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Economic burden of diabetes on patients and their families in Sudan

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To the vulnerable families who are striving
to save the lives of their diabetic children
by maintaining a supply of insulin

ABSTRACT

Diabetes mellitus in Sudan is a growing health problem in all socio-economic classes. The natural history of the disease is associated with poor glycaemic control, a high prevalence of complications and a low quality of life.

Objectives: The studies aimed to estimate the contribution of Sudanese patients and their families to the cost of diabetes care, and to determine the quality of this care. The direct costs and intermediate benefits of attaining good glycaemic control were estimated, and specifically the contribution by adult patients with type 2 diabetes, to manage their disease without reported chronic complications.

Design and methods: Two cross-sectional descriptive studies were conducted in Khartoum State. Parents of 147 children with type 1 diabetes and 822 adult patients with type 2 diabetes attending a public diabetes centre and private diabetes clinics were interviewed Data regarding socio-demographic characteristics, family and patient incomes, costs of diabetes care and metabolic control of the patients were obtained. Glycosylated haemoglobin (HbA1c) as a measure of glycaemic control was measured in a cohort of 123 randomly selected adult patients.

Results: The median annual expenditure of diabetes care during childhood was USD 283 per diabetic child, of which 36% was spent on insulin. The direct median cost of diabetes care of type 2 adult diabetes patients was USD 175 per year, which included the cost of drugs and ambulatory care. These costs represent 23% and 9% of incomes of the families of the diabetic children and the adult patients, respectively. More than half of the income of adult patients was contributed by the spouse or siblings. For households of diabetic children 16% was received as financial help from relatives and friends. Recall of levels of blood glucose monitoring indicated poor glycaemic control in 86% of diabetic children. HbA1c was at unsatisfactory levels in 77% of adult patients. Patients attending private clinics had both higher income and higher costs than those attending public clinics. However, both groups had poor glycaemic control, which may reflect the low direct costs and the minimal care given to all diabetic patients.

Conclusions and recommendations: These studies have emphasized the intensity of the economic burden on Sudanese diabetic patients. This economic burden has generally not been translated into optimum diabetes care in either private or public practices and can be considered as a depletion of family resources and the consequences of an inefficient healthcare system. Diabetic patients and their families pay a considerable part of their income to sponsor health, and in return they receive insufficient care. Implications for health policy are that primary care services should be imposed to attain better diabetes control and that the economic burden on diabetic patients must be alleviated. Future research is needed to gain more understanding of how families cope and mechanisms to improve services in a cost-effective way.

Keywords: Diabetes mellitus type 1, diabetes mellitus type 2, direct costs, metabolic control, low-income countries, Sudan

PUBLICATIONS

This thesis is based on the following papers, which will be referred to in the text by Roman numerals:

I. Elrayah H, Eltom M, Bedri A, Belal A, Rosling H, and Östenson CG. Economic burden on families of childhood type 1 diabetes in urban Sudan. Diabetes Res Clin Pract. 2005Nov;70(2):159-6

II. Elrayah-Eliadarous H, Yassin K, Eltom M, Abdelrahman S, Wahlstrom R and Östenson CG. Direct costs for care and glycaemic control in patients with type 2 diabetes in Sudan. Submitted**.**

Article I has been reprinted with permission from the editor.

CONTENT

ABBREVIATION

AACE	American Association of Clinical Endocrinologists
ADA	American Diabetes Association
DALYs	Disability Adjusted Life Years
DM	Diabetes Mellitus
FMOH	Federal Ministry of Health
GDP	Gross Domestic Product
HbA1c	Glycosylated hemoglobin
LIC	Low Income Countries
LMIC	Low and Middle Income Countries
PHC	Primary Health Care
SMOH	State Ministry of Health
USD	United State Dollars
WHO	World Health Organization

PREFACE

I graduated from the Faculty of Organizational Management 1994 at Ahfad University, Omdurman, Sudan. Thereafter I obtained a diploma in Cost Accounting from Sudan University and a higher diploma in Planning and Development from Khartoum University. After graduation I joined the Endocrinology and Nutrition Research Centre as a research assistant to help organize the paperwork and to contribute to data collection and literature searching.

I considered diabetes as the main focus of my research since I was involved in several diabetes research activities. Furthermore I was chosen as a member to participate in the activities of the Diabetes Association in Khartoum and was appointed to work in the National Diabetes Program office. All these events have triggered me to learn more and further my career in this field.

During this long experience I came to know how dreadful the situation of the Sudanese diabetic patients is. Patients with diabetes are poorly controlled, have many diabetes complications and are unable to afford and access the cost of management and care.

INTRODUCTION

1.1 Diabetes mellitus definition and classification

Diabetes mellitus (DM) is defined as a chronic disease that occurs when the pancreas is deficient of insulin or does not produce enough insulin, or alternatively when the body cannot effectively use the produced insulin. Insulin is a hormone that regulates blood glucose concentration. Hyperglycaemia, or raised blood glucose levels, is a common effect of uncontrolled diabetes and which over time leads to serious damage to many systems of the body, especially the nerves, eyes, kidneys and blood vessels.

The major two clinical classes of DM are childhood diabetes mellitus, insulin-dependent diabetes mellitus (or type 1 diabetes) and adulthood diabetes mellitus, non insulin-dependent diabetes mellitus (or type 2 diabetes mellitus). Type 2 DM accounts for more than 90% of all diabetic patients [1]**.**

Type 1 diabetes is characterized by a lack of insulin production. Without daily administration of insulin Type 1 diabetes is rapidly fatal. Symptoms include excessive excretion of urine (polyuria), thirst (polydipsia), constant hunger, weight loss, vision changes and fatigue causing insulin resistance (reduced insulin action).

Type 2 diabetes results from insufficient insulin or ineffective use of insulin by the body's tissues. Type 2 diabetes comprises 90% of people with diabetes worldwide, and is largely triggered by excess body weight and physical inactivity. Symptoms may be similar to those of Type 1 diabetes but are often less marked. As a result the disease may be diagnosed several years after onset and once complications have already arisen. Until recently this type of diabetes was only described in adults but it may also affect obese children [2] .

1.2 Global epidemiology of diabetes mellitus

Due to aging, accelerated population growth, urbanization and high prevalence of obesity and inactive lifestyle, the number of people with diabetes is increasing globally at a rapid speed. Important differences have been reported in the occurrence of DM and its complications between countries and between ethnic, cultural and even age groups within the same country. The World Health Organization (WHO) predicts that the current diabetic population of 177 million (estimate 2000) people will increase to 370 million by the year 2030 [3]. From another global estimate for the year 2000-2030, the total number of people with diabetes is projected to rise from 171 million in 2000 to 366 million in 2030 [4].

The number is expected to approximately double between 2000 and 2030, based solely upon demographic changes. It has been estimated that 2.1% of the world population may have diabetes, which is predicted to rise to 3% by the year 2010 [5] and other study has estimated an increase to 2.8% in 2000, with projections of 4.8% in 2030 [4].

The greatest relative increases will occur in the Middle Eastern Crescent, sub-Saharan Africa, and India. The incidence of type 1 DM is increasing in many parts of the world and especially in younger children [6]. There are 300-350 new cases of diabetes per year among children aged less than 15 years. The number of new cases has doubled during the last three decades [7]. Most of the expected population growth between 2000 and 2030 will be concentrated in the urban areas of the world [8] The most striking demographic change in global terms will be the increase in the proportion of the population ≥65 years of age [4].

In low and middle income countries the majority of people with diabetes are in the 45-64 year age range [9]. In contrast, the majority of people with diabetes in developed countries are <64 years of age. By 2030, it is estimated that the number of people with diabetes <64 years of age will be more than 82 million in low and middle income countries and >48 million in high income countries [4]. The largest increases in the diabetic populations are projected to be in the most economically productive age groups [10].

1.3 Diabetes mellitus in Africa

Africa is a large continent, but the health care systems of African countries face similar challenges in the delivery of health care. Resources are limited and systems are strained [11]. Diabetes mellitus is no longer rare in Africa. Meta-analytic estimates and recent investigations based on the STEP-wise approach [11] for monitoring the risk factors of non-communicable diseases indicate a prevalence of between 1% and 20%.

