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PSYCHOSOCIAL FUNCTIONING IN INDIVIDUALS LIVING WITH DIABETES MELLITUS IN ZAMBIA

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan Tilburg University op gezag van de rector magnificus, prof.dr. E.H.L Aarts, in het openbaar te verdedigen ten overstaan van een door het college voor promoties aangewezen commissie in de Ruth First zaal van de Universiteit op dinsdag 24 november 2015 om 14.15 uur

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Chapter 1

General Introduction

Background information

The research presented in this thesis aimed at investigating psychosocial functioning in people with diabetes mellitus in Zambia. The sample in the thesis included urban adolescents and adults with both type 1 and type 2 diabetes mellitus. The thesis addressed the following questions:

1. What is the prevalence of diabetes in children in Sub-Saharan Africa (SSA), what are the consequences and risk factors for diabetes and what does diabetes care look like in SSA? (Chapter 2)
2. What are the sources of stress, the ways of coping with stress, the perceived quality of care and the quality of life as experienced by Zambian adolescents living with type 1 diabetes? (Chapter 3)
3. Does the Zambian version of the Problem Areas in Diabetes (PAID) have sound psychometric properties and what are the levels of diabetes-specific emotional distress in people with type 1 and 2 diabetes in Zambia? (Chapter 4)
4. How common is co-morbid depression in individuals with type 1 and 2 diabetes in Zambia? (Chapter 5)
5. What is the association between symptoms of depression with diabetes self-care in individuals with type 1 or 2 diabetes? (Chapter 6)

To place this thesis into context, this introduction provides background information about psychosocial issues among people living in diabetes both globally and within the Zambian context. Additionally, an outline of the thesis is provided.

Psychosocial issues common in diabetes

In 1994, the psychological well-being working group of the World Health Organization/International Diabetes Federation St Vincent Declaration Action Program for Diabetes published guidelines for encouraging psychological well-being in people with diabetes [1]. The guidelines included: improving communication between diabetes health-care teams and the person with diabetes; protecting self-esteem of people with diabetes; responding to individuals' differing needs; helping patients learn about their own individual responses; helping to motivate self-care; monitoring of psychological well-being and proposing organizational changes aimed at optimizing psychological aspects of diabetes care [1]. 20 years down the line, psychosocial aspects of diabetes are almost never taken care of in the Zambian health care system and there is a dearth of research on the subject in Sub-Saharan Africa.

Diabetes is a chronic metabolic disease characterized by hyperglycemia resulting from defects in insulin secretion, insulin action or both [2]. According to the World Health Organization (WHO), diabetes mellitus can be classified into four types: type 1 diabetes, type 2 diabetes, other specific types of diabetes and gestational diabetes mellitus [3]. Type 1 diabetes results from autoimmune destruction of the pancreatic beta cells, causing the loss of insulin production while type 2 diabetes is characterized by insulin resistance and abnormal insulin secretion [2]. Other specific type of diabetes are caused by genetic disorders, infections, diseases of the exocrine pancreases, endocrinopathies and drugs while gestational diabetes is due to glucose intolerance with onset or first recognition during pregnancy [2]. Diabetes can be managed through primary and secondary care. Primary care refers to medical care that a walk-in patient is given by a health care provider who often serves as the contact person and focal point person for further care within a health system, whereas secondary care refers to health care services that are provided by a medical specialist (e.g., cardiologist, nutritionist) following

recommendation or referral from a primary health care provider. Diabetes self-care consists of proper use of medication (insulin or oral medication, correct timing/correct doses especially for type 1 diabetes), counting of carbohydrates, a healthy diet (e.g., low in saturated fat, low in salt, high in vegetables/fruits and moderate in alcohol intake especially for type 2 diabetes), being physically active, monitoring of blood glucose levels, proper foot care and refraining from smoking among others [4]. If not properly cared for, diabetes can lead to microvascular and macrovascular complications. Microvascular complications include diabetes retinopathy, nephropathy and neuropathy. Macrovascular complications include heart attack, stroke and peripheral arterial disease [5].

The importance of addressing psychosocial issues has long been recognized in chronic conditions such as diabetes including the evidence that psychological issues, such as depression and stress, are linked with an increased risk for the onset of diabetes mellitus [6]. In addition, diabetes increases the risk of depression [7, 8], stress [9], diabetes-specific emotions such as fear of hypoglycemia and worrying about (future) complications. These psychological factors, in turn, negatively influence diabetes self-care behavior which in turn can hamper glycemic control. Therefore, psychological wellbeing is itself an important goal of medical care and psychosocial factors are relevant to nearly all aspects of diabetes care [10]. This is particularly true for conditions such as diabetes, since most of the treatment consists of self-care by the patient, such as injecting insulin, checking the blood glucose, counting carbohydrates, eating healthy, balancing carbohydrates with exercise and visit the health care provider(s). Each of these may impact a patient's emotional wellbeing and social life.

One of the biggest behavioral problems among patients with diabetes is suboptimal diabetes self-care. Health behaviors such as eating unhealthy diet, physical inactivity, but also emotional factors such as depression and anxiety can hamper glycemic control [11]. In addition to a healthy diet and sufficient exercise, people with diabetes should also quit or refrain from smoking. Non-adherence to treatment recommendations is often attributed to inadequate knowledge about proper diabetes care, but lack of resources can also play a role. In addition to that, psychosocial challenges may explain suboptimal self-care behaviors, such as lack of social support, chronic stress, time pressure, poverty and traditional beliefs about health or diabetes that are not in line with treatment recommendations [12]. The ultimate goal of adhering to optimal health behaviors is to control blood glucose levels. Self-care behaviors and psychological state of patients, such as dieting, exercising and depression, contribute to diabetes health indicators such as glycemic control [11]. Non-adherence is often attributed to inadequate knowledge about proper diabetes care. However, other psychosocial factors mentioned above may contribute to non-adherent behaviors, such as lack of social support, stress, time pressure and health beliefs and practices that are not in line with the recommended treatment regimens [12]. Other than the aforementioned factors, in adolescents, non-adherence problems can be a result of the increase in counter-regulatory hormones (e.g., growth hormones, cortisol, epinephrine and glucagon) responsible for insulin resistance, a situation also known as "dawn phenomenon" [13]. Dawn phenomenon is the night-to-morning elevation of blood glucose before and after breakfast in subjects with both type 1 and 2 diabetes mellitus. In people without diabetes mellitus, physiology of glucose homeostasis indicates that blood glucose and plasma insulin concentrations remain remarkably flat and constant overnight, with a modest transient increase in insulin secretion just before dawn to restrain hepatic glucose

production and prevent hyperglycemia [53]. People without diabetes mellitus do not show symptoms of the dawn phenomenon.

Several other psychosocial issues can affect people with diabetes including psychiatric disorders and behavioral problems. In adolescents with type 1 diabetes for example, internalizing behaviors (such as depression and anxiety) or externalizing behaviors (such as impulsivity, hyperactivity and aggression) are often reported [14-16]. Further, during diagnosis children just like adults, present feelings of anxiety, sadness and withdrawal. A study in Nigeria showed that children with diabetes were 42% more likely to experience emotional disorder (such as separation anxiety disorder, social phobia, dysthymic disorder, major depression disorder and generalized anxiety disorder) than children with sickle cell disease (38%) and a healthy group (11%) [17].

Diabetes can cause enormous pressure on how the family functions which either can strengthen or break family ties, depending on the characteristics of a family. During adolescence there is increasing independence and adolescents often challenge parents' supervision of their diabetes care for example. This may lead to conflicts within a family. Type 1 diabetes is demanding and affects everyday lives of not only patients with diabetes but also their families and significant others. Advice given by parents or family members (e.g., "Shouldn't you check your blood glucose? I think you are low!") can be perceived as offensive or intrusive behaviors into diabetes management, especially in adolescents who want to be or become independent. On the other hand, constant respectful and unconditional support to patients' diabetes management may improve diabetes treatment outcomes. In low-income homes, apportioning resources to household food stuffs can be a source of conflict, given that patients with diabetes are supposed

to take certain diets that have low saturated fat composition and rich in vegetables, part of a healthy diet, which may not be liked by other family members. This underscores the importance of family and friends in diabetes management. Moreover, there is literature suggesting that friends' support for blood glucose testing is related to patients' disease adaptation and quality of life [14].

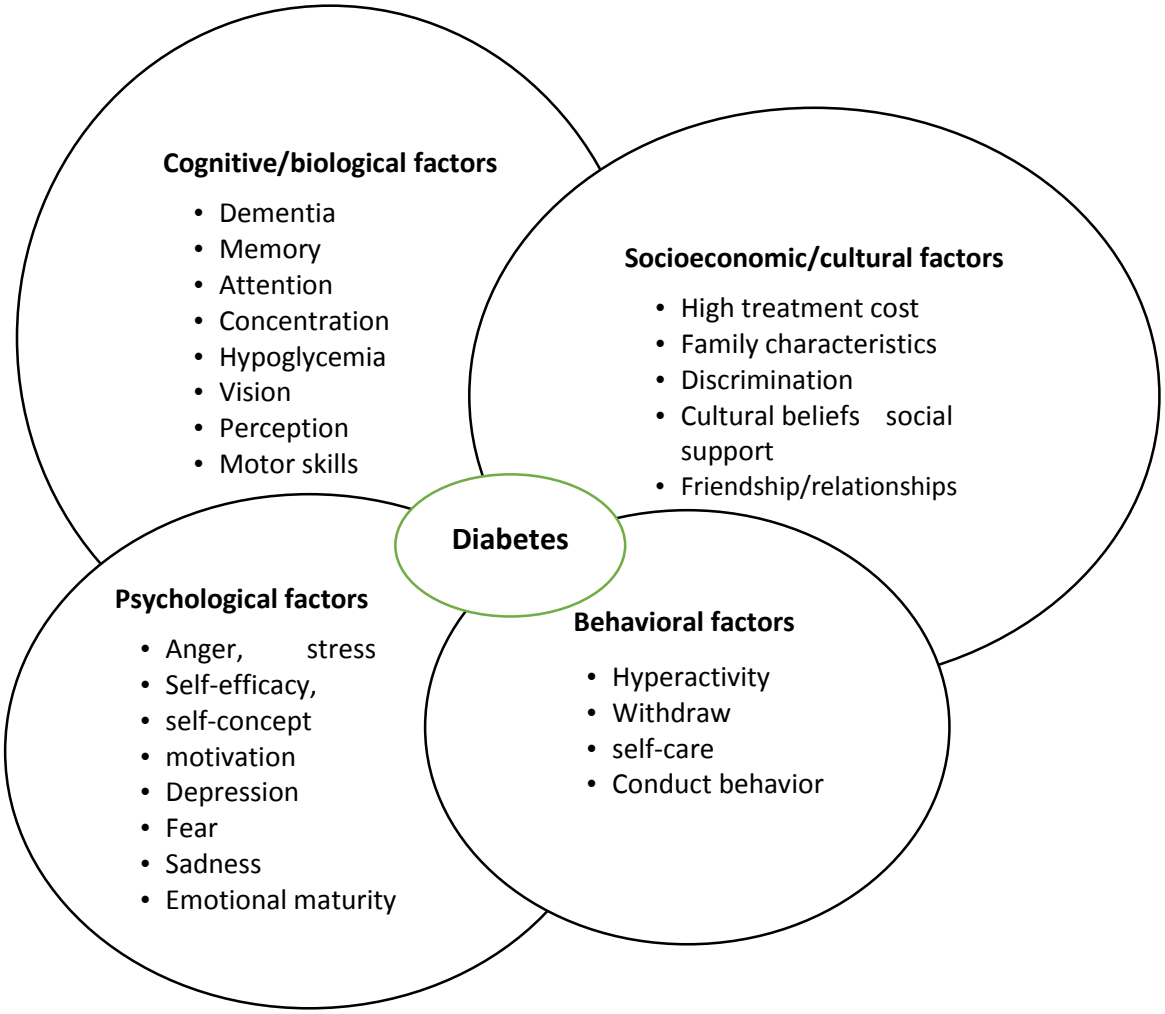
Chronic illnesses are daunting not only to patients but also to others surrounding the patient. It is therefore not surprising that people with chronic illness such as diabetes may potentially find it difficult to have romantic relationships. There are several factors other than diabetes that are implicated to include medical costs, psychological pressure [14], discrimination and traditional beliefs. For instance, in Japan 90% of men and women felt medical expenditure was a factor which affects their marriage rate because of the bills attached to their health status, 30% felt diabetes restricted their school and work attendance, which are useful avenues for meeting a potential romantic partner and 30% felt diabetes restricted them from having an intimate partner relationship [18].

Both type 1 and 2 diabetes have been associated with deteriorating cognitive functioning [19-22]. A study in Sweden revealed that children who developed type 1 diabetes during 1977-2000 had poorer school performance compared to non-diabetes peers (means = 3.14 vs. 3.23, $p < 0.001$) [23]. Common cognitive problems in people with type 1 and 2 diabetes include attention, processing speed and concentration problem [14, 24]. Hypoglycemia seems to be associated with impaired intellectual abilities, memory, attention, perceptual and motor skill problems in people with type 1 and 2 diabetes [14, 24]. Contrary to what was initially thought, review data from human and animal studies show little or no evidence for long term deleterious

impact of recurrent hypoglycemia (RH) on brain functioning but evidence shows that RH causes brain adaptation which enhances cognitive performance when euglycemic, but poses significant threat during future hypoglycemic episodes [25].

Quality of Life (QoL) in people with diabetes is another issue that has received considerable attention of researchers. Age, gender, increased psychiatric and behavioral disorders, socioeconomic status, emotions, co-morbid conditions and instrumental support all seem to be factors that are linked with health-related QoL in people with diabetes across studies [26-28]. However, a systematic review showed that self-reported generic QoL was not impaired in young people with type 1 diabetes, compared to healthy controls; however, parents reported that QoL was lower and disease-specific QoL was also lower [29]. There is also a link between QoL and metabolic control since poor metabolic control burdens the family. For most people with diabetes, having diabetes also has negative financial consequences. In 2009, the World Health Organization reported that the 7.02 million cases of diabetes recorded by the WHO in African countries resulted in a total economic loss of US$ 25.51 billion, a figure which has since increased [30]. Moreover, high income has been positively associated with diabetes ketoacidosis at type I diabetes onset among children in wealthy nations [31]. Common psychosocial issues associated with diabetes are shown in Figure 1.

Figure 1: The psychosocial conceptual model in diabetes



Diabetes in Zambia

As of 2012, it was estimated that there were about 268,000 people aged 20-79 years with diabetes (types not specified) in Zambia [32]. The prevalence rate of diabetes in Zambia is 5.13% [32]. A figure of 221,390 was estimated to be the number of people with undiagnosed diabetes for those aged between 20-79 years old [32]. In addition, it is estimated that there were 10,535 diabetes-related deaths in Zambia. Estimated life expectancy for people with diabetes

was only 11.2 years for those aged 0-14 years and 16.7 years for those aged 15 years and above [33]. In Western countries, life expectancies for people with type 2 diabetes is estimated at 55 years, 5 years after diagnosis [34] and about 68.8 years for those with type 1 diabetes diagnosed aged less than 17 years of age regardless of sex and puberty status [35]. Diabetes is a drain on household resources as a result of chronic and expensive treatment, distance to heath facilities and loss of family members, often breadwinners. The International Diabetes Federation (IDF) estimates that the mean diabetes-related expenditure per person with diabetes in Zambia was approximately US$ 125 per month compared to annual income of an average person in Zambia of US$ 1,490 [36].

Although there is a non-communicable diseases (NCDs) unit at the Ministry of Health (MOH), the country's capacity to provide adequate medical care for persons with diabetes cases and also the prevention of type 2 diabetes is way below expected standards. For instance referral pathways are poorly used and sometimes non-extent [37]. The Diabetes Foundation and International Insulin Foundation (IIF) found that three main problems were related to referrals in Zambia:

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

A survey by IIF showed that healthcare workers where often (no figures reported) unfamiliar with the management of uncommon diseases such as diabetes. Diabetes was often mistaken for

cerebral malaria; 21 out of 199 patients in Tanzania who were diagnosed as having cerebral malaria actually had diabetes mellitus [37]. To counter this lack of knowledge on the management of diabetes, education initiatives for health workers and for patients are at times organized by the MOH and Diabetes Association of Zambia (DAZ). For instance, DAZ organizes educational camps for children annually and children are given the opportunity to interact with other children with diabetes and also learn about different aspects of their diabetes care [37]. Similarly, workshops are often organized for health care workers on diabetes management. DAZ has an advocacy and support role which is important for engaging the communities and the MOH to take a leading role in diabetes care.

