after a serious bout of malaria, they will go to the diabetes clinic to be fully discharged and given a follow-up appointment if necessary.

During each visit the patient will go through the following path:

- 1. Nursing station
- 2. Laboratory measurement of blood glucose, blood pressure, weight and height
- 3. Results are added to the patient's file
- 4. Patient queues
- 5. Consultation with doctor
- 6. Doctor discusses patient history
- 7. Depending on if patient is newly diagnosed, patient will receive education on:
 - What diabetes is
 - What the patient should do
 - Treatment course
 - · Why patient should attend clinics regularly
- 8. Patient is given prescription and instructions
- 9. A follow-up appointment is arranged

The time between appointments will depend on the patient.

- 2 weeks return for new patient to see evolution of condition and to check if they can recall the information they have been given
- 2-3 months for a stabilised patient
- 2 weeks or monthly for Children with Type 1 diabetes, depending on the patient

Appendix 3 – Factors impacting referrals

Figure 4 - Factors affecting referrals from Primary to Secondary care

Community interface	community interface Patient-provider interface		
Household factors:	Patient	Provider	MoH Guidelines and Referral
 Decision to seek care Decision to follow referral Income Transport 	Patient Characteristics: • Socio-demographic • Past experience with health system	Provider Characteristics: • Socio-demographic • Time in current job • Past experience in system	Primary Care setting
A	Severity of illnessDuration of illnessPerception of	 Knowledge of referral site Perceived quality of service Type, severity and duration 	Secondary Care Referral Hospital
Community factors: • Labelling illness • Context of disease • Distance between facilities • Collective experience	competence of local provider	of illness Past experience with particular health problem Perception of patient's capacity to follow through with referral 	 Quality of care Cost of care Size Staffing level Staffing morale

Adapted from Macintyre et al. (146)

Appendix 4 – Different types of studies to estimate the incidence or prevalence of diabetes

Table 1 – Different types of studies to estimate the incidence or prevalence of diabetes

Author	Type of diabetes	Country of study	Screening Method/ Type of Study	Diagnostic criter	iaSample size	Age
McLarty et al. (147)	Type 2 diabetes	Tanzania	FBG	WHO	6,299	15+
Mbanya et al.(148)	Type 2 diabetes	Cameroon	OGTT	WHO	1,767	24-74
Olatunbosun et al. (149)	Type 2 diabetes	Nigeria	OGTT	WHO	875	Urban adults
Levitt et al. (150)	Type 2 diabetes	South Africa	OGTT	WHO	1,000	30+
Elbagir et al. (151)	Type 2 diabetes	Sudan	OGTT	WHO	1,284	25+
Swai et al. (152)	Type 1 diabetes	Tanzania	Prospective registration study			
Beran et al. (11)	Type 1 diabetes	Mozambique and Zambia	Based on registers and discussions			
Elamin et al. (153)	Type 1 diabetes	Sudan	School based questionnaire			
Elamin et al. (154)	Type 1 diabetes	Sudan	Hospital registry			
Ceesay et al. (155)	Type 2 diabetes	Sierra Leone	RBG		501	16+
Kadiki et al. (156)	Type 1 diabetes	Libya	Registers			
Erasmus et al. (157)	Type 2 diabetes	South Africa	OGTT	WHO	374	Factory workers
Owoaje et al. (158)	Type 2 diabetes	Nigeria	FBG	WHO	247	Adults
Ducorps et al. (159)	Type 2 diabetes	Mauritania	RBG	WHO	744	Adults

Appendix 5 – Risk factors included in WHO's STEPS approach

The reason for including these main risk factors is that:

- They have the greatest impact on NCD mortality and morbidity
- Modification is possible through effective primary prevention
- Measurement of risk factors has been proven to be valid
- Measurements can be obtained using appropriate ethical standards (160)

Table 2 – Risk factors included in WHO's STEPS approach that are common to all major NCDs (160)