The prevalence of DM in African communities is increasing due to an ageing population and lifestyle changes associated with rapid urbanisation and westernisation. Traditional rural communities still have very low prevalence, at most 1-2%, except in some specific high-risk groups, whereas up to 13% or more adults in urban communities have DM. Type 2 diabetes is the predominant form (70-90%), the rest being represented by typical type 1 patients and patients with atypical presentations. Due to the high urban growth rate, unhealthy dietary changes, reduction in physical activity and increasing obesity it is estimated that the prevalence of diabetes is going to triple within the next 25 years. In addition, long-term complications occur early in the course of diabetes and affect a high

proportion of patients, and that could be partly explained by uncontrolled hypertension, poor metabolic control and possible ethnic predisposition. The combination of the rising prevalence of diabetes and the high rate of long-term complications in Africans will lead to a drastic increase of the burden of diabetes on health care systems of African countries. The design and implementation of an appropriate strategy for early diagnosis and treatment, and population-based primary prevention of diabetes in these high-risk populations is therefore a public health priority [12].

The disease burden is very high. Recent literature regarding healthcare for diabetes arises from a limited number of countries in Africa. Where assessments of health care have been made it is clear that the cover and quality of services are well below any reasonable minimum [11]. Unknown diabetes in Africa is in the order of 60% to 80% in cases diagnosed in Cameroon, Ghana and Tanzania [13]. The rate of limb amputations varies from 1.4% to 6.7% of diabetic foot cases. Annual mortality linked to diabetes worldwide is estimated at more than one million [14]. In some countries of the Region, the mortality rate is higher than 40 per 10 000 inhabitants [15]. Diabetes is particularly common in Egypt, with a prevalence of 4.3% [15].

The rising prevalence of diabetes, its increasing morbidity and mortality, its disproportionate effect on disadvantaged individuals, communities and nations, and its high human and economic costs clearly establish diabetes as a significant global public health problem [9, 16].

1.4 Diabetes mellitus in Sudan

The prevalence and incidence rates of DM in Sudan, as in many other low-income countries, are increasing to epidemic proportions, leading to the emergence of a public health problem of major socio-economic impact. In the northern states the crude prevalence in 1992 reached 3.4% in those ≥25 years of age [6-8]. It was found to be 5.5% in the Northern State and 8% in Khartoum State. The prevalence was particularly high (10.8%) in a certain community in the Northern State [17]. Type I DM is not rare in Sudan, the prevalence being approximated to 0.1 % among children 7-14 years of age [18].

DM in Sudan is associated with poor glycaemic control, a high prevalence of complications, a low quality of life, and particularly with morbidity [19]. Patients with a median duration of diabetes of 9 years showed a high prevalence of micro- and macro-vascular complications [20]. Retinopathy was evident in approximately 43%, dipstick proteinuria in 22% and neuropathy in 37%. Cardiovascular disease was reported in 28%.

Peripheral vascular disease was reported in 10% and cerebrovascular accidents in 5.5%. As expected, patients with complications were significantly older, had longer disease duration and had higher serum cholesterol and triglyceride concentrations. The glycaemic control was only acceptable (HBA1c <7.5%) in 12.5% of the patients.

The reasons for poor metabolic control are not difficult to understand. Drugs are extremely costly relative to income [21]. This is in part due to high private mark-up prices, but the government's Central Pharmacy is under the control of the Ministry of Finance, and usually makes a profit. Glucose meters are very expensive. Import licensees regard them as a 'boutique' item so add on a large margin. The government also allows a significant import duty to be attached to them. Consequently, they are much more expensive than in many developed countries.

1.5 Cost of diabetes

Economics is a discipline that studies how people choose to use limited resources to satisfy their unlimited wants so that the gain from the available resources can be maximized. Applying the framework of economics to resource allocation in diabetes prevention and control is important for at least 3 reasons. Firstly, diabetes is costly. Secondly, resources that can be devoted to prevention and control of diabetes are limited because of the 'opportunity cost' of doing so. Opportunity costs are the value that is forgone by using resources for one activity instead of another. Thirdly, the need for resources will continue to increase because of the increasing prevalence of diabetes and the demand for comprehensive care and new treatments [22].

Two different approaches have been used to address the economic impact of an increasing incidence of diabetes. The first approach uses disability-adjusted life-years (DALYs) to measure intangible costs associated with diabetes. It combines the number of healthy life-years lost as a result of early mortality with those lost because of disability. The second approach, which has been used more frequently, is the cost-of-illness approach, which includes the concepts of direct, indirect costs [23].

Throughout the world diabetes mellitus afflicts people of all social conditions. The economic and social consequences of diabetes also touch the families and friends of people with diabetes, as well as the medical community and the health system as a whole. Diabetes and its complications impose significant economic consequences on individuals, families, health care systems and countries.

The WHO estimates that during the years 2006-2015 China will lose USD 558 billion in foregone national income due to heart disease, stroke and diabetes [1]. DM is a public health issue of significant economic importance because of the chronic nature of diabetes, its high and globally increasing prevalence, the demand for multi-modal treatment and the serious complications associated with long disease duration [21]. DM has both acute (short–term) and chronic (long–term) complications. Acute metabolic complications include diabetic ketoacidosis, hypoglycaemia and hyperosmolar non-ketotic coma. The major chronic complications are nephropathy, neuropathy, retinopathy, and cardiovascular, cerebrovascular and peripheral vascular disease. People with diabetes are prone to foot problems which are difficult to treat and which may lead to lower limb amputation with devastating socioeconomic consequences for the individual and the society. It has been estimated that 25% of all hospital admissions of diabetic patients are caused by foot problems.

Data from the United States and Europe indicate that healthcare expenditure for patients with diabetes mellitus is significantly higher than for comparable patients without this disease [24, 25] . These and other studies [26, 27] also suggest that the majority of such 'excess' costs can be attributed to diabetes-related complications. Most of the cost of managing type 2 diabetes is associated with the management of diabetes-related complications, especially when hospital treatment is required [28]. Cost estimates for diabetes derived from different studies are difficult to compare because of methodological differences and other differences in cost appraisal [29]. Diabetes is associated with significant morbidity, mortality and economic consequences. In 2002, the US direct medical costs associated with diabetes (types 1 and 2) were estimated at USD 92 billion (70% of total costs) and indirect costs at USD 40 billion (30%), with a total of USD 132 billion [30]. Data from more than 7000 patients in eight European countries indicated that the mean cost per patient with diabetes was USD 2928 annually (1999 values), and the proportion of total healthcare expenditure directed toward diabetes ranged from 1.6% to 6.6% depending on the country [31].

Estimates of the costs of diabetes can provide information to help guide priorities for allocating scarce resources, attracting additional resources and managing available assets to control the health and socioeconomic burdens of diabetes. According to the prevailing cost of illness methodology [23, 32], the economic cost of diabetes can be divided into two categories, direct and indirect [33]. **Direct costs** include costs of outpatient visits, hospitalization, medication and other supplies, as well as the economic and other

sacrifices made by individual patients and their families, e.g. costs of traveling to diabetes clinics. The most important supplies are insulin, tablets, syringes, blood and urine monitoring equipment. Hospitals provide in-patient and out-patient care to treat diabetes and its complications. **Indirect costs** are defined as the production losses due to sick leave, early retirement and early death related to diabetes. Hence while the direct costs reflect the amount of resources used to manage diabetes, the indirect costs are more related to the negative impact of diabetes on health and functional capacity [23]. In a population-based study from Sweden, the production losses due to morbidity in diabetic patients were estimated to be about USD 439 (1994 prices) 57% of the total cost (USD 766) per year [32]. A third category of costs is related to psychosocial aspects of illness or its affect on quality of life, this type of cost only being included occasionally due to the difficulty of its measurement [22].

Few economic studies of diabetes have been accomplished in low-income countries. In a study of newly diagnosed cases of diabetes in Tanzania [34] insulin was a major cost factor for which the purchase of insulin accounted for 68 % of the average annual costs for type 1 outpatients. However, the percentage of costs for doctors and nurses was considerably lower than in high income countries such as in Sweden [35]. Thus diabetes places a severe strain on the limited resources of developing countries. If the patients with diabetes have to pay for their treatment most will be unable to do so and will die.

Global, socioeconomic and educational characteristics may determine the prognosis of diabetes. Difficulties with costs and supplies of insulin and socioeconomic constrains, combined with poor parental understanding of the disease resulted in high mortality of Ethiopian diabetic children, while conversely those with supportive families and secured economic status were excellently controlled [36].