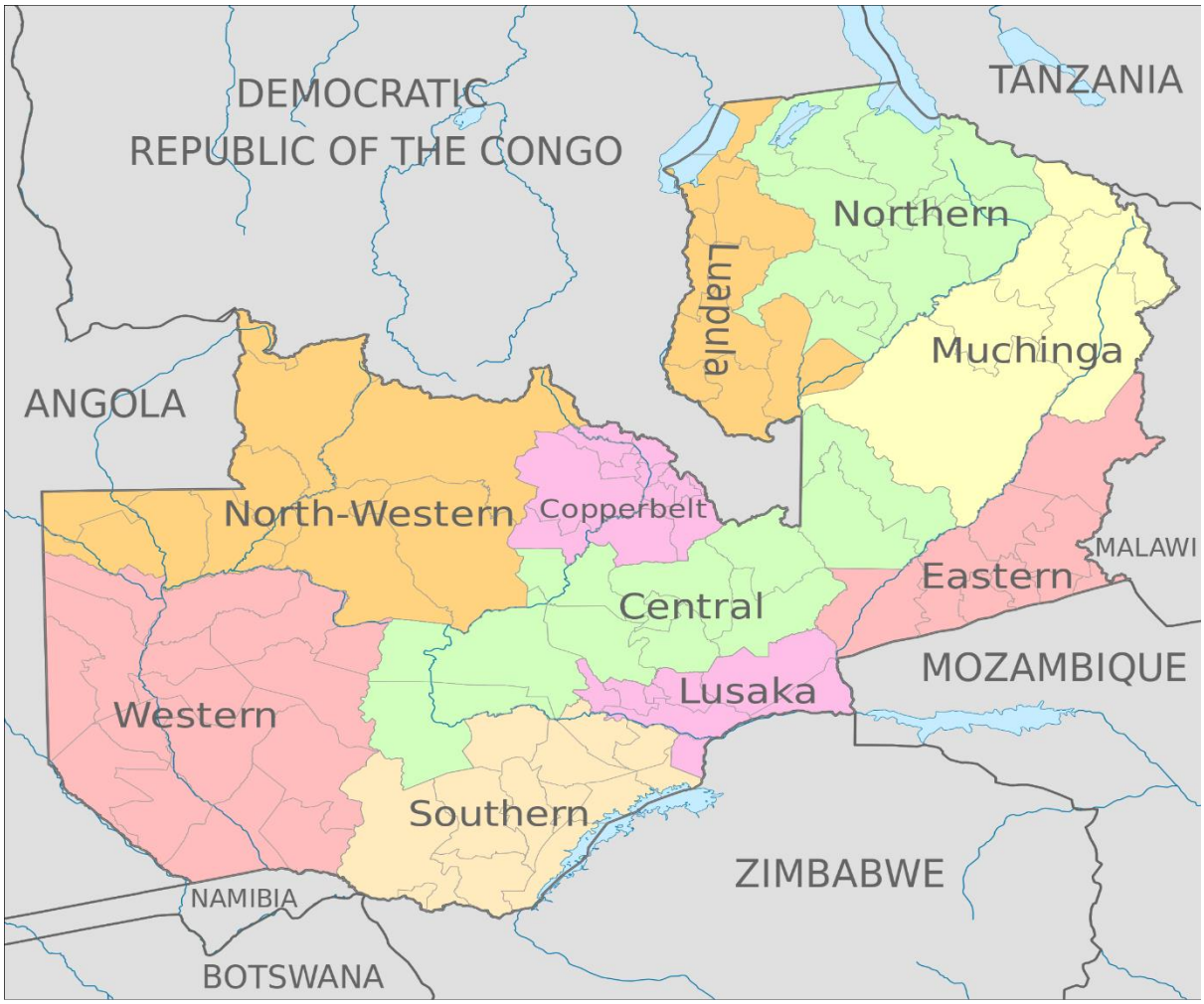
Diabetes care and management in Zambia is faced with a lot of challenges. A survey conducted by IDF and IIF, found that availability of diagnostic and care tools was below expected standards [37]. For instance, only in 61% of surveyed health facilities urine glucose strips were found, 49% of ketone strips and 54% of glucometers. The availability of other essential tools used for diagnosis, treatment and management of diabetes included sphygmomanometer (99%), stadiometer (49%), weighing scales (71%), body mass index charts (19%), Snellen charts (53%) and tendon reflex hammer (48%). Insulin was mostly acquired by tender procedures and tenders accounted for 79% of the total quantity compared to 21% for insulin acquired from private local wholesalers. Tenders accounted for 68% of the total cost of insulin expenditure in Zambia compared to 32% insulin expenditure from wholesalers [37]. It was estimated that purchasing insulin from a tender process could save around 15% of total insulin costs [37]. Consequently, the cost of insulin in Zambia was high. Over 13 years ago, Beran and colleagues found that the average cost per insulin vial was US$ 2.00 and patients paid US$ 0.15 – US$ 1.50 per syringe in Zambia [33]. Nowadays (in 2015) the average cost per insulin

vial is US$ 20.00. Although patients often receive free insulin and syringes from government health care facilities, these commodities are sometimes unavailable and patients have to buy insulin on their own. Psychosocial support for people with diabetes is almost nonexistent. Our research observed that there are no health workers who have been trained to deal with patients' psychosocial problems especially among adolescents [38].

About Zambia: Socioeconomic Situation

Zambia is a landlocked country situated in the southern part of Africa with neighboring countries including Democratic Republic of Congo, Tanzania, Malawi, Mozambique, Zimbabwe, Botswana, Namibia and Angola (see Figure 2).

Figure 2: Zambia and its neighboring countries



Source: *Commonwealth Health. Health in Zambia [39]*

As of 2012, the population of Zambia stood at 13,817,479 and has a median age of 16.5 years. The urban population accounts for 36% of the total population and the annual rate of urban population growth is estimated at 3.2%. The major cities in Zambia are Lusaka with a population of 1,742,979, Kitwe (522,092), Ndola (455,194), Chipata (452,428) and Livingstone (142,034). Others include Mongu, Solwezi, Kasama, Mansa and Kabwe. Life expectancy at birth in the total population as of 2012 stood at 52.6 years, 51.4 years for males and 53.8 years for females [40]. The population of Zambia is predominately of African origin

(99.5%) with about 10 ethnic groups and languages including: Bemba, Tonga, Chewa, Lozi, Nsenga, Tumbuka, Ngoni, Lala, Kaonde, Lunda and other African groups), other 0.5% (includes Europeans, Asians and Americans) [40]. In 2012, the Human Development Index for Zambia was 0.448, a low score positioning the country at 163 out of 187 countries and territories [41]. The gross domestic annual income per capita was US$ 1490 [42]. 80.6% of the total population are literate, based on the definition that those aged 15 and above can read and write [40]. School life expectancy (primary to tertiary education) is 7 years for the total population, 8 years for males and 7 years for females. The 2014 education expenditure was 20.2% of the total budget allocation [43].

The health sector expenditure has seen an increase from 4.8% of the GDP in 2009 to 9.9% in the 2013 expenditure allocation [43]. Despite the increase in expenditure in the health sector, there is a dearth of manpower in the health sector mainly because skilled manpower leave for greener pastures to other countries. The physician density a few years ago was 0.055/ 1000 population [44]. WHO estimates that there were 7.8 nursing and midwifery persons per 10,000 population and 31 community health workers per 10,000 population between the years 2005-2012 [42]. In 2010 there were 0.5 hospitals per 100,000 individuals and 20 hospital beds per 10,000 individuals between the years 2005-2012 [45].

There are very few published studies on diabetes in Zambia. Most of these are epidemiological studies focusing on the prevalence of diabetes and access of insulin among people with diabetes [33, 46-50], a clinical study focusing on glycemic control in people with diabetes [51] and a psychosocial study focusing on the relationship between compliance and quality of life [52]. Given this background, there is a need for studies looking into the psychological impact of

diabetes mellitus in Zambia. Therefore, the general aim of this thesis was to examine psychosocial factors associated with diabetes mellitus in Zambia.

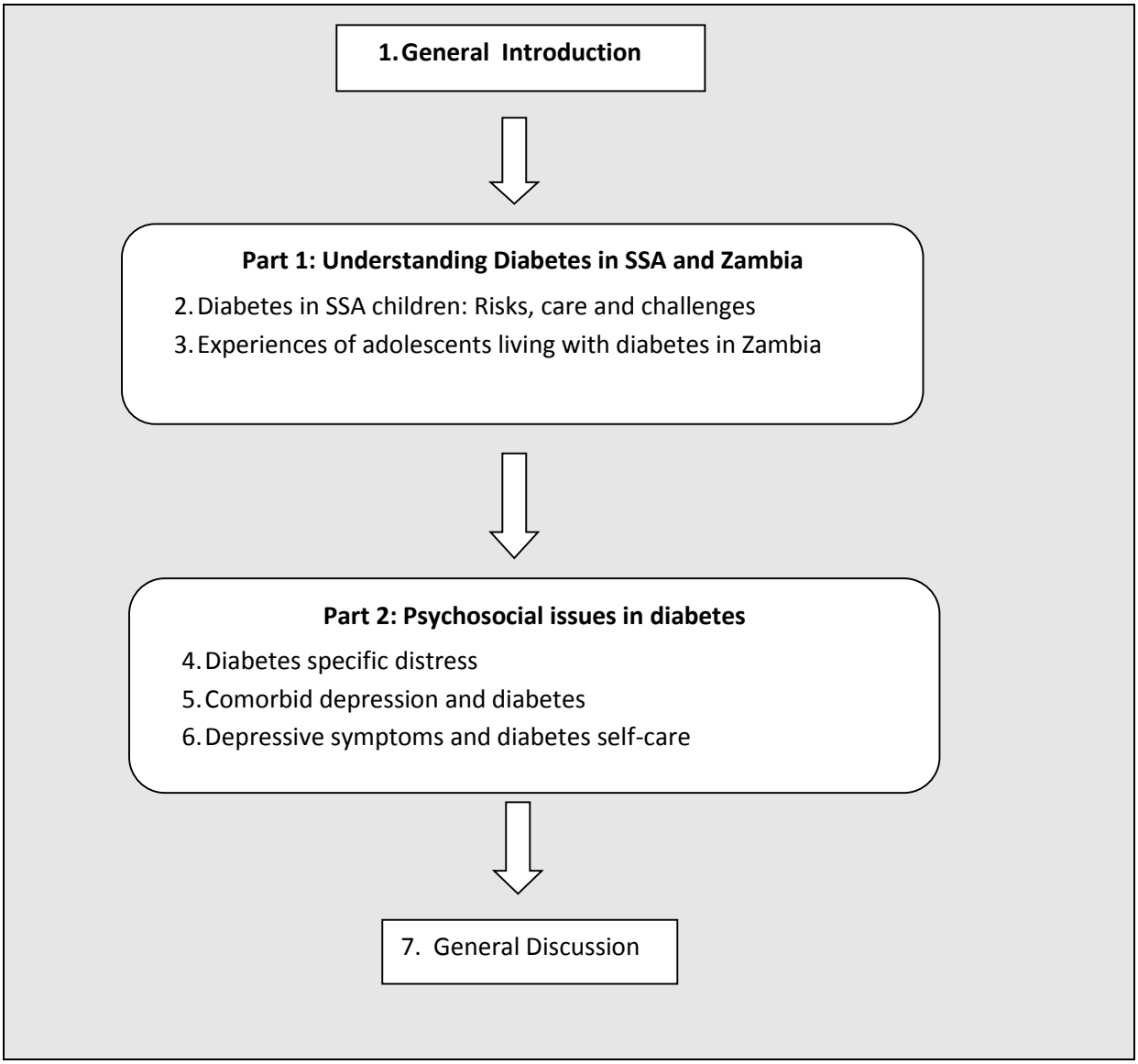
Thesis Outline

The thesis consists of 7 chapters, including a narrative literature review and four empirical papers using cross-sectional data which form the core components of the thesis. The first part presents a general introduction which explores the current situation of diabetes and associated psychosocial issues in Zambia and an examination of demographic characteristics of Zambia. Chapter 2 and 3 focus on understanding diabetes and its implications in Sub-Saharan Africa including Zambia. Specifically Chapter 2 explores literature on diabetes in Sub-Saharan African children: consequences and risks, care and challenges. Chapter 3 of the thesis explores experiences of adolescents living with diabetes in Zambia.

In part 2, Chapters 4–6 focus on data regarding psychosocial functioning associated with diabetes in Zambia. Many self-report measures have been developed to assess diabetes specific-distress, but there are currently no validated self-report measures for researchers and clinicians in Zambia. Therefore, Chapter 4 examines the psychometric properties of the Problem Areas in Diabetes scale, a measure assessing diabetes-specific distress. Equally, many studies have been conducted in the USA and Europe, focusing on diabetes and depression. However, data from Zambia are currently lacking. Depression is a burdensome condition that can also hamper adequate self-care and increase the risk for diabetes complications. Depression is also associated with higher mortality rates. Consequently, Chapter 5 examines comorbid depression and diabetes in Zambia and factors associated with depression. Chapter 6 examines the relationship between depressive symptoms and diabetes self-care. Lastly, the findings of

Chapter 2 through to Chapter 6 are collated, summarized and discussed in Chapter 7. In addition, current developments in literature and recommendations are discussed in chapter 7. A schematic summary of the overview of the thesis is presented in Figure 3.

Figure 3: Overview of the thesis



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Part 1

Understanding Diabetes in Sub-Saharan Africa and Zambia

Chapter 2

Diabetes in Sub-Saharan African Children: Risks, Care and Challenges[1]

[1] This chapter is based on a submitted book chapter. Hapunda, G. & Pouwer, F (Accepted). Abubakar, A. & Van de Vijver, F.J.R.. Applied Developmental Science for Sub-Saharan Africa. New York: Springer (In progress).

ABSTRACT

As of 2012, there were 15 million adults and 36,000 children living with diabetes mellitus in Sub-Saharan Africa (SSA). It is estimated that 12 million people in SSA live with undiagnosed diabetes. The incidence of diabetes vary from country to country; 0.3 per 1000 in Nigeria to 10 per 100,000 in Sudan. These epidemiological data may not reflect a true picture of the prevalence of diabetes especially among children since such data are often non-existent in most countries due to lack of research and resources. Common acute complications of diabetes in SSA include ketoacidosis, hyperosmolar non-ketotic coma and hypoglycemia. Chronic complications include retinopathy, glaucoma, nephropathy and neuropathy. In addition, many children suffer from neuro-cognitive and psychosocial problems. Early onset and duration of the illness and recurrent hypoglycemia episodes are major factors leading to neuro-cognitive and psychosocial problems in children. Children with diabetes tend to show adjustment problems, report depression, anxiety and poor quality of life. Apart from suffering from diabetes, some children have comorbid HIV and AIDS and eye diseases, among others. Few studies document mortality rates of children in SSA, however, life expectancy of children with diabetes is on average five years. In WHO member African countries, millions of dollars were spent on diabetes costs and it is estimated that US$ 1,154.15 per diabetes patient was spent per year. Despite the huge costs associated with diabetes, most essential diabetes commodities, equipment and personnel are still lacking in most countries. In conclusion, diabetes among children in SSA is still a big challenge. More effort by different stakeholders is required to make prevention programs, management and care of diabetes better by improving resources and implementation of health services. In all these processes, traditional healers and technologies must be incorporated.

General introduction

The aim of this chapter was to increase our understanding of the prevalence and consequences of diabetes in SSA and Zambia by summarizing the literature. The questions that are addressed in this chapter include: What is the prevalence of diabetes in children, in SSA? What are the consequences and risk factors for diabetes and what is the quality of diabetes care in SSA? This chapter will also act as a basis for comparison with the current status of diabetes in Zambia. To place this chapter into context, a general synopsis of the etiology of diabetes will be discussed followed by the prevalence of diabetes in African children. Consequences or risks (acute and chronic, psychological and social) of diabetes in patients with diabetes will be discussed. This will be followed by implications in terms of preventative measures and care in Africa and future directions that can be taken into account for diabetes management.

The World Health Organization (WHO) [1] defines diabetes mellitus as a metabolic disorder of multiple etiologies that is characterized by chronic hyperglycemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action or both. Our bodies require glucose which mainly comes from food we eat. Through the small intestine, glucose is absorbed by the capillaries into the bloodstream and it is then ready as a source of energy for body cells. In order for glucose to be transferred from the blood into the body cells, the hormone insulin is a requisite, which is produced by the beta cells in the pancreas. In individuals with diabetes, this process is impaired. This disorder can be inherited and/or acquired [2].

Diabetes mellitus can be classified into different types [1]. These include type 1 diabetes, type 2 diabetes, gestational diabetes mellitus and other specific types of diabetes such as latent autoimmune diabetes in adults (LADA) and maturity onset diabetes of the young (MODY).

Mbanya and Ramiaya [3] distinguished the different types of diabetes; the onset of type 1 diabetes mellitus (T1DM) can occur at any age, but is generally before the age of 40 and results from autoimmune destruction of the pancreatic beta cells, causing a complete loss of insulin production. Patients with this type of diabetes require insulin therapy (i.e. insulin injections or insulin pump therapy) for survival [1].

Type 2 diabetes mellitus (T2DM) is the most common type of diabetes, affecting approximately 90% of the diabetes patients. This type of diabetes often has its onset after the age of 50 (but can also develop before the age of 50) and is characterized by a relative lack of insulin, caused by insulin resistance (cells are less sensitive for insulin) and insufficient insulin secretion (beta cell dysfunction), either of which may predominate but both of which are usually present. The specific reasons for the development of these abnormalities are not yet fully known [3] although obesity, inactivity, composition of diet and heredity seem to play an important role. T2DM can remain unrecognized for many years, as the first symptoms are often ignored: frequent urination, increased thirst, fatigue and weight loss. Many people seem to attribute these symptoms to "old age". Still the diagnosis of type 2 diabetes is often made when microvascular or macrovascular diabetes complications are diagnosed and the patient is checked for diabetes.

Pregnant women can develop gestational diabetes mellitus (GDM). GDM is defined as any degree of glucose intolerance with onset or first recognition during pregnancy [3]. Other specific types of diabetes include MODY and LADA. MODY is a rare type of diabetes resulting from a genetic mutation and can be genetically acquired while LADA is a form of

type 1 diabetes that can occur in adults with the autoimmune process that destroys cells in the pancreas. These last types of diabetes are very uncommon and often misdiagnosed.

Diabetes was less common centuries ago. However, in 1552 BCE the Egyptian physician Hesy-Ra of the 3rd Dynasty was the first known person to describe a patient with diabetes on the Ebers Papyrus. In 250 BC, diabetes was described as the 'melting down' of flesh and limbs into urine [4]. Sattley, points that in the first century AD a Greek, Aretaeus, from Cappadocia, described the destructive nature of the affliction which he named "diabetes" from the Greek word for "Siphon" [5]. In the 17th century, a physician from London Dr. Thomas Willis determined whether his patients had diabetes or not by sampling their urine. If it had a sweet taste he would diagnose them with diabetes mellitus "honeyed" diabetes. In 1889, the German physiologist Oskar Minkowski and the physician Joseph von Mering, showed that if a dog's pancreas was removed, the animal got diabetes. In 1921 in Ontario, Canada, a surgeon Fredrick Banting and his assistants Charles Best and John McLeod, biochemist/physiologist, made a major discovery. They isolated insulin from dogs or cattle and used it to keep a diabetic dog alive for 70 days by injecting the insulin [5]. In 1923, Banting and McLeod won the Nobel Prize in Physiology or Medicine for the discovery of insulin.