		Con	dition	
Risk Factor	Cardiovascular Disease (including heart disease, stroke, hypertension)	Diabetes	Cancer	Respiratory Conditions (including chronic- obstructive pulmonary disease and asthma)
Smoking				
Alcohol				
Nutrition				
Physical Inactivity				
Obesity				
Raised Blood Pressure				
Blood Glucose			\checkmark	
Blood Lipids				

Appendix 6 – Questionnaires that make up the RAPIA

Level	Issues Addressed in each RAPIA questionnaire		
MACRO			
• Ministry of Health	 Organisation of delivery of diabetes care Resources available for diabetes and insulin National Programs for diabetes and insulin Pricing of insulin Distribution of insulin Funding for insulin and diabetes Insulin tendering and purchase 		
Ministry of Trade	Trade issues (laws, barriers to trade)Trade infrastructure		
Ministry of Finance	Funding of health systemTaxes on insulinFunding for insulin and diabetes		
Private Sector	Pricing of insulinDistribution of insulin		
National Diabetes Association	 Issues with diabetes and insulin 		
Central Medical Store	Insulin tendering and purchaseInsulin distribution and storageInsulin pricing		
Educators	Training for diabetes care		
	MESO		
 Regional Health Organisation 	Issues with diabetes and insulinOrganisation of care for people with diabetes		
• Hospitals, Clinics, Health Centres, etc.	 Treatment and management of people with diabetes Access to appropriate tools to diagnose and treat patients Infrastructure present and/or lacking for insulin provision 		
Laboratory	 Infrastructure present and/or lacking for proper diagnosis and follow-up 		
Pharmacy	Insulin distribution and storageInsulin pricing		
	MICRO		
Health Workers and Traditional Healers	 Problems encountered in diagnosis and treatment of patients Training Infrastructure present and/or lacking Tools present and/or lacking 		
Patients	DiagnosisAccess to treatmentCost of treatment		

Appendix 7 – Target areas of each RAPIA questionnaire Table 3 – Target areas of each RAPIA questionnaire

								Questionna	aires						
Target questions with regards to insulin and diabetes care	Ministry of Trade	Ministry of Finance	Ministry of Health	Private Sector	National Diabetes Association	Central Medical Store	Educators	Regional Health Organisation	Regional Central Medical Store	Hospitals, Clinics, Health. Centres, etc	Laboratories	Pharmacies	Health care workers	Traditional Healers	Patients
Funding for diabetes care and insulin		×	×			×		×	×	×					×
Taxes and Import restrictions on insulin	×	×	×	×	×	×			×			×			
Labour Resources			×					×		×					
Organisation of care			×		×			×		×			×	×	×
Supply of insulin and related supplies (cost, mark-ups, taxes, "black market")	×		×	×	×	×		×	×	×	×	×	×		×
Infrastructure			×	×		×		×	×	×	×	×	×		
Tools for monitoring and administration diabetes care			×		×			×		×	×		×		×
Training			×		×		×						×	×	
Awareness and education			×		×		×				×	×	×	×	×
Prevalence, Incidence number of cases seen			×		×		×	×		×	×	×	×	×	
Process of care (from diagnosis to treatment)			×		×			×		×	×	×	×	×	×

Appendix 8 – A stage model for assessing community-based diabetes prevention



Figure 5 – A stage model for assessing community-based diabetes prevention

Adapted from (65)

Appendix 9 – Preventive measures for Type 2 diabetes

Table 4 – Preventive measures for Type 2 diabetes

It should be noted that some of these are small-scale studies and the means to scale these up to population levels is hard to conceive. These studies are provided for information purposes only.