2 BACKGROUND

2.1 Country profile

The Republic of Sudan is the largest country in Africa encompassing an area of 2.5 million square kilometers, corresponding to almost one tenth of the size of Africa. Sudan is located on the border of Arab and Sub-Saharan cultures. Its highly diverse landscape range from desert to tropical forest, and its abundant natural resources include oil, timber, extensive agricultural land, and marine and inland fisheries [37]. The country is also culturally diverse, as it bridges the Islamic culture of North Africa with the largely Christian South, and comprises hundreds of distinct tribal and ethnic groups. Unfortunately, Sudan has long been plagued by civil war and regional conflict. In the fifty years since achieving independence, the country as a whole has been at peace for only eleven years (1972-1983). Adding to the burden of war, Sudan has experienced several severe droughts in the past thirty years and food production in many regions has dropped at the same time that the population has increased. The combined impacts of conflict and food insecurity have caused over five million Sudanese to be both internally and internationally displaced into camps and urban fringes, and over five million to receive international food aid [38].

Sudan comprises hundreds of ethnic and tribal divisions and language groups, with two major distinct cultures: Arab and Black African. Arab populations generally live in the northern states, which cover most of Sudan's territory and include most of the country's largest urban centers. The Black African culture has its heartland in the south but extends north into the Blue Nile state, the Nuba mountains region and the three Darfur states. In addition, several million internally displaced people, mainly from the south, have relocated to the cities and agricultural regions in the north and in the centre of the country. Most of the estimated 25-30 million Sudanese living in the northern regions are Arabic-speaking Muslims, though traditional, non-Arabic mother tongues are also widely used[39].

Figure 1: Map of Sudan

2.2 Economical status

Despite relatively abundant natural resources Sudan is currently a very poor country due to underdevelopment, conflict and political instability. In 2005, the gross domestic product per person was estimated at USD 640 (using Purchasing Power Parity figures), as compared to USD 3,806 and USD 1,248 for neighboring Egypt and Kenya, respectively [40]. While the production and export of oil are growing significantly in importance, Sudan's primary resources are agricultural. Sorghum is the country's principal food crop, and livestock, cotton, sesame, peanuts and gum Arabic are its major agricultural exports.

However, Sudan remains a net importer of food and a major recipient of food aid. Industrial development, which consists of agricultural processing and various light industries located in Khartoum North, is limited in Sudan. The country is reputed to have great mineral recourses but the real extent of this is unknown.

Table 1: Socioeconomic indicators of Sudan [39]

Indicators	Value	Year
Population size (million)	37	2006
Population growth rate (%)	2.6	1998-2003
Life expectancy at birth (years)	57	2004
GDP per capita (USD)	640	2005
Gross enrolment rate in primary education (%)	60	2004
Youth literacy rate (age 15-24) (%)	61	2004
Ratio of girls to boys in primary education (%)	88 : 100	2000
Under five mortality rate (per 1,000 live births)	90	2005
Maternal mortality rate * (per 100,000 live births)	450	2005

* Source [41]

2.3 Health system in Sudan

The healthcare system is a three-tier system (Fig. 2). The federal level is concerned with policy making, planning, supervision, co-ordination, international relations and partnership. The state governments are empowered for planning, policy making and implementation at a state level while the localities are mostly concerned with policy implementation and service delivery including health, education, and development. An intermediate level was introduced in the south following the Comprehensive Peace Agreement. Currently there are 25 states, 10 of which comprise Southern Sudan'. Each state is administered by a Wali (Governor) with a cabinet of 5-7 ministries and 5-12 localities. The Localities are administered by a Commissioner. The decentralized system necessitates huge requirements of human and material resources. These are insufficient in most of the localities and states at the present time. There is an inherent problem with regard to resource distribution between the three levels of governance which render the local level feeble in service delivery. Central transfers are currently an important source of finance for the states and localities, although its functionality and impact need to be austerely studied [42].

Many partners are involved in healthcare provision. Primary Health Care has been adopted as the key strategy for health care provision in Sudan. The recent Federal Ministry of Health (FMOH) policy indicates that the minimum package for PHC services should include: Vaccination of children, Integrated Management of Child Illnesses, Reproductive Health, essential drugs, nutrition, health education and treatment of common illnesses.

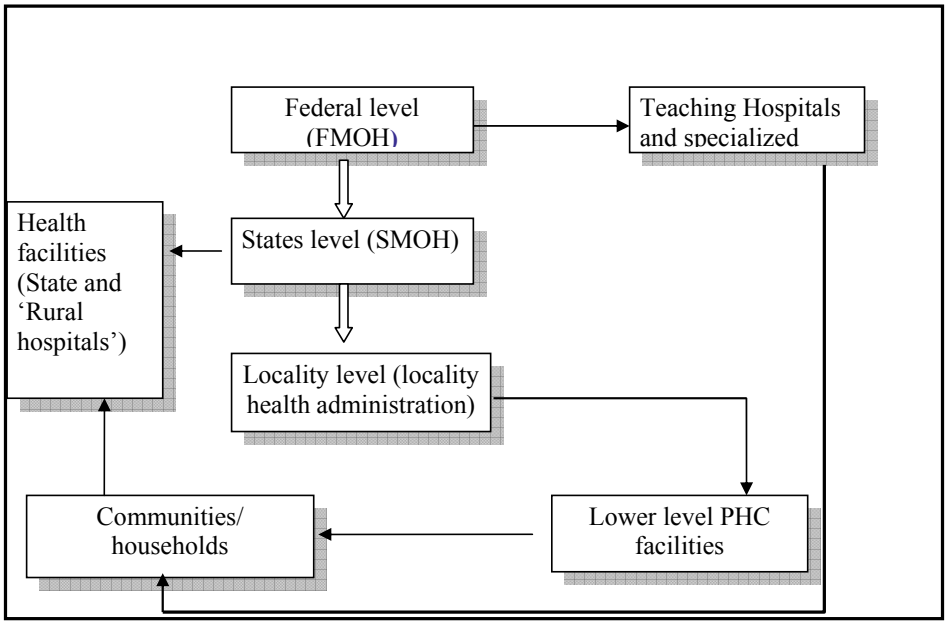

Figure 2: Healthcare system in Sudan [42]

2.4 Service delivery and system resources

The health centre is the first referral level for the lower-level facilities. According to its standards, it is supposed to be headed by a physician (medical officer/GP). Lower level PHC health facilities are supposed to be managed and financed by the localities. Rural Hospitals are considered part of the PHC level and serve as secondary referral level health institutions. Each rural hospital is expected to have an average bed capacity of 40 to 100 beds and to be managed and financed by the State Ministry of Health (SMOH). Tertiary hospitals, include teaching, specialized and general hospitals, are located in State capitals and operated by the SMOH. In addition, the FMOH operates 21 tertiary-level hospitals and specialized centers [42].

Overall coverage by basic health services is low. Furthermore, there are significant urban-rural and regional disparities in the availability of health resources and services. The current health facility :population ratio of one health centre for every 34,000 of the population in the North is below the acceptable level. The situation is even worse in the South where the ratio is one health centre per 75,000 persons.

2.5 Diabetes health delivery system in Sudan

The diabetes care delivery system in Sudan is integrated in the overall national healthcare structures. The organization of diabetes care is based on three levels. Depending on where the patient lives, care is sought via the primary, secondary or tertiary healthcare systems. There are no specialized units for diabetes care in primary care centers. Medical practitioners and nurses, who are often assisted by locally trained health workers, manage the primary care centers. At this level diabetes care forms part of the primary health program, where simple urine testing for glucose is conducted. There is lack of equipment for biochemical analysis, which is a serious limiting factor in establishing diagnosis. Only a few centers in the urban areas have facilities for HbA1c estimation. Therefore in the rural areas, glucosuria may be the only basis for diagnosis. Because of the unavailability of basic diagnosis and diagnostic equipment, the disease and its complications are rarely detected early enough for intervention to be helpful. Patients with glucosuria are usually referred to secondary health care centers or they seek out private clinics, which serve a considerable number of patients who can afford the cost. Primary healthcare services and private clinics attend to the majority of the diabetic patients in the country.

Tertiary health care services receive patients from the secondary structures and occasionally from the primary care. There are only ten trained diabetologists in the country and, regrettably, with the exception of two all work in Khartoum state. In the teaching hospitals diabetes care units are integrated into outpatients clinics as independent units headed by the diabetologist. Members of the unit also include medical residents and occasionally diabetes educators and dieticians. Shortages have become acute and many of the few available trained workers have immigrated to other parts of the world, thus worsening an already poor situation. Diabetes specialist nurses are conspicuously absent. Doctors in other medical and surgical specialties seconded into the unit as necessary.

The outpatient clinics serve as diabetic units and incorporate services such as stabilization and monitoring diabetes control, diabetes education, screening for diabetic complications, training of medical students and residents. There is no recall system to facilitate follow-up visits and no home visits of diabetic patients are available.