Etiology of Diabetes

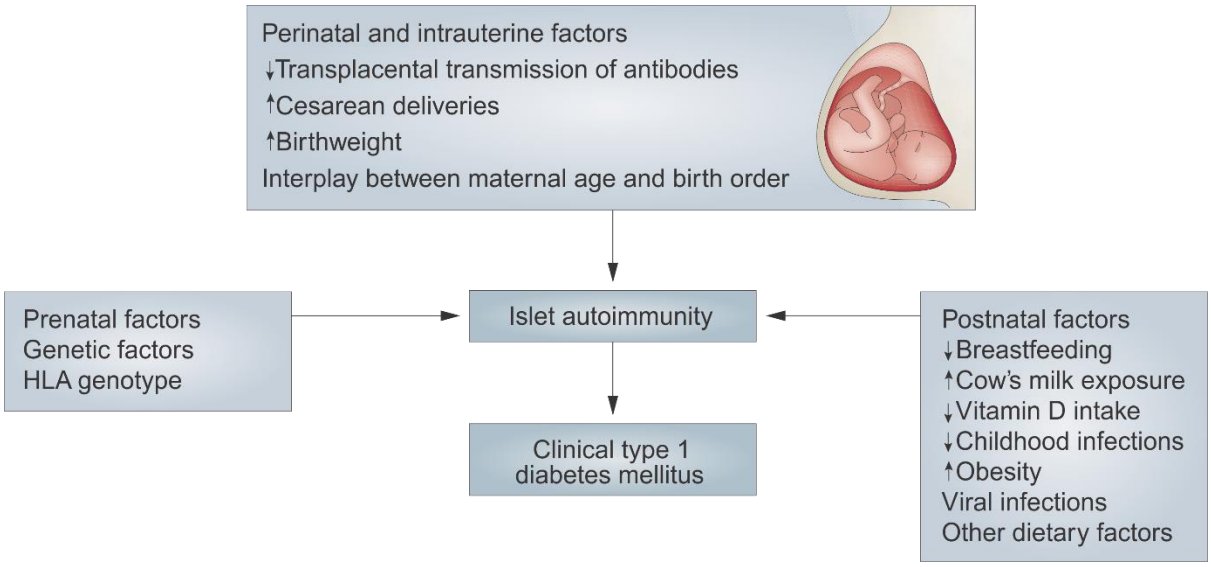
Type 1 Diabetes Mellitus

There is growing literature on genetic susceptibility to diabetes. Alleles or genetic variants associated with T1DM provide either susceptibility or protection from acquiring the disease [6]. Evidence for hereditary influence can be deduced from twin studies. The concordance for T1DM is approximately 50% for monozygotic twins and the risk to a first degree relative is approximately 5% [7]. These findings suggest that there are genes that make certain individuals

susceptible to developing diabetes mellitus. For instance, Bennett and Todd (1996) argued that more than 90% of patients who develop T1DM have DR3, DQ2 or DQ8 haplotypes [8]. They further argued that DR3-DR4 heterozygosity is highest in children who develop diabetes before age 5(50%) and lowest in adults presenting with type I diabetes accounting for about 20-30%. Equally one non-human leukocyte antigen (HLA) gene has been identified on chromosomes to contribute about 10% of the familial aggregation on T1DM [8]. This locus is a polymorphic region that maps to a variable number of tandem nucleotide repeats (VNTR) 5' of the insulin gene and different sizes of this VNTR 5' of the insulin gene is associated with risk of type I diabetes. On the contrary, a long form of the VNTR (≥ 100 repeats, class III) is associated with protection from diabetes [9].

T1DM is considered a multi-factorial disease in which the environmental risk factors trigger an immune-mediated destruction of the pancreatic beta cell in genetically susceptible individuals [10]. Environmental agents such as viruses may play a role in the development of T1DM [6]. Studies suggest that certain viruses and some aspects of early childhood diet may influence T1DM and even T2DM for the later. Enterovirus, mumps, rubella, rotavirus, chickenpox, cow milk, some common child vaccine and nitrates have been associated with T1DM [6]. Further, environmental factors can inhibit the development of autoimmunity. The environments for young infants are far too clean, leading to a deficiency in immunoregulation such as the "Th2" diseases e.g., asthma and the "Th1" diseases, e.g., T1DM are increasing dramatically [12]. Figure 1 depicts hypothesized causes of T1DM.

Figure 1: Some possible causes of type 1diabetes mellitus



Source: Ma & Chan, 2009 (reprinted with permission)

Type 2 Diabetes Mellitus

T2DM is considered by diabetes physicians as a complex and heterogeneous disease with a poorly understood etiology, apart from the fact that there is a strong genetic propensity that becomes overt when exposed to a typical westernized diet [13-14]. A meta-analysis found that there is a 26% risk of developing T2DM for those who consume 1-2 servings per day of sugar-sweetened beverages [15]. Santé diabètes, a Non-Governmental Organization working in the area of diabetes in Africa, points out that in recent years, there has been an overweight problem in Africa especially with the sharp increase in the consumption of food that contains more saturated fat and an increasing number of people with a sedentary lifestyle, as a result of rising income and urbanization in Africa [16]. Urban life style in Africa is characterized by changes in dietary habits involving an increase in consumption of refined sugars and saturated fat and a reduction in fiber intake [17]. These changes will probably further increase the risk of obesity and death. Obesity in turn is particularly associated with an increased risk of developing T2DM

[13]. Among the environmental factors that are hypothesized in the etiology of diabetes is the gut microbiota which may play a critical role in development of T2DM [11].

Data on the levels of obesity in Sub-Saharan Africa is scarce, but it varies between 3 - 44% of the population, depending on ethnicity and urban or rural location [18]. Autoimmunity, physical inactivity, obesity and genetic factors may all contribute to the increasing young age onset of T2DM [19]. Emerging risk factors in Africa include age and ethnicity as confirmed by increasing prevalence in age and in the differences between people from India, blacks and Caucasians in South Africa. The greatest prevalence was found in Indian community of Durban (13%) and elderly colored community of Cape Town (29%) [20].

Epidemiology of Diabetes

The 2012 International Diabetes Federation (IDF) diabetes atlas estimated that there were about 15 million people living with diabetes in Sub-Saharan Africa (SSA) a sharp increase from 12.1 million in 2010 [21]. In 2011, the number of people with diabetes in Africa was expected to increase to 28 million people by 2030 [22]. This figure is enormous for a continent with a population of approximately 876.8 million [23].

Data by the IDF, indicates that there are approximately 36,000 children with diabetes in Africa and that nearly 5,900 children are diagnosed every year [24]. TIDM is more prevalent in girls than boys as documented by studies in Ethiopia, Nigeria, Liberia and Sudan [25]. Type 2 diabetes accounts for over 90% diabetes cases in SSA, although estimates for children are not yet known, there is growing evidence that it is now also affecting African children [16]. Type 1 diabetes accounts for less than 10% of diabetes cases and since T1DM is still a lethal

condition in many parts of Africa and the mortality rates are high, this is probably an underestimation of the true prevalence and potential care needed [26]. Surveillance and proper records are lacking in most cases in many African countries to document the prevalence and incidence of diabetes in children and adults. The International Diabetes Federation (IDF) estimated that about 12 million people in Africa live with undiagnosed diabetes, accounting for 81% of cases [27].

The incidence of T1DM and T2DM in children and adults varies greatly from country to country and many estimates so far have excluded children, because comprehensive statistics for children are still lacking. Estimated prevalence of diabetes in SSA are described in Table 1 below. In SSA, the highest prevalence estimate for diabetes is in the Islands of Reunion with 16% prevalence, followed by the Seychelles with approximately 3,056 (12%) people with diabetes [27]. SSA countries with relatively large populations also seem to have large numbers of people with diabetes with Nigeria at approximately 3 million (5%) followed by South Africa at 2 million (7%). Ethiopia is reported to have an estimated 1,386,660 (3%) of people with diabetes while Angola has approximately 192.61 (3%), Benin approximately 62,090 (2%), Botswana approximately 96,420 (11%), Cameron approximately 517,860 (6%), Comoros approximately 24,300 (9%), Congo approximately 97,670 (6%), Cote d'Ivoire approximately 421,030 (5%), Democratic Republic of Congo approximately 737,090 (3%), Kenya approximately 720,730 (5%), Madagascar approximately 477,470 (5%), Zambia approximately 268,000 (5%) and Zimbabwe at approximately 568,680 (10%) as estimated by IDF [27].

Table 1: Prevalence of diabetes in Sub-Saharan Africa as estimated by the IDF Atlas 2012. These figures excluded people below the age of 20. Country populations as reported by the World Bank.

Country/ Territory	Diabetes cases (20 -79) in 1000s with total country population in parentheses	Diabetes comparative prevalence (%) WHO standards	Diabetes related deaths (20 -79)	Mean Diabetes related expenditure per person with diabetes (USD)	Number of people with undiagnosed diabetes (20 -79) (in 1000s)
Angola	192.61 (15,957,460)	2.91	4,154	276.70	154.09
Benin	62.09 (7,397,985)	1.68	1,162	59.95	51.29
Botswana	96.42 (1,852,243)	10.80	2,962	814.16	77.13
Burkina Faso	182.44 (13,789,736)	2.95	4,826	68.64	150.71
Burundi	97.87 (7,039,534)	2.72	2,781	34.84	80.85
Cameroon	517.86 (17,165,267)	6.15	14,588	109.04	414.29
Cape Verde	13.65 (466,784)	5.43	139	242	10.92
Central African Republic	57.09 (3952281)	3.05	1,850	34.31	47.16
Chad	189.94 (9474792)	3.61	5,569	86.40	156.91
Comoros	24.30 (625,876)	8.39	281	45.64	20.07
Congo (Brazzaville)	97.67 (3445765)	5.52	2,254	142.67	78.13
Congo (Democratic Republic)	737.09 (55,754,885)	3.03	16.355	25.03	608.91
Cote d'Ivoire	421.03 (17,731,840)	4.93	10,263	-	336.82
Djibouti	26.89 (-)	6.30	502	131.09	21.51
Equatorial Guinea	14.57 (589,794)	4.21	326	923.62	11.65
Eritrea	94.62 (4,318,343)	3.41	1,182	17.12	78.17
Ethiopia	1,386.64 (72,526,620)	3.32	23,869	24.91	1,145.50
Gabon	69.96 (1,344,171)	10.19	1,378	388.20	55.97
Gambia	12.79 (1,460,493)	1.97	201	45.63	10.56
Ghana	354.2 (21,119,911)	3.16	6,9973	114.76	292.45
Guinea	187.14 (8,889,321)	4.36	3,459	36.98	154.59
Guinea-Bissau	19.39 (1340814)	3	490	30.35	16.01
Kenya	720.73 (34,702,176)	4.66	17,733	57.58	595.40

Country/ Territory	Diabetes cases (20 -79) in 1000s with total country population in parentheses	Diabetes comparative prevalence (%) WHO standards	Diabetes related deaths (20 -79)	Mean Diabetes related expenditure per person with diabetes (USD)	Number of people with undiagnosed diabetes (20 -79) (in 1000s)
Lesotho	29.96 (2,047,006)	3.46	2,133	101.09	23.97
Liberia	50.23 (3,092,721)	3.12	1,036	47.20	41.49
Madagascar	477.47 (17,357,913)	5.09	6,857	37.64	394.44
Malawi	363.94 (12,472,794)	5.63	12,776	31.27	300.65
Mali	89.30 (12,772,264)	1.67	2,083	70.47	73.77
Mauritania	53.27 (2,964,526)	3.64	948	47.91	44.01
Mauritius	141.64 (1,233,386)	14.76	1,664	478.18	72.34
Mozambique	305.05 (20,246,287)	3.14	11,325	36.82	252
Namibia	75.73 (2,043,339)	7.68	1,727	469.48	60.58
Niger	293.93 (12546945)	4.15	5,333	38.54	242.82
Nigeria	3,165.31 (136,399,438)	4.83	88,681	129.17	2,532.25
Réunion	95.03 (-)	16.01	-	-	76.02
Rwanda	131.21 (9009655)	3.12	3,220	82.32	108.39
Sao Tome & Principe	3.75(150,311)	5.54	51	162	3
Senegal	160.11 (10,581,316)	3.26	2,430	109.52	132.27
Seychelles	5.56 (82,500)	12.13	38	589.33	2.85
Sierra Leone	73.01 (4,952,134)	3.07	2,300	82.80	60.31
Somalia	172.25 (8,170,899)	3.87	3,567	20.03	142.30
South Africa	1,978.25 (46,664,771)	7.04	63,061	695.05	1,582.60
Sudan	1,824.67 (30,101,696)	9.12	29.966	150.50	1,016.98
Swaziland	14.20 (1,016,094)	3.07	856	246.31	11.36
Tanzania	492.95(37,786,946)	2.81	15,156	40.26	407.22
Togo	140.13 (5,288,273)	5.21	2,583	62,88	115.76
Uganda	319.73(27,521,632)	2.85	11,296	83.61	264.13
Western Sahara	18.47 (-)	5.08	-	-	15.28
Zambia	268 (11,192,422)	5.13	10,535	124.96	221.39
Zimbabwe	568.68 (12,597,877)	9.75	29,987	55.58	468.79

Source: IDF Atlas, 2012 & World Bank, 2011

As indicated above, there is a paucity of data on the prevalence of diabetes in African children, but there is evidence that it is an important medical problem in most African countries. For instance, Elamin and colleagues in Sudan reported a survey of nearly 43,000 school going children (age 7 to 11 years) and found a prevalence rate of approximately 1 per 1,000 [28]. This rate is comparable to a reported prevalence rate of approximately 0.3 per 1,000 in Nigeria [29]. The reported incidence was approximately 10 per 100,000 children per year in Sudan [28] and approximately 2 per 100,000 per year in Tanzania [30]. Other studies indicate that the age of onset in South Africa and Ethiopia was later than elsewhere [31-32] and the peak age of onset of type 1 diabetes in Sub-Saharan Africa was a decade later than in the West [29-31]. Ethnic differences in the peak age of onset have also been reported in some African countries. For instance, in South Africa it has been reported that the peak age of onset was about 13 years in the white South Africans (similar to Europeans) but about 23 years in the black South Africans [31]. In addition it affects more girls than boys [31].

Although little is documented on the prevalence of type 2 diabetes in children, it is believed to be increasing in African children [17]. A few African studies that include adolescents reviewed in a systematic review gave insight into the prevalence of T2DM in African adolescents [21]. The prevalence in the general population of T2DM (i.e. both adolescents and adults) as recorded in these studies ranges from approximately 6.06 in Cameron, 4% in Kenya, 3% in Nigeria, 4% in South Africa, 7% in Tanzania and 1% in Uganda as indicated in cross sectional surveys of children and adults in sub-Saharan Africa from 1999 – 2011[21]. The exact figures of children with T2DM are yet to be established.

These figures combined suggest that diabetes mellitus is a huge medical problem in Africa which needs attention and more research focusing on its prevalence, incidence, demographics and clinical characteristics especially in SSA where there is a dearth of proper and valid records of the disease epidemiological data.

Consequences and risks of diabetes in children

The consequences and risks associated with diabetes in children can be categorized into acute and chronic complications.

Acute Complications

In Sub-Saharan Africa, diabetes ketoacidosis (DKA), hyperosmolar non-ketotic coma and hypoglycemia are acute conditions that have been reported. DKA has been found in the range of 7 - 80% in newly diagnosed patients and 25 - 90% in children who have already been diagnosed with diabetes [25]. Mbanya and Ramiaya reported that diabetes ketoacidosis in patients ranges from 25% in Tanzania to 33% in Kenya per year and that it is the most common diabetes emergency which carries high mortality [3]. Though little is known about the mortality associated with hypoglycemia, it is one of the leading reasons for hospitalization of children with diabetes. For instance, a study in South Africa with 43 patients that were admitted at Baragwanath Hospital in Soweto, a total of 51 episodes of hypoglycemia in a 5 months period were recorded [33]. Hypoglycemia has been observed to range between 25 - 55% in Sub-Saharan African diabetes patients [25]. The other complication associated with diabetes is hyperosmolar nonketotic coma which has been reported to be associated with T1DM and less common in T2DM and it accounts for 10% of all hypoglycemic emergencies [3].

Chronic Complications

As early as pre-pubertal age, most Sub-Saharan African children with diabetes will have developed chronic complications of diabetes [25]. According to Dowshen, people with diabetes have a greater risk of developing eye problems including cataracts, retinopathy and glaucoma [34]. A multi-ethnic cohort study indicated that Africans are 55% more at risk than Indians and Caucasians of retinopathy [35]. In Sub-Saharan African children retinopathy prevalence ranges from 10-30% [25]. It was estimated that by 2010, 4,510 people in Africa with diabetes had eye complications and a number of 423,500 were blind due to diabetes complications [18].

Diabetes nephropathy is also common among those diagnosed with diabetes accounting for approximately 2,230,000 people needing dialysis because of kidney problems in Africa [18]. The prevalence rate of nephropathy ranges between 14-33% in children [25]. Another complication that people with long time diabetes may develop is diabetic neuropathy [34]. People with diabetes are also prone to develop cardiovascular diseases with problems such as heart attack, stroke and blockages of blood vessels. It is estimated that 907,500 people have cardiovascular diseases in SSA [18] although heart attacks, strokes, blockages of blood vessels are more likely to be experienced by adults with diabetes [34]. People with diabetes are also susceptible to gum disease (dental problems) and foot problem. About 169,400 people with diabetes have lost a foot because of amputation [18] and foot ulcer is a major cause of hospital admission and bed use for diabetes in some countries for example Cameroon [36]. Diabetes can also cause poor growth among children [25]. Overall, it is important to note that diabetes comes in different types with the effects, infection rates and disease development varying from one to another and from country to country.