Author	Country	Target and numbers	Programme Description	Outcome
Burke et al.(161)	USA	Adults (Mexican Americans and non-Hispanic whites residing in San Antonio, Texas) A total of 3,682 individuals completed both stages of the study.	The number and proportion of incident cases prevented by targeting each BMI category were estimated. In addition the decrease in risk of developing type 2 diabetes associated with weight gain prevention across both the BMI and age spectra was calculated.	The majority of cases of type 2 diabetes were in individuals who were overweight or mildly obese with a family history of type 2 diabetes.
Dowse et al. (162) and Uusitalo et al.(163)	Mauritius	Adults aged 25-74 5,080 and 5,162 subjects in 1987 and 1992 cross sectional surveys	In 1987 the government of Mauritius changed the composition of the commonly used cooking oil from being mostly palm oil to being wholly soya bean oil.	Changing the cooking oil led to an observed decrease in serum cholesterol concentration over five years in the population of Mauritius.
Kosaka et al. (164)	Japan	Male adults with IGT 356 (control group) and 102(intervention group)	The subjects in the control group and in the intervention group were advised to maintain BMI of <24.0 kg/m2 and of <22.0 kg/m2, by diet and exercise. The intervention group received detailed instructions on lifestyle, which were repeated every 3-4 months during hospital visits.	Cumulative 4-year incidence of diabetes was 9.3% in the control group, versus 3.0% in the intervention group, and there was a reduction in risk of diabetes 67.4% (P < 0.001). Differences in the decrease of Body weight were also present with the control group losing 0.39 kg and the intervention group losing 2.18 kg (P < 0.001).
Laaksonen et al. (165)	Finland	Men and women with IGT 487 participants	Impact of Leisure Time Physical Activity	Subjects who increased their Leisure Time Physical Activity to moderate- to-vigorous or strenuous, or structured Leisure Time Physical Activity the most were 63-65% less likely to develop diabetes.
Lindstrom et al. (166)	Finland	522 middle-aged, overweight subjects with IGT who were randomised to either a usual care control group or an intensive lifestyle intervention group.	The control group received general dietary and exercise advice at baseline and had an annual physician's examination. The subjects in the intervention group received additional individualised dietary counselling from a nutritionist. They were also offered circuit-type resistance training sessions and advised to increase overall physical activity. The intervention was the most intensive during the first year, followed by a maintenance period.	The intervention group showed significantly greater improvement in each intervention goal. After 1 and 3 years, weight reductions were 4.5 and 3.5 kg in the intervention group and 1.0 and 0.9 kg in the control group, respectively. Measures of glycemia and lipidemia improved more in the intervention group.

Author	Country	Target and numbers	Programme Description	Outcome
Pan (167)	China	110,660 men and women from 33 health care clinics in the city of Da Qing, China, were screened for IGT and NIDDM. Of these individuals, 577 were classified (using WHO criteria) as having IGT.	Subjects were randomised by clinic into a clinical trial, either to a control group or to one of three active treatment groups: diet only, exercise only, or diet plus exercise. Follow-up evaluation examinations were conducted at 2-year intervals over a 6-year period to identify subjects who developed NIDDM.	The cumulative incidence of diabetes at 6 years was 67.7% (95% CI, 59.8-75.2) in the control group compared with 43.8% (95% CI, 35.5-52.3) in the diet group, 41.1% (95% CI, 33.4-49.4) in the exercise group, and 46.0% (95% CI, 37.3-54.7) in the diet-plus-exercise group (P < 0.05).
Puska et al. (168)	Finland, North Karelia	Adults aged 30-59. Over 10,000 subjects were studied in 1972 and 1977 and roughly 8000 subjects in 1982.	Reductions in smoking, serum cholesterol concentrations, and blood pressure were among the central intermediate objectives.	During the first five years of the project (1972-7) the programme effectively reduced the population mean values of the major coronary risk factors. At 10 years the effects had persisted for serum cholesterol concentrations and blood pressure and were increased for smoking.
Steyn et al. (169)	Review			 Promotion and evaluation of 'healthy' lifestyle programmes, which focus on the following aspects: Early identification of subjects at risk of developing type 2 diabetes Healthy lifestyle programmes/interventions should focus on a life course perspective and not on a specific age group or developmental stage Legislative action will be necessary to promote a healthier lifestyle for all populations. All governments and their employees in the social, health, nutritional, economic and welfare arenas should move forward on an integrated approach to the prevention of the disease and not only in treating the symptoms.
Steyn(169)	Review			There is convincing evidence for a decreased risk of diabetes in adults who are physically active and maintain a normal BMI throughout adulthood, and in overweight adults with IGT who lose weight voluntarily.
Tuomilehto (70)	Finland	Middle-aged and overweight men and women with IGT 172 men and 350 women.	Each subject in the intervention group received individualised counselling aimed at reducing weight, total intake of fat, and intake of saturated fat and increasing intake of fibre and physical activity.	During the trial, the risk of diabetes was reduced by 58 percent (P<0.001) in the intervention group. The reduction in the incidence of diabetes was directly associated with changes in lifestyle.