There are three stand-alone 'public' diabetes care centers. These are under the supervision of the Ministry of Health, but collect fees. Their role, however, is limited by inequitable government resource allocation and a lack of commitment to established policies and strategies. They offer diabetes care in the form of diabetes education, in-patient care, a registry and psychosocial support to some. There are also two private diabetes centers in the country, although with incomplete facilities and few diabetologists or other paramedical educators. Diabetic children attend clinics at the primary health care centers, paediatric out-patient clinics of the general hospitals or private specialists or generalist clinics.

A wide range of laboratory tests for monitoring diabetes control and diabetic complications is available in the tertiary centers. Retinal laser treatment and cataract surgery are obtainable in public and private eye hospitals. Facilities for renal dialysis exist in ten public and six private centres. Renal transplantation with live donor is available in four hospitals.

3 CONCEPTUAL FRAMEWORK

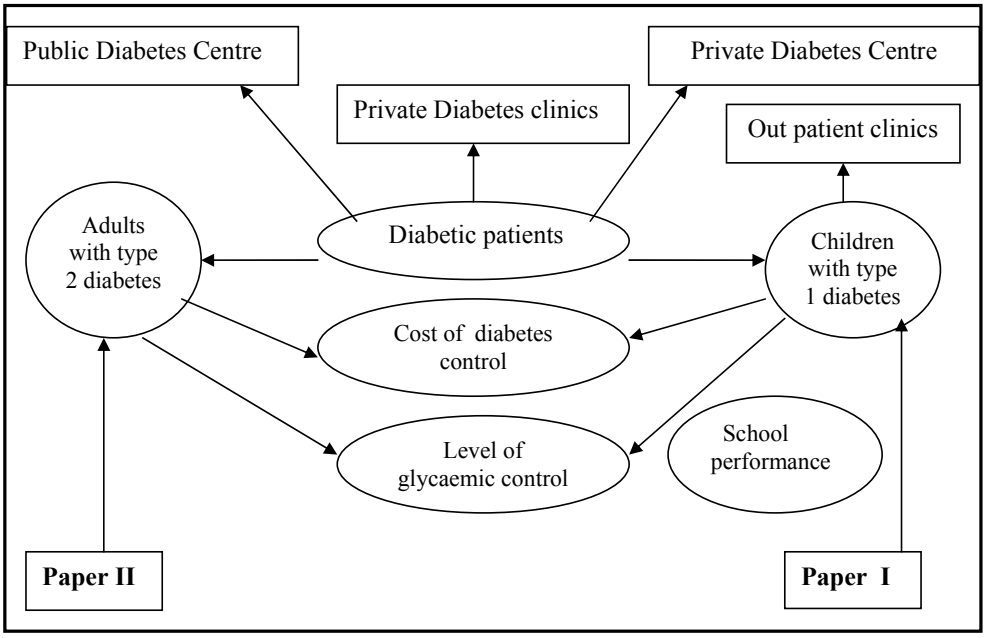

Figure 3: Conceptual framework of the studies

4 RATIONALE OF THE STUDY

This study is justified and rationalized by some emerging facts about diabetes mellitus in Sudan, which as in many other low-income countries is a growing health problem within all socio-economic classes. The high prevalence of diabetes in the Sudan is associated with poor glycaemic control, a high prevalence of complications and a low quality of life. Yet studies of the socioeconomic impact of diabetes have not been conducted. Estimates of the costs of diabetes can provide information to help guide priorities for allocating scarce resources, attracting additional resources and managing available assets to control diabetes. The results from these analyses are expected to help national authorities in Sudan – and in other low-income countries- in formulating strategies, policies and programs to cater for the control of diabetes and its complications.

Governments, healthcare organizations and legislators might be more willing to allocate resources to diabetes services if they were able to correctly appreciate the socioeconomic impact of diabetes in the population. This can also help decision-makers to strike a balance between the urgent needs of diabetes and the merger funds available for health services in the country. Hence the study will support the assessment of the fundamental responsibilities of individuals and societies towards diabetes patients with diabetes.

This indicates an increasing prevalence of DM and its complications to epidemic proportions, leading to the emergence of a major economic impact, particularly when it comes to the costs of the disease and its treatment. However, few economic studies for estimation and assessment of diabetes costs have been accomplished in low-income countries. Such studies indicate that the economic and social burdens imposed by diabetes are probably avoidable given a suitable treatment program.

The present situation has prompted serious investigation on efficacy and cost-effectiveness as well as costs structure and magnitudes relative to family's income in terms of attaining better control of the disease and mitigating its complications. This study is the first investigation to approach this problem in Sudan and may indirectly contribute to the appropriate management of diabetes mellitus in Sudan.

5 AIMS OF THE STUDY

5.1 General aim

The aim of this study was to evaluate the economical burden of diabetes mellitus on patients and their families in Sudan and to assess the effectiveness of care.

5.2 Specific objectives

1. To estimate direct costs of care for children with diabetes type 1 and to assess their glycaemic control.
2. To estimate the direct costs of care in patients with type 2 diabetes and in relation to their own income and to the level of diabetes control.

6 METHODS

6.1 Study context

These two studies were descriptive cross-sectional studies conducted in Khartoum State in Sudan. Study I was conducted among parents of children with diabetes type l during 10 months, May 2003 to February 2004. Study II was conducted among early onset adulthood type 2 diabetics during the period January to December 2005. The two sub-studies presented in this thesis consist of interviews with children's parents and adult patients who were attending public and private diabetes clinics. Glycosylated haemoglobin (HbA1c) as a measure of glycaemic control was determined in samples randomly collected from the adult patient cohort.

The studies were conducted in public and private diabetes centres and clinics in Khartoum and Omdurman cities in Khartoum State. These were the paediatric out-patient clinics in two main hospitals in Khartoum State (Khartoum Teaching Hospital and Omdurman Teaching Hospital), Jabir Abu Eliz (the only public diabetes Center in Khartoum State), Mulazmin Diabetes Center (private centre) and private diabetes specialist clinics. These health facilities deliver care for the vast majority of the diabetic patients in Khartoum State.

Khartoum State is the national capital and commercial centre of Sudan. The confluence of the White Nile and the Blue Nile forms the natural separation of the three towns: Khartoum, Khartoum North and Omdurman. The capital has more than 6 million inhabitants, comprising more than 20% of the population of Sudan. The state has a relatively higher level of healthcare compared to elsewhere in the country. Most healthcare services have relatively adequate numbers of practitioners and specialists.

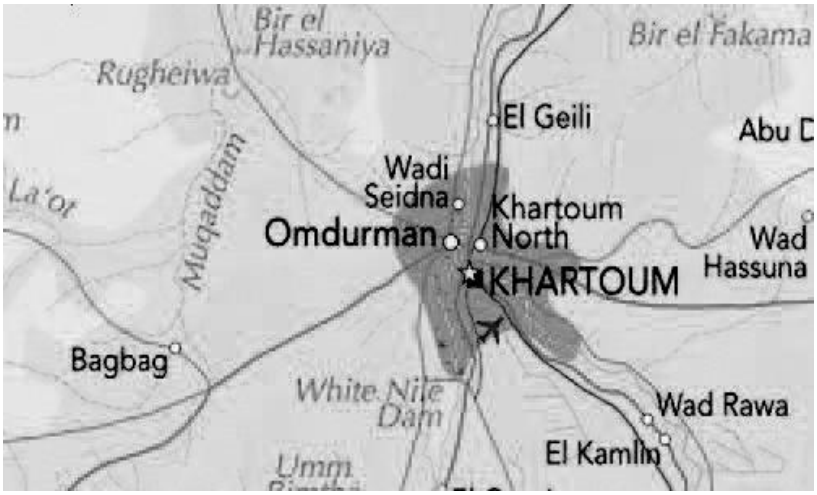

Figure 4: Location of the study setting and map of Khartoum capital.

6.2 Patients and methods

Each facility was visited one day per week. All parents of diabetic children and adult diabetic patients visiting that day were given information about the study and invited to participate.

Out of a total of 164 identified children, parents of 147 (90%) agreed to participate in **study I** and responded to the appointment made to attend the interviews. In **study II**, 822 patients over 30 years of age with duration of diabetes type 2 of between one to five years, attending either public or private diabetes clinics, were interviewed. These represented 92% of the patients visiting the clinics on those days. The study sample is thus representative of diabetes patients in Khartoum state and is comparable with other urban areas of the country.

From 123 randomly selected adult diabetic patients, (52 in public and 71 in private centres), venous whole blood samples were drawn in EDTA-containing tubes for determination of HbA1c.