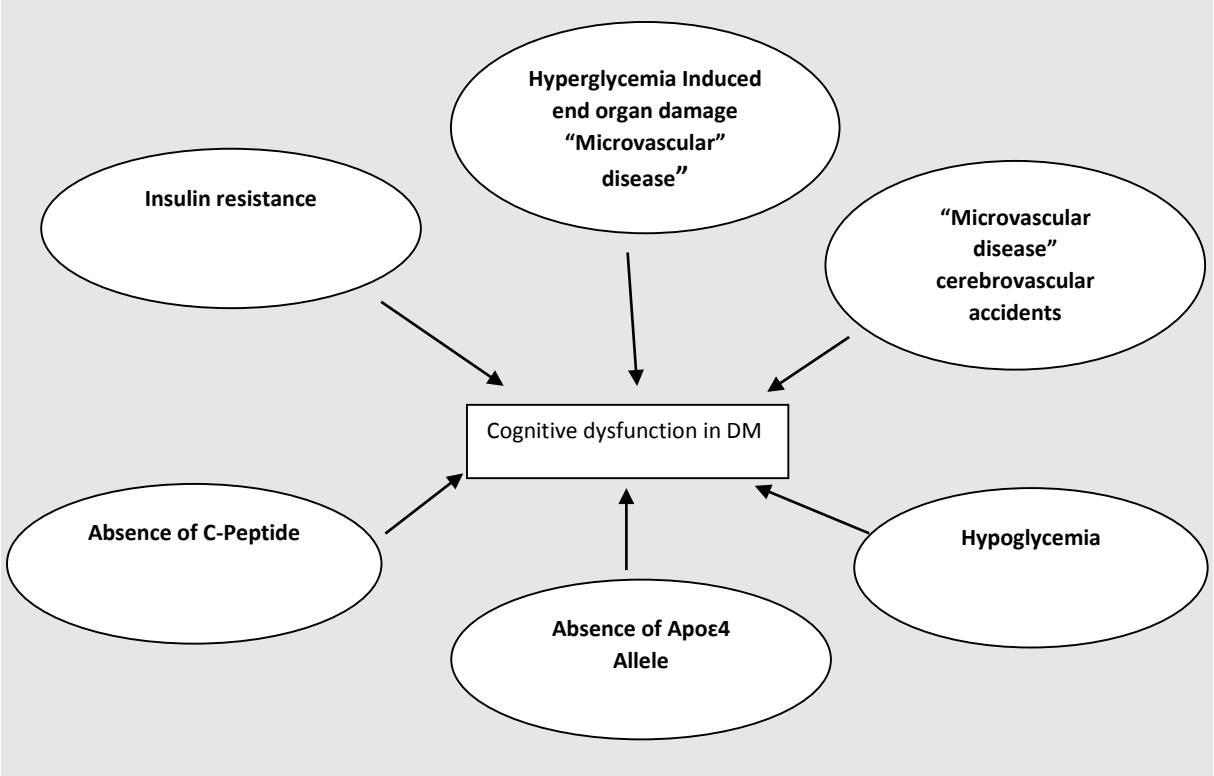
Neuro-Cognitive risks

There is growing evidence indicating that children with diabetes mellitus compared to control subjects are at risk of developing neuro-cognitive difficulties [37]. Children with diabetes are at risk of neuro-cognitive problems given the vulnerability of the young brain to hypoglycemia and hyperglycemia [38]. Using magnetoencephalography (MEG) to assess functional brain connectivity in T1DM patients, compared with sex and education matched with T1DM and control subjects, T1DM had decreased functional connectivity [39]. There was also a positive relationship between cognitive functioning and functioning connectivity. Specific cognitive domains that are affected in children with T1DM include: slowed information processing, psychomotor efficiency, attention, memory, learning, problem solving, motor speed, vocabulary, general intelligence, visuoconstruction, somatosensory examination, motor strength, mental flexibility and executive function. In T2DM, cognitive domains affected by diabetes include; verbal memory, visual retention, working memory, immediate recall, delayed recall, psychomotor speed, executive function, processing speed, complex motor function, verbal fluency and attention [40].

Meta-analytic studies show moderate to high effects of diabetes on most of these domains in children. For instance, children with T1DM have been found to perform significantly worse on tasks assessing visual spatial abilities, motor speed and writing, sustained attention and writing [38] and slightly low performance (d = -0.13) in overall cognitive domains, except learning and memory [37, 41]. Although other studies have shown that children with diabetes perform better in math than matched controls [42].

The risks of developing cognitive difficulties have been linked to early illness onset and illness duration, recurrent hypoglycemic episodes and hypoglycemia [38]. Elsewhere, they have been associated with the presence of microvasular complications and not with the occurrence of severe hypoglycemic episodes or metabolic control [41]. The risks associated with cognitive difficulties have been shown graphically in Figure 2.

Figure 2: Possible mechanistic contributors to cognitive dysfunction in diabetes mellitus



Source: *Kodl & Seaguist, 2008 (reprinted with permission)*

Psychosocial Risks

Some psychosocial issues in children with diabetes have been found to be associated with the diagnosis of diabetes. For instance, children with diabetes have often shown adjustment problems at the onset of diagnosis after the "honeymoon" period has finished [43-44]. Diabetes can also interfere with the daily routine and participation in activities children previously

enjoyed doing following diagnosis. The notion of having a life threatening illness, complex care and management of diabetes is daunting and can be also a source of stress and depression [45]. The worst part is that high levels of stress in children have been associated with poor glycemic control and that prolonged problems with psychosocial adjustments affect diabetes management in early childhood [43]. Immediately following diagnosis, children report mild depression and anxiety, which fluctuates over the years between boys and girls [44]. In a recent systematic review, it was not clear that depression was high among adolescents with T1DM compared with control, although there was evidence of the association between depression and worse glycated hemoglobin (HbA_{1C}) level and other health outcomes [46]. People with impaired glucose metabolism (IGM) or undiagnosed type 2 diabetes are not at increased risk for depression compared with the general population with normal glucose metabolism [47]. However, when compared with T2DM, individuals with IGM have a significantly lower risk of having depressive symptoms.

A systematic review with studies mainly from the USA and Western Europe showed that there are minimal differences in quality of life (QoL) between children and adolescents with T1DM and the health controls [48]. However, there are indications that boys report better generic QoL than girls and also that older children report better generic QoL than younger children.

Co-Morbidity

Co-morbidity is becoming common in an already disease inflicted population, more and more people now have more than one disease in SSA [49-50]. For instance, a study in Ghana found that 46% of patients with type 2 diabetes mellitus also had a plasmodium falciparum (malaria) infection [51]. In a study conducted in Malawi, out of 482 patients with diabetes, 14% were

seropositive with the HIV virus, 35 out of 475 had had stroke, 46% reported foot numbness and 25% had sight threatening eye diseases in type 2 patients in Ghana [52-53]. Psychosocial issues such as depression and stress are also common in children and adults with diabetes [54-55]. The burden of having to manage this disease, the knowledge that the illness is chronic and the potential for the illness to disrupt normal childhood activities could certainly pose psychological difficulties for children and indeed adults with diabetes as shown in a recent meta-analysis [56].

Mortality

There have been relatively few structured mortality studies in Africa, making quantification of outcome difficult [3]. However, it is estimated that a child in Sub-Saharan Africa that is newly diagnosed with type 1 diabetes has a short life expectancy (on average less than 5 year if not properly treated), and it is projected that diabetes deaths will increase by over 80% in upper-middle income countries between 2006 and 2015 [57]. The high death rate, especially among children is often due to a lack of diagnosis or misdiagnosis and the non-availability of insulin because of high prices [16]. Evidence shows that more than twice as many deaths occur in females with diabetes than males [24]. A study in Mali which followed up 20 children with T1DM for 8 years showed that half of the children had deceased after 8 years [16]. In Tanzania, for the period 1981-1987 the five year survival rates (95% confidence intervals) for patients with diabetes requiring and not requiring insulin therapy were 71% (62% to 80%) and 84% (80% to 89%) respectively for known deaths and 60% (51% to 69%) and 82% (77% to 86%) respectively for known plus probable deaths 49 (3.9%) [58-59]. 2012 data by IDF indicate that the number of diabetes related deaths in populated countries like Nigeria was approximately 88,181, South Africa approximately 63,061, Zimbabwe approximately 29,987, Sudan

approximately 29,966 and Ethiopia approximately 23,869 [24]. Other countries like Kenya recorded approximately 17,733, Congo DR approximately 16, 355, Tanzania approximately 15,156, Cameroon approximately 14,588, Mozambique approximately 11,325 and Zambia approximately 10,535 deaths [24]. Table 1 indicates diabetes related deaths in SSA.

Socioeconomic burden

Sub-Saharan African countries have the lowest per capita income compared to the rest of the continent and chronic conditions engender increasingly serious economic and social consequences in the region and threaten health care resources [50]. Diabetes not only has life-long costs of treatment and care but also has negative effects on the productivity of an already financially threatened population. The economic burdens are related to health care costs incurred by society in managing the disease, indirect costs resulting from productivity losses due to patient disability and premature mortality, time spent by family members accompanying patients when seeking health care and intangible costs [60]. At the time of the analysis, the grand total indirect cost was about US$ 8.1 billion (32%) in WHO African countries that is US$ 1,154.15 per diabetes patient. In East African patients, the annual cost for care was $ 229, of which two third was for purchase of insulin as of 2005 [61]. In Khartoum, Sudan, of the total family expenditure on health, 65% was used for the child with diabetes [62]. It is estimated that the direct cost of treating diabetes in the year 2000 ranged from US$ 2302 to US$ 3207 per person [21], in a continent with the per capita for expenditure on health in the same year pegged at US$ 86 [64]. About 7.02 million cases of diabetes recorded by African countries in the year 2000 resulted in a total economic loss of US$ 25.51 billion that is US$ 3633 per patient with diabetes [60]. More details on the economic details of diabetes mellitus in the region and a full

picture of the expenditure on diabetes as estimated by IDF in 2012 [27] can be seen in Table 1.

Challenges in care and treatment

More than three quarter of a century after the discovery of insulin in 1922, insulin is still not available on an uninterrupted basis in many parts of Africa as indicated in a survey by Beran, Yudkin and de Courten [63]. Of course there are variations from country to country or from, urban setting to rural setting. Insulin is generally available in urban health settings. For instance, in Zambia the differences are due to diagnostic infrastructure, distance to health facilities and insulin selling points and difficulties are often faced by those living in rural areas across the provinces [26].

The other problem that hampers adequate health care for children with diabetes is lack of adequately trained health personal in SSA health care systems. The World Health Organization indicated that there were 2 physicians per 10,000 person in Africa [64]. Even when health care personnel were available, they often lacked knowledge on how to diagnose and treat chronic illnesses such as diabetes [61]. In Zambia, there was no qualified diabetologist for children at the time of the inquiry, care and treatment was received from pediatricians who had interest or had been assigned to attend to diabetes cases. The situation is not very different in many SSA countries. This explains why most children with diabetes in Africa are undiagnosed. Table 1 indicates cases of people with undiagnosed diabetes in Africa.

The prevailing situation regarding high tech medical products and equipment is poor, for instance there were 9 hospital beds per 10,000 population in Africa as of 2000-2009 [64]. Health information, research and patient record keeping are often poor, making it difficult to

access health services and advance health knowledge through research and development [64]. Even the number of published studies on diabetes in Sub-Saharan Africa leave more to be desired, at 84 as of 2010 [65].

There are also problems with access to medical instruments and materials such as syringes in most Sub-Saharan African countries. A survey in Mozambique and Zambia found that patients in rural areas had the most difficulties in accessing syringes while in urban areas there were problems with quantification of syringes and trips, which were often in short supply [61]. Furthermore, only the wealthy patients possessed their own glucometers and the majority poor of children relied on their blood sugar being monitored once in a while for free in public hospitals [61]. In some cases, public health facilities did not have medical essentials for caring and treating patients. For instance, only 6% of health centers in Mozambique had facilities for blood glucose testing compared with 25% in Zambia [61]. Countries like Zambia have not even decentralized treatment and care in small and medium sized health facilities, making children travel long, costly and laborious distances to major central hospitals.

In most Sub-Saharan African countries, diagnosis is a problem hence a large number of undiagnosed diabetes patients in Africa as already indicated above. Knowledge and familiarity of diabetes symptom presentation are the major reasons for problems with diagnosis. Health workers in countries like Zambia and Mozambique rarely encounter patients with diabetes and because of this lack of familiarity and tools for proper diagnosis; as a consequence, many patients are missed or misdiagnosed with cerebral malaria or HIV and AIDS [61]. In Sub-Saharan African countries, most of the children who suffer from type 1 diabetes are actually diagnosed when they go into a ketoacidotic coma [16].

The increase in the levels of obesity poses another challenge to children and adolescents with diabetes. Regulating and managing weight is a challenge in adolescents especially that body fat and body mass index (BMI) have been shown to be linked to insulin resistance in Western adolescents [66]. Being overweight and obese is increasingly challenging health practitioners more so that being thin in the African context is associated with poverty. As such, it is prestigious to be fat because it is seen as being attractive and a sign of wealthy [16]. In some countries like Mauritania, girls are forced to eat and become fat so as to be attractive and attract more bridal price. Linked to this, is the difficulties of a suitable diet in most SSA children with diabetes. In most African countries, establishing a suitable diet is problematic due to cost of food, family size and seasonal availability of food [16]. Misconceptions about diet and low levels of understanding regarding insulin use is a challenge and leads to poor diabetes management and frequent complications [61].

Role of Traditional Healers

Another challenge is the role of traditional medicine and beliefs when it comes to treatment and care for diabetes in African children. There are many problems linked with the use of traditional medicine in chronic diseases like diabetes [16]. Some traditional healers claim that they can cure diabetes. This has dangerous and perverse effects on attracting a great number of patients who have been told by modern medicine that they will live with diabetes for the rest of their life. People have faith in them and they are very accessible to the extent that patients shun modern medicine. WHO estimated that in Africa more than 80% of the population consult traditional healers [67]. Associated with this, are certain beliefs of parents and girls who have diabetes: many hold the opinion that living with the diseases affects child bearing which is crucial in African marriages. A retrospective study in Zambian woman who had given birth

between 2006 and 2011 showed that there were 4717 macrosomic and 187 117 normal birth weight out of 219780 newborns who were analyzed. In this study, macrosomia was defined as a birth weight of 4000 grams or more and normal birth weight as 2500–3999 grams. The strongest predictors of macrosomia were high BMI (adjusted odds ratio [AOR] = 2.88; 95% confidence interval [CI] 1.95–4.24), prior macrosomic newborn (AOR, 7.60; 95% CI, 6.81–8.49), and history of diabetes (AOR = 3.09; 95% CI 1.36–6.98). Macrosomic newborns were at increased risk for cesarean delivery (AOR = 1.63; 95% CI 1.35–1.96), fresh still-birth (AOR = 2.24; 95% CI 1.56–3.21), Apgar score of under 7 at 5 minutes (AOR = 2.03; 95% CI 1.33–3.11), and neonatal intensive care admission (AOR = 2.07; 95% CI 1.32–3.23) [77]. Although studies have documented the relationship between maternal glucose levels and macrosomic babies or congenital malformation, if glucose levels are well managed macrosomia and other birth defects can be prevented [68-69]. As such, claims from traditional healers sometimes give hope to patients with such beliefs.

Education on diabetes is also limited among children with diabetes in SSA. In SSA, consultation times are short, resulting in little or no time for patient education and mental health care [3]. Knowledge on prevention, care and how to stay health is critical for children with diabetes, however, lack of resources for education programs, skilled manpower and adequate consultation times are all bottlenecks to diabetes education activities in SSA.

Implications

To begin with, there is a need for epidemiological studies on children with diabetes in SSA. Lack of such studies thwarts knowledge on the extent, characteristics and nature of diabetes in Africa. There must be annual screening for acute and chronic complications associated with

diabetes in order to prevent the occurrence of acute and chronic complications of diabetes in future. This will need increasing funding to non-communicable diseases, training skilled manpower, adequate medical essentials and equipment and developing policies that support these issues.

There is also need for dialogue and partnership with the private sector to make treatment and care for children with diabetes accessible and affordable. This is important especially in countries were the private sector plays a crucial role in the health system. For instance, Beran, Yudkin and de Couten found that the private sector (private wholesalers) in Zambia sold insulin 85-125% more expensive than in the public sector [61]. This is a situation also true for syringes and glucometers in most SSA countries. Therefore, involving different stakeholders in health care can improve health service delivery for children in Africa.

Santé Diabète suggests working in partnership with traditional healers regarding the management of chronic diseases by getting them to collaborate in a healthy and active way [16]. One way of doing this is to pass a set of ideas about diabetes, its complications and treatment. By doing so, traditional healers all over Africa could become useful partners for diabetes education and advocacy since they are already involved in diabetes management although using methods not recommended.

The American Diabetes Association (ADA) recommends that ultimately every child newly diagnosed with diabetes mellitus should be evaluated by a diabetes team consisting of a pediatric endocrinologist, a nurse educator, a dietitian and a mental health professional qualified to provide up to date pediatric-specific education care and support [44]. The psychological health needs of children with physical chronic illness are virtually nonexistent

in most Sub-Saharan African countries [70]. Linked to this is the need for SSA countries to develop comprehensive care programs integrating both physical and psychosocial needs, families and schools in the care and management processes of diabetes as well as understanding the period of childhood especially physical development and the increased sense of autonomy and independence in young people. Further, because family diabetes-related behavior patterns have been documented to affect glycemic control, there is a need to assess both the risk factors and the strength of the child and family at the time of diagnosis, with the hope of intervening [44]. This proposition may not suffice in most SSA countries given the struggle to meet priority needs by patients and governments. SSA countries could look for relative cheap but effective ways to meet the psychosocial needs of children with diabetes. In addition, guided by Maslow's need model, children should have insulin, good housing and healthy diet in order to optimize their psychosocial needs [71]. This is not to say that the later needs are not important, but this proposition makes sense given the prevailing situation in most African contexts.

Prevention programs

We recommend investing in diabetes prevention programs is essential. Lifestyle interventions have been documented to prevent or delay onset of diabetes in individuals with impaired glucose tolerance (IGT). A community healthy lifestyles intervention in a high-risk indigenous Maori rural community of New Zealand showed a 10% decrease in insulin resistance prevalence and associated changes in a group who actively participated in a lifestyle intervention [72]. In the USA, a lifestyle intervention to 1,079 participants significantly resulted in a 58% reduction in the incidence of diabetes [73] and a systematic review showed that life style interventions were successful in reducing the incidence of T2DM [74].

Future developments

Studies have demonstrated the efficacy of using text messaging via cell phone in diabetes patients. For instance, patient confidence in diabetes management significantly improved using their text messaging based diabetes program in an African American population [75]. 68% of African population was expected to have a mobile phone within 5 years [76] at the time of the review. For example in 2014, the Zambia Information and Communication Technology Authority (ZICTA) reported that there were 10.1 million mobile phone subscribers in Zambia out of the approximately 14 million population [78]. Moreover, most mobile phone service providers in Zambia have a portal on their sim card which contain health tips, entertainment, sport etc. Therefore diabetes specific education can be delivered through such portal or dial free numbers. A successful example of the use of mobile phones in the health sector is a study in Southern province of Zambia on early infant diagnosis of HIV infection through mobile phone texting of blood test results which showed that the mean turnaround time for delivery of test results to relevant health facilities from test laboratories fell from 44.2 days at pre-implementation to 26.7 days at post implementation [79].Therefore, opportunities like this one must be utilized by the health care system.