Appendix 10 – Availability of diagnostic tools in Mali, Mozambique and Zambia

Table 5 - Availability of diagnostic tools in Mali, Mozambique and Zambia at different health facilities visited

Country	Presence of urine glucose strips	Presence of ketone strips	Presence of a glucometer
Mali	54%	13%	43%
Mozambique	18%	8%	21%
Zambia	61%	49%	54%

Appendix 11 - Availability of certain tools used in the diagnosis, treatment and management of people with diabetes

The table below shows the availability of some of these tools from the work of the IIF in Mali, Mozambique and Zambia.

Table 6 – Availability of certain tools used in the diagnosis, treatment and management of people with diabetes in Mali, Mozambique and Zambia

Country	Sphygnamometer	Stadiometer	Weighing scales	BMI chart	Snellen charts	Tendon reflex hammer
Mali	89%	67%	100%	33%	10%	55%
Mozambique	53%	36%	89%	26%	24%	60%
Zambia	99%	49%	71%	19%	53%	48%

Appendix 12 – A comparison of insulin orders and population in Mozambique

Table 7 – A comparison of insulin orders and population in Mozambique

Province	Population (170)	Insulin Ordered ¹	Insulin ordered as a percentage of total
Niassa	893,000	150	0.3%
Sofala	1,485,000	1,697	2.8%
Maputo Province	2,000,000	46,130	77.3%
Total	17,655,000	59,657	

¹ Based on quantities requisitioned for 2002 from Central Medical Stores (Mozambique)

Appendix 13 – Total public expenditure on insulin in Zambia

Table 8 – Total public expenditure on insulin in Zambia

Source	Total vials	Percentage of total quantity	Cost	Percentage of total cost
Tender	39,353	79%	US\$181,810	68%
Private local wholesaler	10,260	21%	US\$85,489	32%
Total	49,613		US\$267,299	

Had the 10,260 additional vials been purchased through the tender process, this would have saved US\$38,000, or around 15% of total insulin costs (40).

Appendix 14 – Example of the contents for a NCD policy document

The following can be included in a national NCD policy document:

- 1. Define which NCDs the policy document will address
- 2. Global picture for each disease chosen
- 3. Sub-Saharan African situation for each disease chosen
- 4. Country situation for each disease chosen
- 5. NCDs at a community level
- Risk factors
 Non modifiable risk factors
 Modifiable risk factors
- 7. Costs of diseases and complications
- 8. Prevention and control strategies using evidence based interventions for each specific disease
 - 8.1. Primary
 - 8.2. Secondary
 - 8.3. Tertiary
- 9. Health services for NCDs
 - 9.1. Available
 - 9.2. Lacking
- 10. Role of different stakeholders
 - 10.1. National Government
 - 10.2. Ministry of Health
 - 10.3. WHO
 - 10.4. Other International Organisations
 - 10.5. Donors
 - 10.6. Health facilities
 - 10.7. Healthcare workers
 - 10.8. Patient Organisations
- 11. Curative services within country
 - 11.1. Primary
 - 11.2. Secondary
 - 11.3. Tertiary
 - 11.4. Other non-governmental facilities
 - 11.5. Private sector
- 12. Economic burden for each disease
 - 12.1. Patient
 - 12.2. Health system
- 13. Morbidity and mortality of NCDs
- 14. Current status of NCD programmes
- 15. Overall SWOT analysis of NCD policy in country
 - 15.1.Strengths
 - 15.2.Weaknesses
 - 15.3.Opportunities
 - 15.4.Threats
- 16. Action plan with milestones
- 17. Role for each stakeholder in moving the process forward

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