6.3 Data collection and tools

In the interviews of the parents of the diabetic children and diabetic adults, a semi-structured questionnaire (Appendices I and II) was used to gather information regarding metabolic control and frequency of episodes of hypoglycaemia and hyperglycaemia. The interviews included socio-demographic characteristics, school performance of the diabetic

children before the diagnosis of diabetes and current status. Values of last month and last year of income of the family of the diabetic children, and income of adult diabetic patients was obtained. Contribution of spouses and siblings to the income of the diabetic adult patients was also noted.

During the interview the respondent was asked to state their income. As it was not expected that the respondent had a fixed monthly income, the interviewer tried to remind the respondent of all incomes received from various sources during the recall period. The amount then given as income can be expected to be an approximate figure. This sum was noted by the interviewer and at a later stage recalculated from the local currency to US dollars and at this stage rounded off to give an even number of dollars.

Expenditure on health of the family of the diabetic children and adult patients were obtained for periods of 24 hours, 3 months and one year. Thus information was collected about the use and costs of insulin, syringes, drugs, urine and blood tests as well as the number of visits to doctors and number and length of hospital stays during these periods.

6.4 Statistical analysis

Data were analyzed using SPSS and Excel programs and presented as mean ± SD or median and interquartile range. Chi square test, Student's t-test and Mc Nemar two-sided change test were used for evaluation of statistical significance. Differences between pairs of groups were tested by Student's test and Mann-Whitney's U-test. In all tests $P<0.05$ was defined as being significant. The confidence intervals (CI) were calculated for percentage of unsatisfactory results in blood glucose level compared between public and private patients.

6.5 Laboratory Analysis

Glycosylated haemoglobin analysis was conducted using High Performance Liquid Chromatography. The level for acceptable glycaemic control was <6.5%, which concords with the recommendation from the European Diabetes policy group.

6.6 Ethical clearance

Ethical approval for both studies was obtained from the Ethics Committee of Karolinska Institutet, Stockholm, Sweden, and the Ministry of Health, Sudan. In both studies consent forms were used to inform participants about the purposes and objectives of the studies.

7 RESULTS

7.1 Patient characteristics and family income

In **Study I**, the mean annual income of the households with diabetic children was estimated at USD 1810; however, because of the skewed distribution the median household income was estimated lower as USD 1222. In the quartile of families with lowest income the annual income was less than USD 600. Income as used in the study included permanent income such as salaries as well as other temporary sources, which were mainly donations from relatives and friends. These temporary sources accounted for 16% of the mean total family income. Families of diabetic children who were attending private clinics had significantly higher mean spouse salaries (USD 227) than those attending public clinics (USD 56, $p<0.03$), although there was no significant difference in total income between the two groups.

For **study II**, in addition to personal income, contributions from other sources (which were mainly from the spouse and siblings) were included. The median annual income was estimated as being USD 1923. Patients over 60 years of age had an average annual median income of USD 1923, which was more than in those below this age (USD 1846, $p<0.05$). The proportion of income received by the older age group of patients from their siblings or relatives was significantly higher (USD 1265) than that received by the younger age group (USD 1135, $p<0.01$). However, for the females their spousal contribution (USD 1385) was significantly higher than that for males receiving contribution (USD 692) from their spouse ($p<0.01$). The same was true for sibling contributions, thus making the total average income of females not significantly lower than that of males. The median income of patients attending private clinics (USD 2068) was significantly higher than that of those attending public clinics (USD 1250, $p<0.03$).

For both type 1 and type 2 diabetics it appeared that income had a clear impact on the behaviour of seeking medical treatment for patients and their families. This is reflected by our finding that the mean income of patients attending private clinics was significantly higher than of those attending public clinics. This gives an indication of the patients' ability to pay, as we expect the cost of treatment to be higher in private clinics relative to public ones.

7.2 Expenditure on health

In **Study I** the recall of previous year family expenditure on health revealed that 65% of the expenditure was used by the diabetic child whereas the older and the younger siblings were estimated to use 16% and 5%, respectively, of the total health expenditure (figure 5).

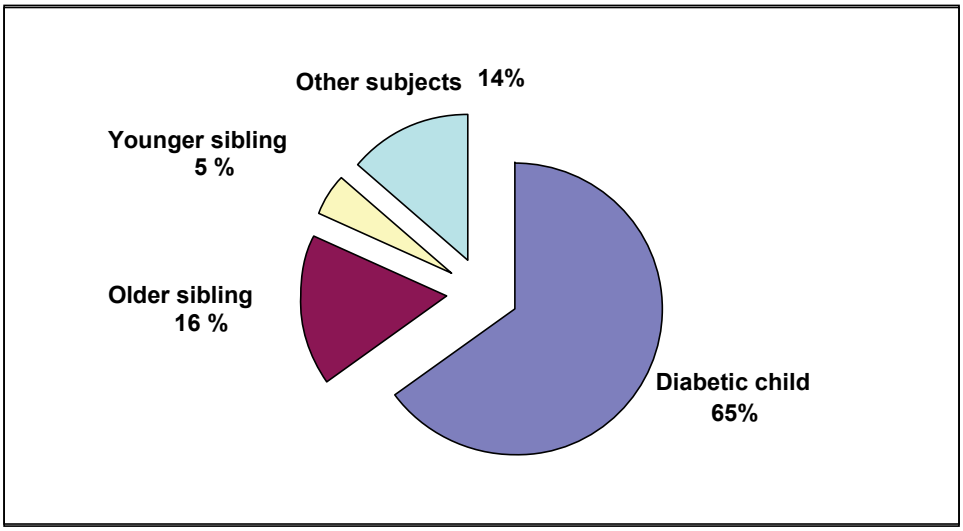

Figure 5: Family expenditure on health

The total median direct cost of diabetes care was USD 283. Of this, more than one third was spent on insulin. Families of diabetic children who were attending private clinics had a significantly higher total expenditure on health and tests of blood glucose than those who were attending the public clinics (Table 2). During the previous six months the diabetic children had visited the doctors for consultation six times on average. The recall showed that the mean frequency of visits of the patients to the doctors in the public health centers (6.4$\pm$5.0) (mean + S.D) was significantly higher than that to the doctors in the private centers (4.9$\pm$4.4, p<0.05). As patients who were attending public centers made more frequent visits to the doctors than did the private patients, they were paying relatively less of a fee per visit.

Table 2: Cost of diabetes care of the parents of diabetic children attending public and private health centers

Expenditure	Public health centers*	Private health centers*	*p*-value
Insulin	109 ±74	123 ±73	N.S.**
Urine test	40 ± 36	34 ± 25	N.S.
Blood test for glucose	43 ± 69	121 ± 214	0.01
Hospital admission	102 ± 160	75 ± 57	N.S.
Doctor fees	87 ± 108	80 ± 101	N.S.
Total cost	378 ± 162	435 ± 267	0.01

*Data (mean ± SD) are expressed in USD.** N.S. Not significant

Study II Of the total number of patients, 73% had received ambulatory care in private clinics. During the last six months, 85% of patients visited their doctor more than twice. The annual median direct cost of diabetes control, including ambulatory care and drugs was estimated at being USD 175. Diabetic patients using private healthcare facilities spent significantly higher average total expenditure on diabetes control than those using public healthcare facilities. The cost of ambulatory care (doctor fees and cost of investigations) was specifically higher for private facility users than for public facility users (p<0.01). Diabetic patients who were above sixty years of age spent significantly more on all items of diabetic care, with the exception of drugs, than their younger counterparts (p<0.01; Fig. 6).