In summary, there seem to be an increase in the incidence of diabetes in SSA and comorbid psychosocial problems including depression, anxiety and distress among others among individuals with diabetes are reported. Although there is abundant evidence in developed nations, little is known about the psychosocial issues affecting children with diabetes in SSA and Zambia. Therefore, more studies on psychosocial problems affecting children with diabetes in SSA are needed. As established earlier, data on diabetes in Zambia is scarce. Therefore, this narrative review of data on diabetes in Africa acted as a basis for comparing the state of diabetes

not only in Zambia but also in Sub-Saharan Africa. The comparison assumes some degree of equivalence on socioeconomic status across Sub Saharan Africa. Although socioeconomic and cultural factors are not exactly the same in Africa, cross–cultural validation may be the only way to understand the state of diabetes in Zambia in the absence of more substantive evidence.

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Chapter 3

Living with Type 1 Diabetes is Challenging for Zambian Adolescents: Qualitative Data on Stress, Coping with Stress and Quality of Care and Life[2]

[2] This chapter is based on a published article. Hapunda, G, Abubakar, A. Van de Vijver, FJR & Pouwers, F (2015) Living with type 1 diabetes is challenging for Zambian adolescents: qualitative data on stress, coping with stress and quality of care and life. *BMC Endocrine Disorders* 2015, **15**:20 doi:10.1186/s12902-015-0013-6

ABSTRACT

Aim: Psychosocial problems are common in patients living with diabetes. However, data on psychosocial issues affecting patients with diabetes in Zambia are scarce. The present study explored sources of stress, stress coping strategies, stigma and perceived quality of life and care as experienced by adolescents living with Type 1 Diabetes in Zambia.

Methods: Semi-structured interviews were carried out. Three groups of participants involving adolescents with Type 1 Diabetes (n=10), caregivers (n=8) and health practitioners (n=4) were interviewed. Transcripts were analyzed using a thematic approach.

Results: Stress was commonly reported by adolescents mainly stemming from social, psychological and physical sources. To deal with stress, adolescents often employed different coping strategies such as adapting, accepting and avoiding among others. Both internal factors (those relating to the patients themselves) and external factors (those related to the context of the patients') influenced the patients' quality of health care. In addition, low quality of life was an issue among adolescents and their families. Poor diet, low socioeconomic status and lack of medicine were factors affecting quality of health care.

Conclusion: Stress was an issue affecting adolescents; the coping strategies employed were sometimes maladaptive such as avoiding injecting themselves to escape stress. Several aspects of quality of life were suboptimal in both adolescents and their families, such as stigmatization, short life expectancy, low socioeconomic status and poor social participation. Findings show that there is an urgent need for a strong response from all stakeholders (governments, patients, organizations and companies) to improve diabetes care and living conditions for young people with type 1 diabetes living in Zambia.

Background

Diabetes is one of the leading causes of mortality and disability around the world. The most common complications of diabetes that lead to mortality and disability include cardiovascular diseases, neuropathy, nephropathy, retinopathy and foot ulcers [1]. It is also common to find co-morbid problems among diabetes patients such as depression [2], hypertension [3], HIV and AIDS [4] and malaria especially in developing countries. To prevent acute and chronic complications of diabetes, treatment and care must be optimized by patients with diabetes and their health care team, for example by achieving and/or maintaining a good level of glycemic control.

Constantly seeking treatment and engaging in everyday self-care activities such as frequent glucose monitoring, following a meal plan and correctly preparing or remembering to take insulin or oral medications at the right times can be a source of diabetes-specific emotional stress and can be difficult to follow a regime in times of stress for people with diabetes [5]. Stress refers to a physiological or a psychological response to external stimuli or to stressful events themselves which can be negative or positive or both [5]. Common signs of stress in patients include changes in sleep patterns, changes in appetite, anxious thoughts and irritability [6]. General emotional stress can affect the blood glucose levels and glycemic control and interfere with the ability to self-manage diabetes. Moreover, it has been found to be associated with poor quality of life [5, 7]. Stressful experiences influence diabetes control not only because of the devastating effect on poor blood glucose control but also because of the association between high blood glucose levels and the development of diabetes related complications [5, 8]. For example, in prospective studies involving individuals with type 1 diabetes, patients who reported negative stress showed deteriorating glycemic control over time

[9]. In addition to the physiological influence that stress has on glycemia, stress interferes with the ability to self-manage diabetes such as monitoring glucose frequently, following a meal plan and correctly preparing or remembering to take insulin or oral medication at the right time [5]. In adolescents with Type 1 diabetes specifically, research shows that stress stems from the need to manage a complex medical condition that requires daily completion of multiple self-care behaviors, the impact of diabetes on social interactions with family members, peers and teachers as well as the interference of symptoms such as hypoglycemia with daily activities [10]. The observed effect of stress on individuals with diabetes shows great intra-individual and inter-individual variance depending on situational factors, type and amount of stress, personal characteristics and coping strategies [11]. The few African studies that have been conducted suggest that there is a link between stress and development of diabetes. In Kenya for example, patients linked diabetes to stress caused by disharmony and conflicts within the family and strong emotions due to shock [12]. In South Africa, children with diabetes were found to have experienced more frequent stressful events compared to control children [13].

Chronic stress is an important risk factor for depression and depressed persons with diabetes have considerably lower Quality of Life (QoL) [14]. Most of the studies in this area have been conducted in Western countries, African data are still scarce. For instance, in Zambia at baseline, mean values of QoL was significantly lower in adolescents with diabetes compared to healthy controls (19 vs. 22) [15]. In a Nigerian sample of 251 patients with diabetes, poor QoL was associated with diabetes-related physical complications, lower education status and having type 2 diabetes [16]. In Sub-Saharan countries, low QoL is exacerbated by inaccessibility of medical care and the relatively high costs of insulin, a lack of medical tools such as blood glucometers, poor infrastructure, inadequate training of health workers and

increased risk of misdiagnosis and failure to detect diabetes [17]. Given the above background, in the present study we explored sources of stress, ways of coping with stress, perceived quality of care and life as experienced by Zambian adolescents living with type 1 diabetes (T1D) from the viewpoints of the adolescents themselves, their caregivers and their health care providers. Specific objectives were to explore:

1. The adolescents' sources of stress and the coping strategies that they used to deal with stress;
2. The perceived quality of health care and barriers to quality care for the adolescents;
3. The views of stakeholders on how diabetes affects the adolescents' lives and their families.

Methods

Study location

Zambia is located in the southern part of Africa with an estimated population of 13,000,000 inhabitants. Zambia is categorized as a lower middle income nation [18]. Lusaka is the biggest city in Zambia with 1,742,979 inhabitants [19].

Study site

The study was conducted at the Diabetes Clinic within the Pediatric Department of the University Teaching Hospital (UTH), the main referral hospital in Lusaka city. The Diabetes clinic provides services to approximately 109 diabetes patients (age range: newborns to 17 year olds). The services offered to them include medical reviews and examinations, such as blood glucose and ketone testing, treatment and disease management plans, diabetes education and whenever available, free supply of medical essentials, such as needles and syringes.

Sampling procedure and sample size determination

Participants (adolescents, guardians of adolescents and health providers of adolescents with diabetes) were recruited using a purposive sampling method from the University Teaching Hospital in Lusaka. Adolescents with diabetes had to be aged between 12 and 18 years and currently using insulin therapy to meet inclusion criteria. Adolescents were included in the study because they were key informants on their experience living with diabetes. Guardians had to be primary caregivers (guardian here means anyone responsible of taking care of the adolescent). It was important to include guardians because they had first-hand experience living with an adolescent with diabetes while health care practitioners had to work at the diabetes clinic to be involved in the study. Health care practitioners were included because they interacted with adolescents during clinical care; hence their views on experiences of adolescents with diabetes were valuable. 25 participants were approached but three (1 female guardian and an adolescent girl and 1 male guardian) declined to participate in the study. The final sample size was 22, comprising 10 adolescents with T1D, 8 guardians of adolescents with T1D and 4 health care practitioners (Table 1). We were able to reach interview data saturation from our adolescents' interviews[3]. However, because only a few guardians accompanied the adolescents during medical appointments we did not reach data saturation in the guardians; time and cost could not allow us to follow them up in their respective homes. Further, given a small number of health care providers who routinely attend to adolescents with diabetes, we interviewed all we could identify at the time of the study.

[3] Saturation here means no new themes (information) emerged from the data from interview more subjects.

Table 1. Demographic characteristics of informants

Adolescents with Type 1 diabetes		**N**	**%**
Sex	Males	2	20
	Females	8	80
Age			
	12-15 years (1 each)	4	40
	16 years	3	30
	17 years	3	30
Mean Age 15.3 years			
Grade	Grade 6	2	20
	Grade 8	2	20
	Grade 9	2	20
	Grade 10	2	20
	Grade 11-12	2	20
Duration on insulin			
	1 years	1	10
	2 years	2	20
	3 years	3	30
	5-6 years (1 each)	2	20
	7 years	2	20
Lives with			
	Biological parents	8	80
	Sibling (sister)	1	10
	Grandparent(s)	1	10
Guardians		**N**	**%**
Sex			
	Male(s)	2	25
	Females	6	75
Age	30-54 years	8	100
Mean age 37.3 years			
Number of children keeping			
	2 children	2	25
	4 children	2	25
	5 children	2	25
	7 children	2	25

Data collection

The current study employed semi-structured interviews, because this qualitative methodology is particularly useful when researchers aim to understand the lived experiences, opinions, stories and views of the specific respondents on a certain phenomenon [20]. Interviews were conducted using open-ended questions. All interviews were held in a quiet place that was most convenient to participants and interviews were conducted by the first author (Given Hapunda). The majority of interviews were conducted in English and five in either Bemba, Nyanja or Tonga (three local Bantu languages). The interviewer is a native Tonga speaker and individual multilingualism is common in Zambia. Interviews were audio recorded after permission of the participant and notes were also taken by the researcher. Interviews that were in the local languages were translated to English and all transcripts were checked by a research assistant who was fluent in the three local languages and English. Guiding questions focused on source of stress, coping strategies and perceived quality of care and life as experienced by adolescents living with T1D. Semi-structured interviews were not piloted but they were discussed with health practitioners under the diabetes association for content-related validity (expert validity) before data was collected. The interviews lasted between 25 and 40 minutes.

Ethical approval

The study was approved by the ethics committee of the School of Humanities and Social Sciences, University of Zambia (reference number IRB: 00006464, IORG: 005376); all participants gave written informed consent.

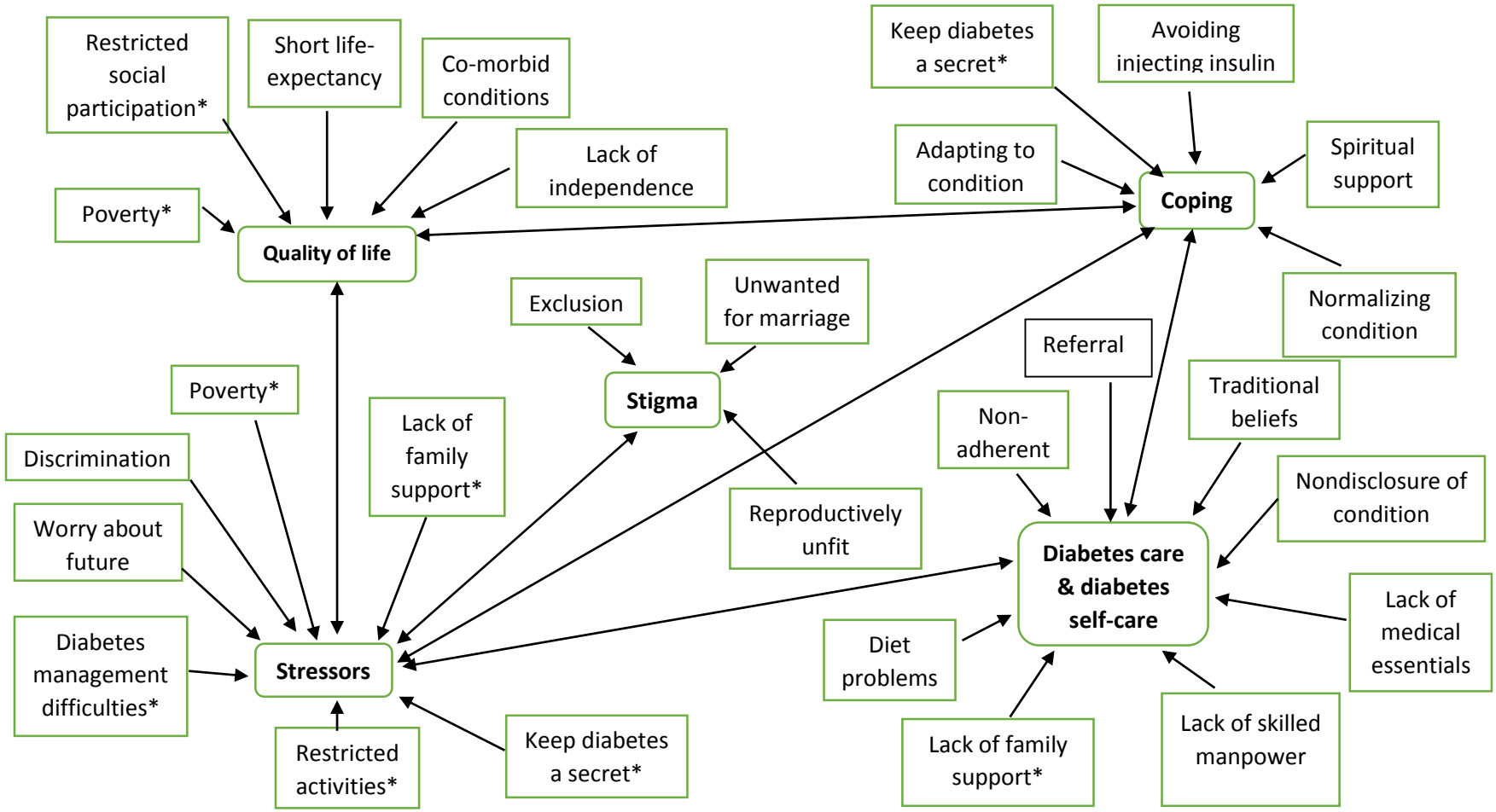
Data analysis

Audio recorded interviews were transcribed verbatim and translated to English whenever applicable and further checked for accuracy. In order to develop the themes and the categories, as near as possible to the material, an inductive category process was used [21]. After careful and thorough reading and re-reading, the initial coding and categorization of the themes was done by the first author and verified by the second author to ensure trustworthiness. Sentences or paragraphs related through their content or context were assigned codes and related codes were finally categorized as themes in a tally table. This process continued until no new themes emerged from the data. Emergent themes were discussed and refined by authors G.H and A.A. Data were analyzed manually.

Results

The study explored: stressors, stress coping strategies, diabetes care, quality of diabetes health care and life as experienced by young patients with diabetes in Zambia. Here we present data on the main forms of stressors in patients with diabetes which fall under social stressors (e.g., discrimination), psychological stressors (e.g., worry about the future) and physical stressors (e.g., poverty) and data on ways patients dealt with stressors to include: adapting to the stressor, avoiding the stressor, seeking spiritual support and normalizing the condition. Further, factors that influenced patients' perceptions of quality of health care are presented under the headings of internal factors (within control of patients) and external factors (outside the control of patients). The main issues that affected adolescents' QoL and their families are presented as poor wellbeing, restricted social participation and perceived lack of independence. A thematic mapping to indicate possible associations among the themes identified is presented in Figure 1.

Figure 1: Thematic and sub-thematic mapping: possible associations



*cross-cutting sub-themes

Stressors

About 18% [4/22] of the participants reported that adolescents experienced social stressors. An important social stressor in adolescents came from their need not to disclose their diabetes condition to others. Many adolescents worked hard to keep their condition a private issue. They were also stressed because of the discrimination they faced from others, mainly because peers thought diabetes is a communicable disease:

> *Sometimes they face segregation, they let them play alone or let them do things alone because some of them think that it is communicable and they can get it if they hang out with them*. ***Pediatrician***

Another factor that contributed to social stress was lack of family support as exemplified by some family members pressuring the adolescents to stop injecting themselves insulin:

> *In my family, they want me to stop injecting myself with insulin. What they say stresses me a lot. They say that injecting myself is damaging my body.* ***Female, grade 9***

Psychological stressors were reported by 36% [8/22] participants and involved the feeling that the adolescents were different from other peers. Most adolescents were frustrated and wondered why they had to do certain things that their peers were not doing, such as carrying insulin and injection kits. Adolescents, especially the girls, were also stressed by the fact that the use of insulin was contributing to their weight gain but they still had to continue using it:

> *Insulin makes them fat and when you look at adolescent particularly if I narrow it to the girls, they want to be slim.* ***Pediatrician***

Adolescents were also scared of diabetes related death which became a source of stress especially among the boys who thought having diabetes was a death sentence. There was also a worry especially among the female guardians and adolescents girls with diabetes that they were unwanted by men who think that they cannot bear a child:

Children with such condition (diabetes) find it difficult to get married and cannot have children. Diabetes comes with many complications; so many men will not want to marry such a girl. ***Female guardian 36 years old***

Sometimes I just ask why me? I have friends and most of them have no diabetes. But what I hate most is that I cannot take (eat) sweet things (food – authors' insertion). And I also now wonder whether people with diabetes give birth, so I feel stressed. ***Female grade 10***

About 59% [13/22] of participants mentioned that adolescents face physical stressors. Physical stressors revolved around self-care activities including dietary limitations that adolescents faced because certain food stuffs (e.g., cakes and soft drinks) were not healthy and thus their intake was discouraged. In addition to diet restrictions, strict and rigid diabetes self-care was a source of stress especially the thought of injecting themselves multiple and painful insulin shots per day:

Some inject themselves two times a day some three times a day. So the thing of injecting themselves every time is a stress as well. It brings stress to them whereby you have to be thinking about that needle and if you don't do that anything can happen. ***Diabetes Peer educator***

I become depressed because of injecting myself, you see I have been injecting myself for seven years on the same spot but what can I do it's my life. Most of my stress comes from injecting myself. ***Female, grade 12***

Adolescents were stressed by the limitations they faced. For example, previously enjoyed activities were no longer possible due to the challenges of the danger of severe low blood sugar levels or of carrying medical essentials and also the worries of parents that adolescents may be unable to take care of themselves outside their parents' homes. Many adolescents had challenges managing their sugar levels and experienced side effects of low or high sugar levels:

> *I am stressed if the blood sugar is high I start feeling very sick and sometimes vomiting and become tired. I even get slim such that I start looking like I am HIV infected (Laughs).* ***Female grade 10***

For girls, having infections in their sexual organs (vaginal thrush) as a result of diabetes was stressful perhaps because they worried that they may have contracted sexually transmitted infections which are rampant among Zambian adolescents:

> *Female adolescents often get stressed in the sense that they usually have vaginal thrush and that stresses them more because they think how did I get it especially if they do not engage in sexual relationships.* ***Pediatrician***

In addition, about 27% [6/22] of participants mentioned that adolescents experienced social stigmatization from peers and society especially among girls with diabetes who are seemingly not wanted for marriage. Social stigmatization was also common during play with peers. Adolescents were often excluded from play because others thought the condition was communicable:

> *Sometimes my friends refuse playing with me, like my cousin used to say that we can't play with you because you have a disease and we don't want to catch it.* ***Girl, grade 9***

Coping strategies

To cope with stress, about 14% [3/22] of participants mentioned that adolescents adapted to the situation, especially those that were diagnosed when they were still children, mainly because they were accustomed to having diabetes and managing it. Adolescents reframed the situation by thinking about their condition in a more positive way so as to get the best out of their health conditions. Other adolescents tried to change the situation through attending psychosocial support and psycho-education activities:

> *It also helps for instance through counselling like psychosocial support and not just educating them and giving support to both adolescents and their parents.* ***Diabetes Peer Educator***

Avoiding the stressor was also mentioned by about 14% [3/22] participants to be a coping strategy that adolescents used such as by avoiding injecting themselves insulin or engaging in activities that would distract them from stressful thoughts but also make them forget to take insulin:

> *I have to find what to do. Like when I am at school I have to start playing with my friends that way, I stop thinking about those things (stressors – authors' insertion).* ***Female, grade 11***

In addition, some adolescents accepted their diabetes by looking at the upside *"what does not kill you makes you stronger"*. Diabetes was looked at as an opportunity for personal growth. Seeking spiritual help through prayers was also a common 36% (8/22) strategy adolescents and their guardians used to cope with diabetes related stress:

Prayers! I pray a lot. Mostly alone but sometimes with my family members. I usually go for prayers on Tuesdays, Thursdays, Fridays, Saturdays and Sundays. ***Male, grade 8***

For me it is to pray and go to church. You see if you go to church you get a lot of encouragement and support and that helps a lot to deal with her situation. ***Female guardian aged 30***

Normalizing the situation so that the adolescents did not feel they were alone with their condition were other common coping strategies 10/22 (45%) among adolescents:

We try to integrate them with other peers with diabetes so that they don't feel they are alone in this situation. Once, they see their friends and know that they are also going through the same things as them it helps reduce the stress they go through. ***Pediatrician***

Diabetes care and diabetes self-care

Health care providers and guardians were the only ones who reported (83% [10/12]) that non-adherence to diabetes self-care activities and keeping diabetes a secret (which hindered help and care from others when adolescents were in need) were the main internally driven factors that affected the quality of care among adolescents. Non-adherent behaviors included not attending clinical appointments at the clinic, not changing site for injecting insulin, taking wrong dosages of insulin and avoiding taking insulin:

Especially the girls when they reach adolescence they do not want to inject themselves with insulin in certain parts of the body like shoulder (upper arm - ***authors' insertion****) and thighs because these parts are important to a girl cosmetically but they are also good parts for insulin absorption. In addition insulin makes them fat, so they avoid it.*

Nurse in Charge of Diabetes Clinic

About 86% [19/22] of the participants also mentioned external factors as major problems for diabetes care and self-care. Externally driven factors that were reported to influence the quality of diabetes care included diet problems among adolescents because of poor economic background and lack of medical commodities which could make some patients stay for days without insulin:

> *Sometimes I come at the hospital and I find that there is no medicine, insulin, so they can be keeping more insulin and other medication.* ***Male, grade 8***
>
> *Monitoring of sugar is practically impossible in our environment because when you look at a glucometer it is roughly about US$ 47.60 – US$ 65 and that just a one off thing because they need also strips which are expensive roughly about US$40 for 50 strips".* ***Pediatrician***

Quality of care was affected by lack of family support in managing diabetes especially among young adolescents and traditional belief that certain herbs could cure diabetes:

> *Others have their own beliefs that if you continue taking the medicine like insulin worsens the condition so they stop and start giving them (adolescents) herbal medicine.*
>
> ***Nurse in Charge of Diabetes Clinic***

Language limitations also affect quality of care because most Zambian languages have no equivalent words for some English diabetes and care-related words. As with many technical words, insulin does not feature in standard colloquial English any more than it does in any of the Zambian languages making it difficult to explain things:

> *There are certain things that you cannot properly explain in a local language for instance when you say insulin, this person wants to understand what insulin is. Many*

times we don't know the equivalent words in local languages, so language is a barrier.

Diabetes Peer educator

In addition, lack of trained and specialized manpower to deal with diabetes cases especially diagnosing diabetes and delays in referrals. Data also revealed that respondents had the impression that diabetes was not yet among the priority diseases for authorities compared to malaria, HIV and AIDS. Co-morbid conditions also made it difficult to manage diabetes especially for children with malaria or HIV and AIDS. Specifically, adolescents and caregivers reported lack of nearby health facilities, expensive and sometimes inaccessible insulin, challenges handling medicine and following a recommended diet as some of the factors that were affecting quality of care. Others included poverty. Many patients bemoaned lack of money to buy food when they had an appointment at the hospital and they had to wait for a while before they could receive attention:

The biggest is distance and transport- you see we all have to come here (UTH) because in clinics they don't do reviews. So we all have to come here for reviews and some come very far and transport is very expensive. But also transport money and money for food. Especially if I am here and I am hungry I need money to buy the food, I was told to be eating but I cannot get money here. ***Grade 8 male***

The medicine that we receive requires that we keep it in the fridge but when I am at the farm I don't know how I can handle this medication. ***Female guardian aged 36***

How diabetes affects adolescents' QoL and their families

Diabetes was regarded as being associated with a shorter life expectancy due to various external factors including poor health care system, socioeconomic circumstances, lifestyle choices and unavailability of certain medical essentials:

> *So really when you talk about an African child with diabetes the life span is quite short because of the health care system and the availability of the critical things that they need to survive on that is the insulin. And also the commodities, the needles, the syringes are unavailable sometimes.* ***Pediatrician***

Other factors included poor socioeconomic circumstances (86% [19/22]), which hamper the use of advanced technologies to manage diabetes. Co-morbidity (14% [3/22]), emotional (32% [7/22]), cognitive (18% [4/22]) and physical health problems (14% [3/22]) were also issues that affected the QoL of adolescents and their families:

> *My mother gets very emotional like she even cries and sometimes she tells me, "If I could take it away from you I would have done it". But also sometimes when I am at school, I lose concentration and many times I can't see properly on the blackboard.* ***Female grade 12***

The fact that having diabetes limited adolescents' participation in social activities because their movements were restricted was mentioned by about 18% (4/22) as affecting their QoL. Many reported that they were expected not to stay away from their guardians' homes for a long period of time in order for them to be monitored by adults:

> *Sometimes if I want to do something or go somewhere they tell me, you have diabetes you don't have to go somewhere, because one time I collapsed while at school because*

of hypoglycemic episodes and in the past I used to play with my friends for a long time, but now within a short period of time I have to go and eat. ***Male in grade 8***

Adolescents' sense of independence was mentioned by about 27% [6/22] as it seemed to have been adversely affected because of their condition. Many adolescents felt their guardians were constantly monitoring them. In addition, adolescents were worried about adjusting in their future roles without interference from others especially when experiencing hypoglycemia. This theme was mentioned about 55% [12/22] by our participants:

My parents now have to monitor me and constantly ask me if I have injected or eaten. I feel bad. ***Female, grade 10***

Discussion

This study explored sources of stress, ways of coping with stress, perceived quality of care and life of Zambian adolescents living with T1D. To the best of our knowledge, this is the first qualitative study in Zambia to explore this subject providing views from all these three key stakeholders (adolescents, caregivers and health professionals).

Having diabetes was regarded and experienced as an important source of stress in the present sample. Lack of support from family and others was reported to exacerbate stress in children and adolescents as they still depend on adults. The adolescents reported multiple sources of stress. There is not only an urgent need to help lower the stress levels experienced by adolescents, but also a strong need to educate family members. It was for example shocking to note that a family member gave potentially life endangering advice to a young person with T1D to stop injecting herself with insulin. Families can play a powerful role in the treatment

of chronic illness not only by offering instrumental support but also by providing unconditional support and the opportunity for expression of emotions [22]. Evidence has shown that family functioning and stronger support are related to more optimal metabolic control in T1D [23]. Interventions involving joint sessions between adolescents and significant family members should be encouraged so that health care providers can give useful information about diabetes and also about the danger of certain traditional healing practices. They can also teach adequate skills that empower families in the process of not only adapting to the situation but also helping the adolescent manage the blood glucose levels and thus live a more fulfilling life with diabetes. However, family and other instrumental support systems are by far not enough; other sources of stress should be resolved through improving treatment and care, by increasing access to insulin, glucometers, strips and other basic medical essentials for patients with diabetes.

The adolescents in the present study used three main coping strategies: 1. "adapting", for example by accepting that one has diabetes. This coping style seemed more common in those who were diagnosed when they were still young; 2. "Normalizing", such as assuring the adolescent patients they are not the only ones with diabetes; 3. "Avoiding" such as avoiding insulin injections or avoiding to talk about having diabetes. However, some of these strategies (notably avoidance) are not helpful and effective at least for long-term benefits; avoiding and engaging in distracting activities are short term strategies since most of the patients still come back to confront the stressor. In a Taiwanese sample of adolescents with T1D, avoidance was used when faced with unpleasant situations like increased inquisitiveness from peers about their conditions, leading to stopping self-management related behaviors in order to minimize attention from others [24]. Research shows that young patients with poor glycemic control are more likely to be stressed when they use maladaptive coping strategies [25]. The use of

maladaptive coping strategies such as avoiding insulin injections is likely to exacerbate condition. Therefore, adolescents must be taught skills that are more adaptive such as improving self-care skills and healthy lifestyles coupled with positively interpreting their situations, doing something about the source of stress and accepting their health circumstances. Almost a decade since the publication of a case study by Beran and colleagues [26] diabetes health care in Zambia is still suboptimal. Patients still have difficulties acquiring insulin because of high costs and sometimes erratic availability. A study by the International Insulin Foundation in 2006 found that patients could only access insulin 26-49% of the time. Today the situation has not improved much according to the perceptions of adolescents, guardians and health care providers. The syringes used to cost between $0.01-$1.50 [27] but now only the patients in urban bigger hospitals are given free syringes whenever available, because sometimes the hospitals do run out of these commodities, whereas patients in rural areas still need to buy syringes. However, these commodities are not always available in hospitals and some patients stay for days without such medical essentials. Testing costs for outpatients used to be as high as $51.60 a month [26], now at least in urban big hospital testing is free because many patients cannot afford to buy their own glucometers. Patients still have problems accessing health care facilities because local clinics do not offer specialized diabetes care due to lack of adequate trained health care providers, leading to increased risk of misdiagnosis and late detection of diabetes. However, the Ministry of Health in Zambia now recognizes non-communicable diseases (NCD) as increasingly common conditions in the country and have since developed a strategic plan regarding NCD including diabetes. The NCD program has since embarked on a number of interventions for the prevention and early detection of NCDs. These include; the development of treatment protocol, development of clinical nutrition and dietary guidelines, training of health workers in the management of NCDs and raising

awareness levels of NCDs among other [28]. Future studies should evaluate the impact of the strategic plan on the diabetes health-care system, especially commodity availability for patients and needed health care providers and skills.

We found stigmatization and discrimination to be common experiences among our patients, particularly by peers and society at large. Peers often thought diabetes was contagious and thus avoided interacting with the patients while society had beliefs that diabetes patients were not reproductively fit and had low status value in romantic relationships especially among the girls. Similar beliefs were reported in Japan where both women and men with insulin dependent diabetes were 22% less likely to be married compared to 65% for their aged matched controls [29]. Stigma was practiced through restricting patients from engaging in most everyday activities, such as sports. The sources and causes of stigma in patients with diabetes differ across cultures. For instance, in Australia, stigma was perpetuated by the media, friends, health care professionals and teachers who often had a notion that diabetes was a self-inflicted condition and stigmatization often took the form of negative social judgments and exclusions from activities [30]. In Iran, persons with T1D were reported to be stigmatized as miserable humans, rejected marriage candidates and were deprived of a normal life because they were equated to disabled people who could not enjoy life [31]. Thus, it also seems important to educate family members and friends about diabetes in Zambia.

A systematic review on the quality of life of children with T1D showed worry and treatment barriers, diabetes symptoms and worries, communication and treatment barriers, family burden related to diabetes, disease impact and disease related worries as the main issues that affect the quality of life in mainly Western children with T1D [32]. Our results were somewhat similar;

however we found at least one more salient aspect in our sample: adolescents reported a limited sense of independence and social participation to be issues adversely affecting their lives; health care providers confirmed this perception. Being monitored by adults was one of the issues that affected adolescents' sense of independence. Restricted and sometimes short play time were some of the issues that affect social participation and their lives. Improved treatment that can reduce dependence and perceived sense of intrusiveness from significant others such as the use of insulin pumps and care can improve the QoL of adolescents from developing countries. However insulin pumps are not available in Zambia because most patients cannot afford them. Our results are in sharp contrast with those obtained in developed countries, where on average, children with T1D show no difference in physical, psychosocial and overall quality of life as compared to their healthy peers [32].

Parental monitoring or support from significant others is essential for diabetes care in children and adolescents. Less parental monitoring is a risk for poor glycemic control [33]. However, monitoring and support should never be perceived as intrusive by the adolescent to avoid the impression that it affects their sense of independence. When adolescents perceive their parents to be intruding in their personal lives, they are likely to get rebellious which often leads to parent-adolescent conflict. It would therefore be important that parents of adolescents with diabetes learn to show support without risking a conflict. Families and parents must agree about diabetes management responsibilities, show supportive behaviors towards adolescents and collaborative problem solving plans, all of which have been shown to be associated with better regimen adherence and glycemic control [34].

This study had some limitations. To begin with, although the qualitative design enabled us to examine detailed experiences of the subjects in the study and to discover themes as well as their subjective views of the experience of living with diabetes, we cannot provide quantitative figures to underscore our findings, nor can we claim representativeness of our findings. Secondly we were unable to collect information from healthy peers to confirm the social stigmatization reported by our adolescents.

In conclusion, lack of health care resources, stress and stigmatization, poor health care and inadequate advice by family and friends, due to a lack of knowledge are common problem in Zambian adolescents with diabetes. Adaptive strategies to buffer stress such as positive reframing and accepting of the condition, may be helpful to adolescents with diabetes. Major barriers are not only poverty and poor access to diabetes care, but also lack of knowledge among family members and friends. These barriers need to be removed in order to improve the quality of diabetes care and the quality of life of young persons with diabetes in Zambia. The themes related to stress, stigma and diabetes care and self-care seemed interwoven, therefore solving some problems may have trickle down effects on other problems. Health authorities and policy makers in developing countries face the challenge of improving health care delivery to patients with T1D who also face high poverty levels. While therapies such as Continuous Subcutaneous Insulin Infusion (CSII) have shown robust improvements in glycemic control, reduced severe hypoglycemia and general QoL, only very few patients in Zambia can afford such therapies. Overcoming the economic barriers to providing good diabetes care in Zambian is still a formidable task.

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Part 2

Psychosocial Functioning in People with Diabetes

Chapter 4

Validity and Reliability of the Zambian Version of the Problem Areas in Diabetes Scale (PAID): A Triangulation with Cognitive Interviews[4]

[4] Based on a journal article that has been submitted for review. Hapunda, G. Abubakar, A. Pouwer, F & van de Vijver, F. (Submitted) Validity and Reliability of the Zambian Version of the Problem Areas in Diabetes Scale (PAID) in Diabetes Patients: A Triangulation with Cognitive Interviews

ABSTRACT

Background: Data on diabetes-specific emotional distress among people living with diabetes in Sub-Saharan Africa are lacking. The present study aims to examine the psychometric properties of the Zambian version of the Problem Area in Diabetes (PAID) scale and to determine the levels of diabetes-specific emotional distress in Zambian people with diabetes.

Methods: A total of 157 Zambians living with type 1 and 2 diabetes completed the 20-item PAID, Self-Care Inventory (SCI), Fear for Hypoglycemia Scale (HFS) and the Major Depression Inventory (MDI) in study 1. Exploratory factor analysis (EFA), Cronbach's alpha and lambda2, item-total correlations, Pearson's product moment correlations and regression analysis were performed. In study 2, eight patients participated in cognitive interviews, in order to evaluate the extent to which participants were able to comprehend the scale items.

Results: EFA showed that a one-factor solution was the best interpretable solution. Internal consistency of the PAID in the Zambian version of the PAID was 0.90 and stable across the types of diabetes. Diabetes-specific emotional problems were common, with problem endorsements ranging from 22 – 61% across PAID items. The PAID showed low to moderate associations with the SCI, HFS and the MDI. Cognitive interviews showed that participants were able to comprehend question intent while a few participants faced some challenges with the meaning of words such as “anxious” and “physician” and with comprehension of some items.

Conclusion: The Zambian version of the PAID is a reliable and valid measure to assess diabetes-specific distress. Zambian people with diabetes expressed high levels of diabetes-specific distress; yet some items may need to be simplified or clarified to enhance comprehensibility. Policy makers, clinicians, researchers and people with diabetes need to

combine forces to find ways to reduce the high levels of diabetes-specific emotional distress in Zambians living with diabetes.