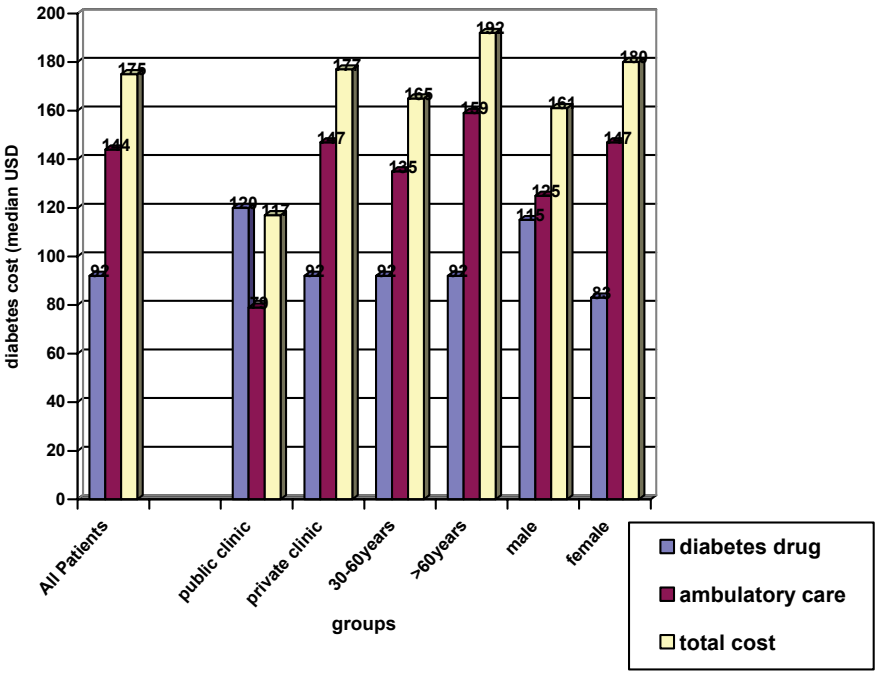

Figure 6: Median annual cost care of patients with type 2 diabetes in USD

Table 3 shows that males older than 60 years spent significantly more than those younger than 60 years on total diabetes care, while older females spent significantly more on ambulatory care (doctor fees and investigations) than did younger females. **Table 4** shows that in patients attending public clinics there was no significant difference in cost of diabetes care between different age groups. However, for patients older than 60 years and attending private clinics, the cost of diabetes care was higher than for those less than 60 years.

Table 3: Median (interquartile range) annual cost of diabetes care in USD for age groups and divided by sex

Categories / Item	Age Group yrs	Males N = 331	pvalue	Age Group yrs	Females N = 491	P value
Diabetes drugs	30 - 60	97 (55 -162)	ns	30 - 60	92 (55 -208)	ns
	>60	115 (69 -335)		>60	92 (56 -139)	
Ambulatory care (Out-patient)	30 - 60	119 (69 -199)	ns	30 - 60	144 (89 – 197)	**0.05**
	>60	154 (83 -211)		>60	159 (105 - 203)	
Total cost of Diabetes control	30 – 60	139 (73 - 211)	**0.001**	30-60	175 (107 – 262)	ns
	> 60	192 (116 - 308)		> 60	192 (149 - 264)	

Table 4: Median (interquartile range) annual cost of diabetes care in USD for age groups and in relation to private and public clinics

Categories / Item	Age Group yrs	Attending public clinics N = 69	P value	Age Group yrs	Attending private clinics N = 753	P value
Diabetes drugs	30 - 60	125 (51-314)	ns	30 - 60	92 (55 -190)	ns
	>60	92 (62 -505)		>60	92 (55 -185)	
Ambulatory care (Out-patient)	30 - 60	92 (41-140)	ns	30 - 60	142 (82 -200)	**0.006**
	>60	159 (49–88)		>60	147 (106 -212)	
Total cost of Diabetes control	30 - 60	98 (42-213)	ns	30 - 60	169 (97 - 242)	**0.001**
	> 60	192 (73 -316)		> 60	177 (138 - 287)	

7.3 Diabetes control and acute complications

For diabetic children, responses by the parents revealed that the most frequent pre-meal or fasting blood glucose levels during the last 6 months were unsatisfactory in 86% of the patients. Their most frequent pre-meal blood glucose level was 9 mmol/l or higher. However, it was noted that 26% of the study group had not tested their blood glucose during the last 6 months. There was a negative correlation between the mother's educational level and fasting blood glucose level of the diabetic child ($p<0.02$), but the father's educational level was not of significance. There was no correlation between the parents' income and glycaemic control (Fig.7), nor was there a difference in diabetes control between children attending private and public clinics. Acute complications of diabetes, as evidenced by ketone bodies in urine, were reported in 46% of the children. Hypoglycaemia that needed special attention had occurred in 37% of the patients. Of the type 1 diabetic patients, 57% had been admitted at least once to the hospital within the last year, the main causes of admission being diabetic ketosis (72%), hypoglycaemia (6%), malaria (11%) or other medical disorders or surgical intervention (9%).

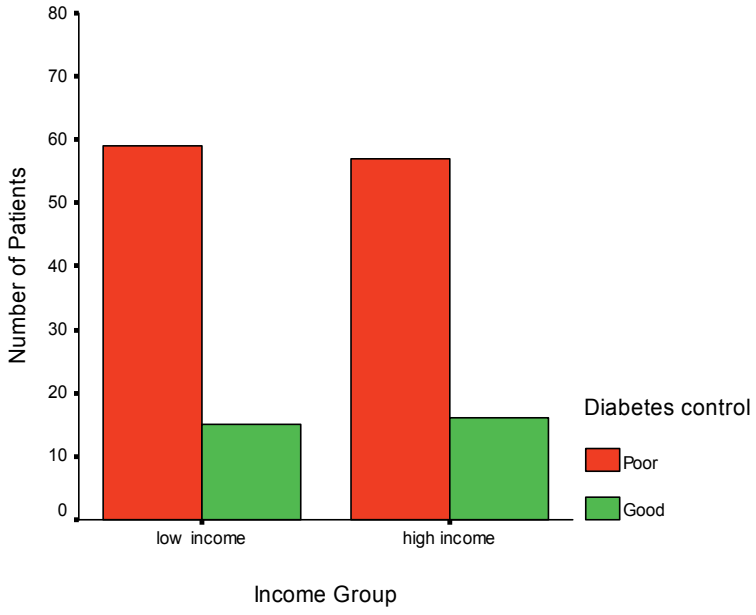

Figure 7: Diabetes control among children to low and high income parents

The outcome for adults with type 2 diabetes was not better compared with that for diabetic children. Glycosylated haemoglobin or HbA1C was determined to be unsatisfactory (HbA1c more than 6.5%) in 77% of patients (Mean + SEM 8.2 + 0.12). On recall of most frequent blood glucose levels in the last 3 months, fasting blood glucose levels of 4.4-6.7 mmol/L were reported by 15% of patients. However, almost two thirds reported fasting blood sugar levels of more than 8.9 mmol/L. There was no significant difference in the reported levels of fasting blood glucose during the last three months between males and females.

Of the patients studied, 81% performed their blood and urine tests in private laboratories, 7.5% visited public laboratories and 2.3% conducted their tests using both facilities. Home Blood Glucose Monitoring (HBGM) was carried out by only 9% of the patients, with no gender difference. Only 11% of patients who were conducting HBGM had tested their blood for glucose more than three times during the previous months. Hypoglycaemia that needed special attention had occurred among 16% of the patients. With regard to complications, 25% of the patients had been admitted to hospital during the previous year. Of these, 37% had acute infection and ketosis, 8% had hypoglycaemia, 13% had malaria, 35% had surgical causes and 7% had other complications and causes for in-patient treatment.

8 DISCUSSION

This thesis has mainly focused on the economic burden of disease encountered by Sudanese diabetic patients and their families. Although several studies conducted during the last 10 years in Sudan have investigated many clinical aspects of diabetes mellitus, none of them has addressed the economic burden of the disease [43-45]. Unlike cost estimates derived from the data of diabetic individuals identified from the general population or diabetes registers, this study design has the advantage of interviewing individuals face-to-face, thus obtaining relatively precise estimates of the cost of diabetes. This means that information about costs and utilization patterns of individuals is collected directly, rather than estimating the cost from aggregated categories [24, 46]. In this study the burden of diabetes was examined in terms of resources used by diabetic patients, while the benefit was reflected by the degree of diabetes control. With low benefit in terms of poor metabolic control one would anticipate high burden of diabetes in terms of years, with a lower quality of life, Disability Adjusted Life Years (DALYs) [23].

8.1 Diabetes cost and expenditure on health

This study demonstrated that the total cost of diabetes during childhood diabetes constituted a major part of the total income of the household of the diabetic child. We also determined that the cost of diabetes was USD 175 per year, derived from an annual income of USD 1923. More than half of this amount was contributed by the spouse or siblings. Comparatively little work has been done to assess the costs of diabetes in LMIC countries. In Cameroon, the average direct medical cost of treating a patient with diabetes in 2001 was USD 489, of which 34% was spent on anti-diabetic drugs. The direct medical costs for treating all diabetic patients in Cameroon represented about 3.5% of the national budget for the 2001–2002 financial year [47]. Diabetes care management estimates from Malawi, based on international prices for essential drugs and Malawi hospital cost data, suggest that a type 1 diabetic patient spends about USD 100 per annum on the purchase of insulin, while a type 2 diabetic patient spends annually USD 25 annually on oral hypoglycaemic agents [48]. It is clear, however, that families with the lowest incomes bear the highest relative financial burden of diabetes [49]. In the USA, diabetes costs have been estimated at 9% of household expenditure for low-income families [50]. In fact there are many direct costs involved in the care and management of diabetes for the individual and the healthcare system, as well as for the community at large. These range from the relatively low cost items such as primary care

consultations and outpatient episodes, to the very high cost items such as long hospital in-patient stays for treatments of complications.