Introduction

Diabetes has become a major public health concern globally and Sub-Saharan African (SSA) has not been spared. An estimated 15 million people in SSA are living with diabetes [1]. In Zambia alone, approximately 437,570 people are known to have diabetes although this is potentially a gross underestimation of the magnitude of the problem since many diabetes cases remain undiagnosed and the health care institutions do not keep systematic records of those who go for care. The number of people with undiagnosed diabetes in Zambia is estimated at 221,000 [1].

Evidence from mainly European and North American studies has shown that being diagnosed with diabetes either type 1 mellitus (TIDM) or type 2 mellitus (T2DM) can be daunting and demanding and its treatment and care can impact work, interpersonal relationships, social functioning, as well as physical and emotional well-being of patients [2-5]. Psychosocial distress not only burdens patients but can also hamper adequate self-care behaviors, consequently compromising glycemic control [4, 6-7].

Depression has also been reported to be a common problem in people with diabetes, which is associated with suboptimal glycated hemoglobin (HbA_{1C}) level, higher mortality rates and impaired quality of life [8-14]. Diabetes-specific emotional distress appeared to mediate the relationship between depression and glycemic control [15]. Hence, it is not surprising that depression symptoms and diabetes-specific emotional distress are highly correlated; both affect glycemic control and quality of life, among others [15]. Addressing diabetes-specific emotional distress can presumably simultaneously lower depression and help improve health outcomes of patients with diabetes mellitus.

Having diabetes mellitus in Zambia differs from having diabetes in Europe or the US. Access to care is often problematic, cost of insulin and/or syringes are high, especially in rural areas [16]. Further, in Zambia certain cultural beliefs prevail that can impede the functioning of diabetes patients such as: "a girl with diabetes cannot have children" or "diabetes complications such as foot ulcers result from witchcraft" found in an earlier study in Zambia [17]. Given this array of issues specific to Zambia and Africa, a study of diabetes-specific emotional distress in Zambia is needed.

To be able to adequately monitor the levels of diabetes-specific emotional stress, there is need for adequately developed and standardized measures for monitoring and identifying those experiencing distress. The Problem Areas in Diabetes Scale (PAID) is a widely used measure to monitor diabetes related distress. The PAID has been translated and used to assess diabetes-specific emotional problems in many countries, such as Brazil, China, Iceland, Iran, the Netherlands, Norway, Sweden, Turkey and the US [3, 6-7, 18-24]. Given its wide use, good psychometric properties and clinical utility, this measure has the potential to fill the gap in assessment measures in the diabetes population in Africa. However, its factor structure has been found to differ across studies. For instance, some studies reported the scale to be composed of one [3, 20], two [6], three [7] and four factors or scales [18-19]. The measure has not been evaluated and validated in the African context to date. Therefore, the aim of the present study was to examine psychometric properties of the PAID in Zambian people with diabetes and to determine the level of diabetes-specific emotional distress in that group using cross-sectional data and cognitive interviews

Methods

The study comprised of two data: quantitative data to test the validity and reliability of the PAID and cognitive interview to assess the adequacy, comprehensibility and cultural appropriateness of the PAID among the urban sample.

Study 1

Subjects

The study sample comprised of outpatients with either type 1 diabetes mellitus (T1DM) or type 2 diabetes mellitus (T2DM) from major hospitals in Lusaka, Ndola, Kitwe and Livingstone. Patients were classified T1DM or T2DM based on what was indicated on the patients' hospital record cards. Patients were invited to participate in the study if they were at least 12 years old and were diagnosed at least 6 months before the study. In total 157 patients signed the consent form and were recruited over a one-year period. Of the 157 participants, 80 were females (51%). We did not find significant differences in gender compositions from our sample. Mean age was 39±17 years with age ranging from 12-68 years. Of the total sample, 115 (73%) were adults and 42 (27%) adolescents. Table 1 shows the detailed demographic characteristics of the participants.

Table 1: Demographic characteristics of 157 participants with type 1 and type 2 diabetes

Sex, *n* (%)	
Females	80 (51%)
Age, mean (*SD*)	39±17
Age range	12-68 years
Type of diabetes n (%)	
Type 1	93 (59%)
Type 2	58 (37%)
Unknown	6 (4%)
Developmental stage *n* (%)	
Adolescents	42 (27%)
Adults	115 (73%)
BMI mean (*SD*)	25 (5)
Males	25 (5)
Females	26 (5)
Adolescents	22 (4)
Adults	27 (5)
Educational levels *n* (%)	
Adolescents (42)	
5-7th Grade (Primary school)	14 (31%)
8-12th Grade (Secondary school)	16 (38%)
Missing	14 (31%)
Adults (115)	
Primary education	10 (9%)
Secondary education	29 (25%)
Tertiary education	22 (19%)
Unknown	54 (47%)
Marital status (Adults/115) *n* (%)	
Single	6 (5%)
Married	80 (70%)
Missing	29 (25%)

Measures

Demographic variables. Questions asked about age, sex, education level, properties and services owned by families of participants and diabetes type. In addition, the body mass index of the participants was recorded.

Diabetes-specific emotional distress. The PAID is a 20-item self-report measure used to assess diabetes-specific emotional distress [2], including a range of feelings such as diabetes related anger, fear, depression, worry and guilt. Items can be responded to on a scale from 0 (not a

problem) to 4 (serious problem). An overall score for PAID can be calculated by adding all of the item scores and multiplying by 1.25, which gives a total score ranging from 0-100. Higher scores indicate more distress. Reported Cronbach's alpha for the PAID is 0.84 to 0.96 [3, 6-7, 18-24].

Fear of Hypoglycemia. The Hypoglycemia Fear Survey (HFS) consists of 26 items. HFS comprises two scales assessing "worries about hypoglycemia" and "hypoglycemia-related behaviors". The items are rated on a 5-point scale ranging from 1 (never) to 5 (very often). It has a Cronbach's alpha of 0.90 suggesting high internal consistency [25].

Diabetes Self-Care. The 13 item Self-Care Inventory (SCI) is a self-report measure used to assess patients' perceptions of their adherence to diabetes self-care recommendations over the previous 1-2 months. Individuals rate themselves on a 5-point Likert scale that reflects on how well they followed recommendations for self-care during the past month (i.e., 1 = "never do it" to 5 = "always do this as recommended, without fail"). Higher scores indicate more optimal diabetes self-care. Cronbach's alpha for the SCI was 0.84 for T1DM and 0.85 for T2DM [26].

Depression. The Major Depression Inventory (MDI) is a 12-item self-report questionnaire used to assess depression. Items of the MDI ask the patient to rate how long in the past two weeks each of the symptoms of the depressive syndrome was present on a six point scale ranging from 0 "not at all" to 5 "all time". It can be used as an instrument measuring severity of depression with a range from 0 - 50. The internal consistency of the MDI appeared to be good as indicated by Cronbach's alphas of 0.89 and 0.94 [27, 28].

Translation of Measures

Zambia is a multi-lingual country with 5 main languages and English as the official language. Measures were administered in English and in 2 local languages; Nyanja and Bemba. Back translations were done by two native speakers in each language and were fluent in the other language and English. The translators met to discuss the translation together with the first author to discuss the translation in each language and the differences between forward and back translation versions. The goal was to maximize both linguistic and psychological equivalence. The final translation was piloted on 6 adolescents with type 1 diabetes and feedback on their understanding of the items was obtained.

Statistical analyses

Demographic characteristics in the total sample were examined using descriptive statistics. Missing data from the PAID were determined as Missing Complete at Random (MCAR) and replaced using Expectation Maximization/ Maximum Likelihood (EM) in SPSS. To assess the factor structure of the PAID, exploratory factor analysis was conducted; we used direct oblique rotation (direct oblimin), Keiser-Mayer-Olkin measure of sampling and Bartlett's test of sphericity using the scree plot criterion. Keiser-Mayer-Olkin values of greater than 0.6 indicate that data are suitable for conducting a factor analysis [29-30]. Oblique rotation was used because factors of the PAID were expected to be moderately correlated. Factor loadings of 0.30 or higher have been recommended for a sample size of 300 or more [31]. The reliability was evaluated using data on the type of diabetes (T1DM and T2DM) and included Cronbach's alpha and lambda2 (i.e. for PAID total alpha and alpha for each subscale). Values above 0.70 are regarded as satisfactory [32]. Concurrent validity was assessed using Pearson’s correlation between PAID total score and other psychosocial variables of interest. In addition, item total

correlation was computed to evaluate the degree to which differences among patients' responses to the items were consistent differences in their total PAID scores. Correlations among measures of the same attribute should be between 0.40 and 0.80 [7]. A lower correlation indicates either an unacceptably low reliability of one of the measures, or that the measures are measuring different phenomena [33]. Discriminant validity was examined by conducting a multiple regression analysis to determine the extent to which PAID scores were predicted by body mass index, depression, fear for hypoglycemia and diabetes self-care after adjusting for age, diabetes type, gender and socioeconomic status.

Results

The lowest PAID item with missing value accounted for 1.4% and highest item accounted for 3.8%. In particular, 5 items had the largest missing value percentages; "feeling constantly burned out by constant effort to manage diabetes" (3.8%), "feeling constantly concerned with food" (3.8%), "feeling diabetes is taking up too much of your mental and physical energy" (2.5%), "not accepting diabetes" (2.5%) and "feeling overwhelmed by your diabetes regimens" (2.5%). These items accounted for 15.1% missing values.

Item total correlation showed that he greatest increase in alpha resulted from deleting the following items; "coping with complications" (0.06), "feeling constantly concerned about food" (0.17), "deprivation regarding food and meals" (0.23), "feeling overwhelmed by diabetes regimens" (0.24) and "not having a clear and concrete goal for diabetes" (0.33). Removal of these items increased alpha only by 0.03 (0.91).

The Bartlett test of sphericity was highly significant ($\chi^2(190) = 1005.533$, $p < .001$). The KMO value was 0.86. These statistics suggest that EFA can be adequately applied. In the second step principal component analysis using oblique rotation (direct Oblimin) was conducted and inspection of the Eigenvalues yielded a maximum of five factors: 6.69, 2.14, 1.35, 1.14 and 1.02 (values before rotation). Given the ambiguity as to the number of factors reported in the literature, we explored solutions with different numbers of factors, working back from five factors. The 5-factor solution could not be used, as many items loaded on more than one factor and some of the factors could not be interpreted.

Consistent with Snoek and colleagues [18], a forced four-factor model was inspected. However, the results were not consistent with the four-factor described by Snoek and colleagues, who found the following four factors: 1) emotional problems related to diabetes 2) treatment problems 3) food problems 4) lack of social support [18]. As can be seen in Table 4, our four-factor solution was not interpretable with the exception of factor 1 which had some resemblance to Snoek and colleagues' emotional subscale; yet, items from the food related, social support and treatment related distress subscales loaded on the same factor.

Table 2: PAID mean scores on items and subdimensions for the male and female samples with type 1 and type 2 diabetes

Subdimension	Type 1 diabetes			Type 2 diabetes		
	Males	Females		Males	Females	
N	47	46	P-value	28	30	p-Value
	M SD 95% CI	***M SD 95% CI***		***M SD 95% CI***	***M SD 95% CI***	
Diabetes-related emotional problems	30.9±15.3 (26.4-34.5)	30.0±13.8 (26.9-35.6)		31.6±14.1 (26.1-37.1)	34.3±13.9 (29.0-31.5)	
Feeling that diabetes is taking up too much mental and physical energy	3.1±2.1 (2.5-3.8)	2.8±2.1 (2.3-3.4)	.62	3.3±2.3 (2.5-4.1)	3.9±1.8 (3.1-4.5)	.38
Not knowing if the mood or feeling you are experiencing are related to your blood glucose	2.6±2.1 (2.0-3.3)	2.9±2.1 (2.3-3.5)	.60	3.5±2.0 (2.6-4.1)	3.3±2.0 (2.5-4.0)	.64
Feeling guilt/anxious when you get off track with your diabetes management	3.3±1.9 (2.8-3.9)	2.5±2.1 (1.9-3.1)	.09	3.6±1.9 (2.9-4.3)	3.3±2.0 (2.5-4.0)	.36
Feeling constantly burned out by the constant effort to manage diabetes	2.9±2.1 (2.3-3.5)	2.4±2.3 (1.8-3.0)	.35	3.0±2.1 (2.1-3.8)	3.3±1.9 (2.5-3.9)	.83
Coping with complications of diabetes	1.9±2.1 (1.3-2.5)	2.1±2.1 (1.5-2.8)	.32	**1.4±2.0 (0.6-2.1)**	**3.1±2.1 (2.3-3.9)**	**.02***
Feeling depressed when you think about living with diabetes	2.8±2.3 (2.1-3.8)	3.1±2.0 (2.5-3.8)	.23	3.0±2.1 (2.1-3.9)	3.0±2.0 (2.3-3.8)	.93
Worry about low blood sugar reactions	3.1±2.0 (2.5-3.8)	3.0±2.0 (2.5-3.6)	.96	3.3±2.1 (2.4-4.1)	3.1±2.0 (2.4-3.9)	.95
Feeling scared when you think about living with diabetes	2.6±2.3 (2.0-3.3)	2.9±2.1 (2.3-3.5)	.61	2.6±2.1 (1.8-3.5)	2.9±2.3 (2.0-3.6)	.64
Feeling overwhelmed by your diabetes regimen	1.3±1.8 (0.8-1.8)	1.9±1.8 (1.4-2.4)	.09	0.8± 1.6 (0.1-1.4)	**1.9±2.0 (1.3-2.6)**	**.01****
Worrying about the future and possibility of serious complications	3.0±2.1 (2.4-3.8)	3.4±2.0 (2.8-3.9)	.50	3.6±2.0 (2.9-4.4)	2.6±2.3 (1.8-3.4)	.06†
Not accepting diabetes	2.5±2.3 (1.8-3.1)	2.1±2.1 (1.5-2.8)	.52	2.6±2.5 (1.6-3.5)	2.3±2.4 (1.3-3.1)	.28
Treatment-related problems	***6.6±4.4 (5.3-7.9)***	***7.1±4.9 (5.6-5.5)***		***8.0±4.5 (6.3-9.8)***	***7.6±4.1 (6.1-9.3)***	
Not having clear and concrete treatment goals for your diabetes care	2.4±2.0 (1.8-2.9)	2.3±2.1 (1.8-2.9)	1.0	2.0±2.3 (1.3-2.9)	3.1±2.1 (2.4-3.9)	.06†
Feeling discouraged with your diabetes regimens	2.5±2.1 (1.6-2.9)	2.3±2.1 (1.6-2.9)	.87	2.8±2.1 (1.9-3.5)	2.5±2.3 (1.8-3.4)	.64
Feeling unsatisfied with your diabetes physician	2.0±1.1 (1.4-2.6)	2.6±25 (1.9-3.3)	.40	**3.3±2.5 (2.4-4.1)**	**2.0±2.1 (1.1-2.8)**	**.02***
Food-related problems	***6.4±4.5 (5.0-7.6)***	***6.8±4.3 (5.5-8.0)***		***6.1±4.3 (4.4-7.8)***	***7.3±5.3 (5.3-9.3)***	
Feelings of deprivation regarding food and meals	2.0±2.1 (1.4-2.5)	2.3±2.3 (1.6-2.9)	.48	2.0±2.3 (1.1-2.9)	2.8±2.3 (1.9-36)	.27
Feeling constantly concerned about food	2.3±2.3 (1.6-2.9)	2.4±2.1 (1.8-3.0)	.71	1.9±2.3 (1.0-2.6)	2.4±2.4 (2.6-3.3)	.19
Uncomfortable interactions around diabetes with family/friends (e.g., other people telling you what to eat)	2.1±2.0 (1.5-2.8)	2.1±2.1 (1.5-2.6)	.45	2.5±2.5 (1.4-3.1)	2.1±2.1 (1.4-2.9)	.80
Social support-related problems	***5.1±4.0 (4.0-6.4)***	***4.6±3.9 (3.5-5.9)***		***5.6±4.0 (4.0-7.1)***	***4.4±3.0 (3.4-5.5)***	
Feeling that friends/family are not supportive of diabetes management efforts	2.9±2.5 (2.5-3.6)	2.4±2.3 (1.6-3.0)	.31	3.4±2.1 (2.5-4.3)	2.3±2.1 (2.6-3.2)	.99
Feeling alone with diabetes	2.3±2.1 (1.6-2.9)	2.3±2.3 (1.6-3.0)	.86	2.3±2.3 (1.4-3.1)	2.1±2.1 (1.4-3.0)	.81
PAID 20-item scale ***40.3±34***	***49.0±24.0 (41.8-56.0)***	***49.5±23.0 (42.6-56.40)***	***.84***	***51.4±21.9 (42.8-59.9)***	***53.5±20.9 (45.8-61.4)***	***.74***
Total PAID 16 items ***3.8±27.2***						

Transformed from 0-4 scale (0-80) to a scale 0-5(0-100) by multiplying the results by 1.25;* <.05, ** <0.01, † borderline. M = mean, SD= standard deviation, 95%CI = confidence intervals at 95% based on gender and type of diabetes.