For comparison, a study from Tanzania [34] reported that the average annual direct cost of diabetes care for a patient requiring insulin was USD 287. The purchase of insulin accounted for 68% (USD 156) of the average annual outpatient cost of patients requiring insulin. The supply of insulin in many countries in Africa is erratic, even at large hospitals [51-55] and the prospects for people with type 1 diabetes are poor. In India, annual family income in urban diabetic subjects was USD 2227, while total median expenditure on healthcare was 227. Treatment costs increased with duration of diabetes, presence of complications, hospitalization, surgery, insulin therapy, and urban setting [56]. In Europe the *per capita* direct cost of type 2 diabetes in a sample of European countries during 1998 ranged from Euro 1305 to Euro 3295 (USD 1370 to 3460) [31]. This indicates that the annual expenditure of diabetes in Sudan and other developing countries is very likely to be too low to support the quality of care needed to substantially decrease the risk of late diabetic complications.

Diabetes is expensive to manage, and the *per capita* costs of managing diabetic patients are 2-4 fold higher than for a non-diabetic patients [42]. Sudanese healthcare is under-funded with a total expenditure *per capita* amounting to only USD20. The budgeted central healthcare expenditure was USD 4 *per capita* which is only around 0.6% of the GDP. It is estimated that the out-of-pocket expenditure exceeds 70% of total healthcare expenditure [42] Similarly in other LIC countries, a study in India shows that healthcare resources are very limited, with only 5%, (USD 23 *per capita*) [33]. For comparison, the annual direct medical costs per patient with type 2 diabetes mellitus in Hong Kong were around USD 1492, of which the government paid 91% [57]. The lack of a free national healthcare service in most sub- Saharan countries means that the burden of diabetes care is on the patient or the family. A preliminary study from Cameroon reports that diabetes care is paid for by patients (50%), family (44%), employer (2%), charities (2%) and 2% by others, including the government [58].

In the USA, the direct medical and indirect expenditures attributable to diabetes in 2002 were estimated at USD 132 billion [30]. Direct medical expenditures alone totalled USD 92 billion and comprised 23 billion for diabetes care, USD 25 billion for chronic complications attributable to diabetes and USD 44 billion for excess prevalence of general medical conditions. In addition, the study documented that 52% of direct medical expenditures were incurred by people 65 years old or older [30]. Because of the differences

in study methods employed [29, 59] the results of many previous studies are difficult to compare. Future cost and cost-effectiveness studies should use standardised methods [31].

Paying for healthcare can be unfair in two different ways. It can expose families to large unexpected expenses, costs that could not be overseen and which have to be paid out-of-pocket at the moment of utilization of services rather than being covered by some kind of prepayment. Or it can impose regression of payment in which those least able to contribute pay proportionately more than those that are better off. In our study the direct cost of diabetes care required 65% of the health expenditure of the whole family. Insulin constituted about one third of the total diabetes care expenditure. Under such circumstances people buy care even if it costs them their long-term livelihood, because medical expenses are often forced payments. In traditional economic analyses, poorer groups´ payment for healthcare is typically used as evidence of a willingness to pay. However, this considerable contribution of the family was not reciprocated with optimal healthcare of the patients, as reflected by the sub-optimal glycaemic control in both public and private practices. More detailed cost-benefit analysis needs to be addressed.

8.2 Impact on school performance

Socioeconomic and educational characteristics influence the prognosis of individuals with diabetes. The high rate of illiteracy of mothers may have contributed to impairment of the care of the diabetic child. In addition, the illiteracy of the fathers could hamper a good financial support to the diabetic child and may keep patients away from hospitals until their condition is much more severe. Another study conducted in Egypt [60] highlights the fact that the low levels of educational attainment can limit the extent to which patients can manage the problems associated with diabetes. The poor metabolic control exhibited in this study was associated with a negative impact on educational attainment and school performance of the diabetic child. Because of inadequate intermittent treatment, most diabetic children were in poor health and frequent hospital admissions prevented them from attending their school. Of the newly diagnosed diabetic children in Sudan 81% presented to hospitals with diabetes ketoacidosis [61].

8.3 Quality of diabetes care

Results from this study and those of others [19, 43, 44] indicate that good quality of diabetes care has yet to be achieved in Sudan. Both in the study of type 1 diabetes in children and in the study of adult type 2 diabetics, we found that more than two thirds of the patients were

not optimally controlled, regardless of whether they were attending private or public health clinics. This economic burden has then generally not translated into optimum diabetes care in either private or public practices and can be considered as a depletion of family resources and an inefficient healthcare delivery system.

To maintain a healthy quality of life, diabetic patients must have access to appropriate medication, quality care and good medical advice. A study by Gilmer *et al* reported a relationship between worsening glycaemic control and increasing healthcare costs [62]. The ADA, for example, recommends achieving an HbA1c goal of <7.0% [63] whereas the AACE recommends a goal of <6.5%. Maintenance of such glycaemic levels will significantly reduce complications in both type 1 and type 2 diabetes. Results from the UKPDS [64] demonstrated that there is no HbA1c threshold at which further lowering does not reduce the risk of complications until the normal range (<6.0%) is reached. Glycaemic control can be viewed as an intermediary outcome indicator of effectiveness of treatment, as it is known to be related to the long-term prognosis of the disease. Additionally, it is likely that poor glycaemic control is a consequence of failure to address other risk factors, such as insufficient awareness of lifestyle risks. Improved glycaemic control is also associated with substantial quality-of-life and health economic benefits. Favourable health economic outcomes include higher retained employment rates, greater productive capacity, less absenteeism and fewer restricted activity days [65].

As indicated previously, more than 75% of either type 1 and type 2 diabetic patients never self-monitored their blood glucose [43]. In diabetes care the regularity of blood glucose control may indicate the quality of the process of care. In our study, Home Blood Glucose Monitoring (HBGM) was only performed by one out of ten adult patients. HbA1c is the ideal way to monitor blood glucose when the facilities and resources are available (one practical consideration in Africa being maintaining the correct ambient air temperature [53]. but for most people with diabetes in Africa this option is inaccessible. Even when available, HbA_{1c} is measured in less than 5% of patients [52, 66-68]. Fasting blood glucose is probably the most affordable means of monitoring people with diabetes, although even this might not be available [52]. Random blood glucose is the most common means of monitoring [52, 67], which can be helpful in people with type 2 diabetes if the time of the last meal is also recorded. Urine glucose measurements can be useful in identifying people with blood glucose levels that require immediate attention. The current availability and use of methods for monitoring blood glucose means that very few people with diabetes in Africa are likely to achieve normal levels of glycosylated haemoglobin.

One of the main factors that encouraged the private provision of health services was the perceived deterioration of the quality of services provided by the public healthcare facilities [69]. In addition, the introduction of user fees in the public domain providing health services made the ratio of quality/cost more favourable for the private sector, as the higher user charges in the private sector were accompanied by its higher quality (15). No studies of the negative impacts of the user charge policy on equity have been performed in Sudan, despite long-standing concern about its effects and renewed debate.

8.4 Methodological considerations

One limitations of the study is that there could have been under-reporting of family income which would have caused an overestimation of the percentage of income spent on healthcare. This was most likely to have occurred in the high-income group. Secondly, we did not have data from a comparable population indicating the general family healthcare expenses. The major objective of the study was to note the direct cost of treating a chronic disease without reporting complications, which would be higher than that of general healthcare. There were missing data for 26 percent of the children in study I regarding blood glucose monitoring at home, which makes the data less valid for the whole population of children in the study. In relation to our findings, it can be assumed that it is more likely that those not reporting any monitoring of blood glucose levels rather are those with less well controlled diabetes than the opposite. If such is the case our findings would underestimate the already low level of diabetic control."

Collecting proper indirect cost estimates was beyond the scope of the study. However, in many cases in which estimates have been made [14,16], these costs of lost production may be as great or even greater than direct healthcare costs. The economic burden of diabetes was estimated in Sweden on the basis of human capital theory [32]. The indirect cost was dominant and amounted to 57% of the total cost. A similar example, the US estimate of direct costs, was USD 44 billion compared to USD 54 billion of loss of productivity during the same year. Combining the cost estimates for 25 Latin American countries suggests that costs of lost production may be as much as five times the direct healthcare cost [24]. This may be because there is limited access to high quality care with, consequently, a high incidence of complications, disability and premature mortality. Families too, of course, suffer loss of earnings as a result of diabetes and its consequences. Pain, anxiety, inconvenience and other factors which decrease quality of life are intangible costs, which were difficult to assess in our study.

Although intensive therapy increases treatment costs, it substantially reduces the cost of treating diabetes-related complications and increases the amount of time free of complications. For example, a study based on outcome data from the UKPDS trial, determined that intensive therapy increased costs by USD 1138 in 1997 per patient but reduced the cost of complications by USD 1597 [70].

In addition, economic assessment studies should be based on standard research methods and reliable data to ensure validity and comparability of results. Finally, areas of economic research should be broadened, such as studying issues related to prevention of diabetes. Patients and their families need to be involved and aware of the demands of controlling the disease to avoid the consequences of complications.

9 CONCLUSIONS AND RECOMMENDATIONS

Proper treatment of diabetes is not costly, but not treating diabetes properly is very costly. This study has addressed the economic magnitude of diabetes mellitus in Sudan and has emphasized the grave problems of diabetes care and management that result in poor glycaemic control, with its consequences of potentially increased morbidity and a low quality of life. It has been concluded that the current practices in treating diabetes (both type 1 and type 2), are far from being sufficient in Sudan. Low quality is combined with inefficient care delivery. The increasing prevalence of diabetes in Sudan requires more efforts from patients, families and the health system. Diabetes care has to be made available and accessible to those who need it and not merely for those who demand it, particularly in public healthcare facilities. In order to encourage vulnerable families to take steps in controlling diabetes and mitigating its complications and impacts, alternative funds can be created so as to contribute to financing quantity and quality care of diabetes in public healthcare facilities. This seems to be reasonable as there are user charges for having health services in public utilities, including those for diabetes. Furthermore, pricing of diabetes care in private centers and clinics and by private physicians has to be overseen and controlled since there seems to be some sort of monopoly in provision of diabetes care in Sudan. Finally, all those involved in diabetes care need to be aware of what drives costs. Demand for economic research will continue to increase because of the need to assess the growing number of interventions available to prevent and treat diabetes. In addition, future economic studies should continue to expand the scope of research. For example, economic analysis can examine how such economic factors as level of income and education, lifestyle selection, and awareness of the importance of the control are associated with diabetes and its complications. Economic studies demonstrate that diabetes is a very costly disease and that interventions used to prevent and control diabetes may differ greatly in terms of costs per health outcome gained. Health providers and policymakers should use this information in making clinical and policy decisions in order to use resources efficiently. Efforts are needed to improve the quality of economic studies and to expand economic research to new areas in the future.

Recommendations

- Health policy makers in Sudan should be provided with sufficient information that demonstrates budgeting of diabetes care.
- The government, in addition to striving to combat communicable diseases, despite scarcity of resources, needs to appreciate the magnitude of non-communicable diseases and especially of diabetes.
- Families with a diabetic child should get the necessary socio-economic support and families of diabetic patients with chronic complications should receive appropriate medical and social support.
- Continuous educational diabetes programs for diabetic patients and their families free of charge for children and all patients with diabetes and follow-up significance are required.
- Provision of insulin and other anti-diabetic drugs as well as care equipments should be encouraged at a low cost.
- Improvements in primary care services for people with diabetes to reduce the cost of diabetes care at higher levels such as control of blood pressure and blood lipids.

Implications for future research

"As has been depicted in this thesis there is a drawback in diabetes care in Sudan. This is particularly emphasized in terms of budget utilization for different aspects of care. Several research areas need to be covered: Cost analysis studies in relation to the quality of life of diabetic patients in general and in certain groups with complications of diabetes; Evaluation studies on the quality of health services for diabetes in relation to costs to elucidate appropriate mechanisms to improve the services; Explorative studies on coping mechanisms among parents with diabetic children and adults with diabetes to get more insight into their understanding of the disease, their coping mechanisms and their awareness of their own role in controlling the disease to avoid complications"

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Health Cost of Childhood Diabetes

Date of interview: _____ Place_____
Interviewer_____

1. PERSONAL DATA

Parents and head of household (HHH).

Data	*Father*	*Mother*	*HHH*
Name			
Age			
Education*			
Occupation*			
Address			
Telephone			

Siblings (Age wise): -

Name	***Sex***	***Age***	**School level***	***School performance****	***Any chronic illness***

Child affected: -

Name _____ ___ *Sex* _____ *Age* _____ *Date of Diagnosis* _____

- Level of schooling

☐ *Pre school* ☐ *Primary* ☐ *Intermediate*

- Performance in school before diagnosis

☐ Excellent ☐ V. good ☐ Good ☐ Fair ☐ Bad

- Performance in school at present

☐ *Excellent* ☐ *V. good* ☐ *Good* ☐ *Fair* ☐ *Bad*

** Refer to Guide lines for classification*

2. ABOUT DIABETES OF YOUR CHILD: -

- Do you think the diabetes control of your child is?

☐ *Very good* ☐ *Good* ☐ *Fair* ☐ *Poor* ☐ *Very poor*

- What was the most frequent level of sugar in urine during last 3 months

☐ *Not applicable* ☐ *Applicable State :-*_____

☐ ***No sugar*** ☐ + ☐ ++ ☐ +++ ☐ ++++

- What was the most frequent range of blood sugar: -

☐ *Not applicable* ☐ *Applicable, State:-*

☐ 70 – 140 ☐ 140 – 180 ☐ 180 – 250 ☐ 250 – 300 ☐ *300*

- During last 6 months how many episodes of ketones in urine?

☐ *No Ketones* ☐ *Ketones. State:*_____

- During last 6 months how many episodes of hypoglycemia?

☐ *Not applicable* ☐ *Applicable, state:-* _____

3. INSULIN:-

- What types of insulin do you always take? ☐ *Beef* ☐ *Human*

- During last week what was the daily insulin regimen?

- Is this the usual regimen

☐ *Yes* ☐ *No, state:-*_____

- Total daily dose (interviewer)_____

- From where do you usually get your insulin?

☐ *Private* ☐ *Public* ☐ *Others,state*_____

- Do you have other Sources where you get your insulin?

☐ *No* ☐ *Yes, state:*_____

- How often do you get your supply form this sources?_____

- ***Do you always have enough supply of insulin?*** ☐ *Yes* ☐ *No*

- If the answer is No, the reason is: - ☐ *Unavailable* ☐ *unaffordable* ☐ *both*

4. ***URINE TEST: -***

Urine for sugar has been determined regularly during last 6 months at

☐ *Public lab.* ☐ *Private Lab* ☐ *Home* ☐ *Not applicable*

How many times did your child test his blood sugar during last

☐ *1 month* ☐ *3 month*

- Total cost per year (interviewer): _____

5. ***BLOOD TEST: -***

- Blood sugar has been determined regularly during last 6 months at

☐ *Public lab.* ☐ *Private Lab* ☐ *Home* ☐ *Not applicable*

- How many times did your child test his blood sugar during last

◯ *1 Month* ◯ *3 months*

- Total cost per year (Researcher)? _____
- Who usually pays the cost ? _____

☐ *Father* ☐ *Mother* ☐ *HHH*
Others, state _____

6. OTHER TESTS:-

- What was the cost of other test during the last 3 month?
_____

7. ***VISIT TO CILINC AND HOSPITAL ADMISSIONS:***

- Where does your child usually go for control of his/her diabetes

☐ *Private unit* ☐ *Public unit* ☐ *Other, state_____*

- ***In states of emergency does the child usually go to: -***

☐ *Public unit* ☐ *Private unit* ☐ *Other, state_____*

- How Many times did the child visit the doctor / health center during: -

◯ *6 months*

What was the total cost per each visit including tests and transportation?

- Had the child been admitted to the hospital during the Last year?

☐ *No* ☐ *Yes* *If the answer is yes?*

- How many times? _____
- How many days? _____
- What was the reason of admission? _____
- What was the total cost? _____

- *Who had financed the treatment?* ☐ *Parents* ☐ *Other, state:* _____

- *Is this the usual source of finance?* ☐ *Yes* ☐ *No, state* _____

8. INCOME:-

- Net income of household (Sudanese pounds): -

From	**Last month**	**Last year**
salary / own resources		
spouse		
relatives / friends		
Total		

- Expenditure of household on health (Sudanese pounds): -

To	***Last month***	***Last year***
whole family		
diabetic child		
child older than the diabetic child		
child younger than the diabetic child		