Table 3: Proportion of participants that endorsed an item as a "serious problem"¶

PAID 20 items	Type 1 diabetes		Type 2 diabetes		Type 1&2 diabetes	p-value
	Males	Females	Males	Females		(type 1 vs.2)
N	47	46	28	30	157	
	%(n)	***%(n)***	***%(n)***	***%(n)***	***%(n)***	
Diabetes-related emotional problems						
Worry about low blood sugar reactions	57(27/47)*	59(27/46)*	61(17/28)	63(19/30)*	61(95/157)*	.20
Feeling that diabetes is taking up too much mental and physical energy	62(29/47)*	50(23/46)	68(19/28)*	67(20/30)*	60(94/157)*	.14
Feeling guilt/anxious when you get off track with your diabetes management	66(31/47)*	41(19/46)	75(21/28)*	60(18/30)*	58(91/157)*	.25
Worrying about the future and possibility of serious complications	55(26/47)*	61(28/46)*	71(20/28)*	47(14/30)	57(90/157)*	.60
Feeling depressed when you think about living with diabetes	55(26/47)*	54(25/46)*	57(16/28)	53(16/30)	54(84/157)	.97
Feeling scared when you think about living with diabetes	53(25/47)	54(25/46)*	50(14/28)	53(16/30)	52(82/157)	.91
Not knowing if the mood or feeling you are experiencing are related to your blood glucose	47(22/47)	54(25/46)*	61(17/28)*	53(16/30)	53(83/157)	.11
Feeling constantly burned out by the constant effort to manage diabetes	51(24/47)	37(17/46)	54(15/28)	63(19/30)*	49(77/157)	.29
Not accepting diabetes	45(21/47)	37(17/46)	50(14/28)	43(13/30)	41(64/157)	.86
Coping with complications of diabetes	38(17/47)	39(18/46)	21(6/28)	60(18/30)*	40(62/157)	.47
Feeling angry when you think about living with diabetes	40(19/47)	30(14/46)	39(11/28)	50(15/30)	39(61/157)	.25
Feeling overwhelmed by your diabetes regimen	19(9/47)	28(13/46)	11(3/28)	27(8/30)	22(34/157)	.69
Treatment-related problems						
Not having clear and concrete treatment goals for your diabetes care	38(18/47)	37(17/46)	36(10/28)	63(19/30)*	41(65/157)	.35
Feeling unsatisfied with your diabetes physician	34(16/47)	46(21/46)	61(17/28)*	33(10/30)	41(65/157)	.40
Feeling discouraged with your diabetes regimens	36(17/47)	39(18/46)	46(13/28)	43(13/30)	40(62/157)	.32
Food-related problems						
Feeling constantly concerned about food	45(21/47)	44(20/46)	32(9/28)	43(13/30)	42(66/157)	.37
Feelings of deprivation regarding food and meals	34(16/47)	44(20/46)	32(9/28)	50(15/30)	40(63/157)	.60
Uncomfortable interactions around diabetes with family/friends (e.g., other people telling you what to eat)	38(18/47)	35(16/46)	39(11/28)	40(12/30)	37(58/157)	.92
Social support-related problems						
Feeling that friends/family are not supportive of diabetes management eff	55(26/47)*	41(19/46)	64(18/28)*	40(12/30)	48(75/157)	.86
Feeling alone with diabetes	40(19/47)	44(20/46)	43(12/28)	37(11/30)	40(63/157)	. 73

¶Total PAID ranges from 0 - 80 on a scale (0-1)"not a problem", (2)"a little problem" & (3-4) "serious problem". * Very high areas concerning diabetes specific distress in Zambian patients. % of aggregated data based on gender and type of diabetes.

Table 4: 1-,2-,3-,4- and 5- factor solution for the PAID as reported by 157 Zambian participants (aged 12-68 years) with type 1 and 2 diabetes

Shortened item content	Factor solution														
	1 Factor	2 Factor		3 Factor			4 Factor				5 Factor				
	F1	F1	F2	F1	F2	F3	F1	F2	F3	F4	F1	F2	F3	F4	F5
Feeling depressed?	.71	.70		.76			.75				.74				
Worry about low blood sugar reactions?	.58		.62		.63			.76				.77			
Worry about complications?	.70	.70		.69			.68				.69				
Feeling angry?	.63	.60		.74		-.40	.72		-.40		.71		-.37		
Feeling scared?	.73	.73		.77			.62				.63				
Feeling discouraged with treatment...?	.73	.72		.75			.64				.61				
Mood related to diabetes?	.63	.63		.54			.61		.31		.59				
Feeling “burned out”?	.70	.67		.60			.64				.53				-.40
Feelings of guilt or anxiety?	.65	.64		.63			.55				.55				
Diabetes is taking up to much energy?	.59	.54		.51			.53				.57				
Uncomfortable social situation?	.63	.65		.60						.76				.76	
Feeling that others are not supportive?	.67	.67		.55		.39			.31	.63				.65	-.31
Feeling alone with your diabetes?	.62	.64		.69						.72				.70	
Not “accepting” your diabetes?	.68	.72		.63		.31	.30			.51				.53	
Unsatisfied with diabetes physician?	.56	.60		.40		.64			.59	.44			.53	.46	
Concerned about food and eating?	**.11**		.72		.73			.75				.87			
Feelings of deprivation regarding food?	**.17**		.76		.73			.79				.76			
Coping with complications?	**-.00**		.69		.75			.66		-.42		.59		-.42	
Not having clear and concrete goal?	.36		.43		.43			.38							-.90
Feeling overwhelmed by your diabetes?	**.23**		.59		.41	-.59		.49	-.57				-.79		-.32
Eigenvalue before rotation	6.69	6.69	2.14	6.69	2.14	1.35	6.69	2.14	1.35	1.14	6.69	2.14	1.35	1.14	1.02
% variance before rotation	33.45	33.45	10.70	33.45	10.70	6.73	33.45	10.70	6.73	5.71	33.45	10.70	6.73	5.71	5.12
Eigenvalue after rotation		6.65	2.39	6.58	2.41	1.78	6.03	2.39	1.55	4.08	5.91	2.11	1.41	4.17	2.22

Principal factor analysis using oblique rotation (Direct Oblimin).

Table 5: Correlations between the total PAID, Diabetes self-care, Fear for hypoglycemia, Age, SES, Body Mass Index and Major Depression Inventory

	Diabetes self-care	Fear for hypoglycemia	Age	SES[¶]	BMI	MDI[ǁ]
PAID total	0.30**	0.35**	0.12	0.00	-0.14	0.39**

** $p < 0.01$, *$p < 0.05$.

¶ Socio- Economic Status

ǁ Major Depression Inventory total score

We also inspected a three factor model and a two factor model using EFA; both solutions were not interpretable. The first factor of the two factor solution consisted of items assessing "diabetes stress" and a second factor containing items covering not only "food-related problems" but also items covering "coping with complications and being overwhelmed with the diabetes regimens". The second factor had item combinations that rendered it difficult to interpret, partly because of various secondary loadings. Therefore the two-factor solution was discarded.

Lastly, we examined a one-factor solution. Our data provided the strongest support for a one factor model although it had four items with low loadings below 0.30 (concerned about food and eating = .11, deprivation regarding food = .17, coping with complication = -.00 and feeling overwhelmed by your diabetes = .23). Although item total correction suggested removing 5 items, 16 items were maintained and used because the factor loadings of these items were greater than 0.30. The retained items had factor loadings ranging from 0.36 to 0.73. Internal consistency remained high even after removing these items Cronbach's alpha 0.90 (lambda2 = 0.90).

The internal consistency of the total PAID, as indicated by Cronbach's alpha, was 0.88 (lambda2 = 0.89), for the 16 items PAID alpha was 0.90 (lambda2 = 0.90). For subjects with T1DM Cronbach's alpha was 0.89 (lambda2 = 0.90) while for subjects with T2DM Cronbach's alpha was 0.86 (lambda2 = 0.88). Inspections of the item total correlations revealed that 15 out of 20 items were worthy of retention. Cronbach's alpha for HFS was 0.80 and lambda2 0.81, 0.71 and lambda2 0.74 for SCI and 0.79 and lambda2 0.80 for the MDI.

Table 3 shows that regardless of the type of diabetes, "Worry about low blood sugar reactions" was most endorsed as a serious problem (i.e. score of 3 or 4 (i.e. "a problem" /a serious problem") among T2DM patients and in all patients (62% and 61% respectively). Overall 60% of the patients (T1DM and T2DM) endorsed "the feeling that diabetes was taking up too much of their mental and physical energy" to be a serious problem.

Women with T2DM scored higher (54±21 (95% CI: 46-61) than men or women with T1DM 49.0±24.0 (41.8-56.0), 49.5±23.0 (42.6-56.40) respectively. Men with T2DM scored higher 51±22 (95% CI: 43 - 60) than men 49±24 (95% CI: 42 - 56) and women 50±23 (95% CI: 43 - 60) with T1DM and these differences were significant (see table 2).

Concurrent validity of the PAID was evaluated by assessing the correlations between the PAID and age, BMI, SES, fear for hypoglycemia, depression and diabetes self-care. Table 5 shows the correlation between the PAID and other variables of interest. There was a moderately significant correlation between the PAID with the diabetes self-care $r(157) = -0.30$, fear for hypos $r(157) = 0.35$ and depression $r(157) = 0.39$ scores. However, there was no significant correlation between the PAID and age $r(157) = 0.12$, socioeconomic status $r(156) = -0.01$ and Body Mass Index $r(157) = -0.14$.

Table 6 shows a stepwise multiple regression model that examined the relationship of six variables with the total PAID score. In the first step, demographic variables were entered as control variables; no significant associations were found with diabetes distress. In the second step, clinical variables (body mass index, depression, diabetes self-care and fear for hypoglycemia) were entered. These variables were positively associated with total PAID

scores, except for body mass index which was negatively associated with diabetes-distress. The strongest predictor of diabetes-specific distress was fear for hypoglycemia (beta = 0.29), followed by depression beta = 0.27, perceived diabetes self-care was the third most significant predictor of diabetes-specific distress (beta = 0.25). The predictor variables explained 32% ($p < 0.01$) of total variance of the PAID.

Table 6: Stepwise multiple regression analyses predicting PAID by demographic and clinical characteristics in 157 patients with T1DM and T2DM

Models	Beta	*t*	*P*
Model 1: Demographic characteristics			
Age	.122	1.286	.23
Being T2DM	.029	.313	.95
Being female	.011	.138	.95
Socioeconomic status	.005	.054	.95
R^2 = .020			
Adj R^2 = -.007			
Model 2: clinical characteristics			
Body mass index	-.107	-1.348	.08
Depression (MDI)	.268	3.122	.001***
Fear for hypoglycemia	.289	3.456	.001***
Diabetes self-care	.252	3.249	.001***
R^2 = .335***			
Adj R^2 =.315***			

*$p < 0.05$, ** $p < 0.01$, ***$p < .001$.

Study 2

As a further study of the adequacy of the PAID in the Zambian context, we conducted a qualitative study, addressing the adequacy of the instrument's instructions, items and response

scale. We used cognitive interviews to assess the adequacy, comprehensibility and cultural appropriateness [34].

Subjects

Eight patients with diabetes (3 adolescents and 5 adults) participated in the study. These cognitive interviews focused on the 20 items of the PAID. Patients were asked to provide verbal feedback on each item regarding 1) response categories, 2) clarity, 3) the respondent's knowledge about the specific topics that were inquired and recall of experiences and sensitivity of the items and overall impression of the content (see Table 7). All interviews were conducted in English, were audio-recorded and verbatim transcribed. Interviews lasted between 30-45 minutes. Of the 8 patients that were interviewed only one had completed the PAID scale earlier during the research project.

Table 7: Cognitive interview question

Warm up question/instruction clarity
Tell me what this introduction is telling you?
Comprehension (question intent and meaning of term)
Can you tell me in your own words what this question was asking?
What does the [word/term] mean to you as it has been used in this question?
Tell me what you were thinking when I asked about [topic]?
Assumption
How well does this question apply to you?
Can you tell me more about that?
Knowledge /memory
How much would you say you know about [topic]?
How much though would you say you have given to this?
How easy or difficult is it to remember [event]?
You said [answer]. How sure are you about that?
How did you come up with that answer?
Sensitivity/social desirability
Is it ok to talk about this diabetes problem area or it's uncomfortable?
The question uses the [word/term]. Does that sound ok or would you choose something different?
Specific and general probes
Why do you think that [topic] is the most serious diabetes problem?
How did you arrive at that answer?
Was it easy or hard to answer?
I noticed that you hesitated. Tell me what you were thinking?

Data analysis

Verbatim transcriptions were first read through several times in order to get familiar with the data. After established familiarity with the data, each question response was analyzed and comments assigned to each response based on the cognitive theory model by Tourangeau [35]. The model consist of four processes: 1) comprehension of the question (question intent and meaning of terms), 2) retrieval from memory of relevant information (recallability` of information and recall strategy – recalling each one individually vs. estimation strategy), 3) decision process (motivation – devotion of mental effort to answer question and sensitivity of question or indication of social desirability) and 4) response process which involves matching responses to scale categories.

Results

In general most of our patients could understand the majority of the items (16/20 = 80% of the items). The following items were problematic to understand for some patients: "feeling constantly burnout by constant effort to manage diabetes and not having a clear and concrete goal for managing diabetes care". Some adolescents and adults had challenges with specific words in items although they were able to deduce the meaning of the entire question. The words and concepts that the patients found challenging were "overwhelmed", "regimens", "unsatisfied", "burnout", "physicians" and "concrete goal". The patients were also able to suggest some replacements to the words they initially had challenges with to include "treatment plan" for "regimens", "unhappy" or "happy" for "unsatisfied", "doctor" for "physicians". In some cases it was difficult to recall occurrences of certain events evoked by the questions such as when patients were angry, guilty or anxious and uncomfortable. These challenges were

mostly noted among young people. Table 8 outlines common problems that were identified as indicated above.

Table 8: Problematic issues identified after cognitive interviews analyses

Comprehension problems: Question intent	**Tally**	**Adolescent vs. adult patient**
Feeling constantly burnout by the constant effort to manage diabetes	III	both
Example response*: it was asking if I feel lazy to manage my diabetes*		
Coping with complications of diabetes	II	both
Example response*: it was asking about my blood sugar and about my diabetes*		
Not having clear and concrete goals for your diabetes care	II	both
Example response*: it was asking if I have set goal for my future on what I want to do and how I plan to do it*		
Feeling that diabetes is taking up too much of your mental and physical energy	I	adolescent
Example response*: it was asking how I feel physically and how I feel diabetes is affecting my life*		

Comprehension problems: meaning of terms	**Tally**	**Proposed change by patients**	**Adolescent vs adult patients**
Anxious	I	-	Adolescent
Regimens	II	Treatment plan	Both
Burnout	~~III~~	-	Both
Unsatisfied	I	Happy or unhappy	Adolescent
Physician	III	Doctor	Adolescents
Overwhelmed	I	-	Adult
Concrete goals	III	-	Both
Coping	I		Adolescent
Deprivation	I	-	Adolescent

Recall problem of specific events evoked by questions
Feeling ***guilt or anxious** when you get off track with your diabetes management
Feeling ***angry** when you think of living with diabetes
***Uncomfortable** interactions around diabetes with family or friends

* Moments patients could not recall the last time they experience something like that

Discussion

The aim of current study was to examine the latent structure, reliability and validity of the PAID among individuals with type 1 or 2 diabetes in Zambia**.** Results of our study strongly support a one-factor solution of the Zambian translation of the PAID, although four items "concerned with complications", "feelings of deprivation regarding food", "coping with complications" and "feeling overwhelmed by diabetes" had factor loadings less than 0.30. These low loadings may result from the fact that all our subjects were outpatients, without any serious complications. It remains unclear why the item "concerned about food" had a low loading considering that initial interviews by the first author with the patients showed that it was a major concern [17].

Our data rejected the two factor model found in Iceland by Sigurdardottir and Benediktsson, [6], the three-factor model found in Sweden by Amsberg and colleagues [7] and the four factor model found in the USA/The Netherlands [18-19]. A one factor model was also found the USA/The Netherlands [18]. Originally, the PAID was conceptualized as a unidimensional scale [2]; therefore, our one-factor structure using all 20 items remains plausible. Moreover, in studies among Chinese [20], Dutch and US [18] individuals with diabetes, the one-factor solution was also supported. The Zambian version of the PAID showed high internal consistency with Cronbach's alpha and lambda2 which has recently been recommended in the literature because it shows the least amount of bias [36]. Consequently, a total of 16 items at least from EFA results seem useful for clinical assessment to detect diabetes-related distress and suggest psychological help to Zambian patients with such distress, with possibly some words changes as suggested by the cognitive interview study.

Our study also found that most patients endorsed, “worrying about low blood sugar reactions”, “feeling that diabetes is taking up too much mental and physical energy”, “feeling guilt/anxious when you get off track with your diabetes management”, “worrying about future and possible serious complications” and “feeling depressed when you think about living with diabetes” as the most bothersome diabetes-specific problems which is consistent with findings by Sigurdardottir and Benediktsson [6]; worrying about the future and possible complications and feeling guilty when you get off track with your diabetes management were also found to be the most commonly endorsed by Snoek and associates [18]. It was not surprising that our patients endorsed these items, considering that the mean score for fear for hypoglycemia was relatively high (58±12) and the diabetes self-care score was below average (48±9). Moreover, having a hypoglycemic episode in Zambia might be more stressful, as medical care is less available compared to Europe or the US. Further, all the participants with T1DM were on insulin injection therapy which has been shown to be physically and mentally challenging. Patients are required to buy their own strips for blood glucose testing which are often unaffordable for most patients. Generally, diabetes patients get off track with diabetes management and care which can cause a sense of guilt and anxiety.

The mean value for the 16 items of the PAID was 33.8±27.2 (would be 40.3±33 in case for 20 items) suggesting that the Zambian participants experienced high levels of diabetes-specific emotional distress. In the Icelandic participants (T1DM only) the mean value for the PAID was 28±18, Swedish participants (T1DM only) 27±18, Dutch, 24±19 and USA participants 31±23. The results suggest that living with diabetes in Zambia is perceived as much more stressful compared to Western Europe and the US and that it imposes many demands on the patients, which may exacerbate diabetes-specific emotional distress. These differences in levels of

diabetes-specific emotional distress may reflect differences in access to physical and mental health care and costs associated with diabetes management. Another explanation could be cultural differences in the experience of psychological problems. Graue and colleagues also speculated that differences in diabetes-specific emotional distress across countries may be due to cultural differences in the explanation of psychological problems [24]. Most importantly, definitions and attributes of depression are dominated by Western cultural assumptions which may not reflect the conceptualization and treatment of depression in Zambia. To the best of our knowledge diabetes patients in Zambia are not given any psychosocial help; moreover about 48% of our participants indicated that family/friends were not supportive of their diabetes management efforts (Table 3).

In the present study, the PAID scores were positively associated with fear for hypoglycemia, depression and negatively associated with diabetes self-care. Equally PAID scores were predicted by the patients' depression levels, diabetes self-care and fear of hypoglycemia. This was expected as literature has shown associations between self-care and depression and with other variable such as body mass index, SES, glycemic control although the later were not associated with self-care in our sample [37-41].

Overall, the cognitive interviews demonstrate that our respondents were able to comprehend the scale items and to link them to the scale category. Four items ("feeling constantly burnout by constant effort to manage diabetes", "not having a clear and concrete goal for managing diabetes care", "coping with complications of diabetes" and feeling diabetes was taking up too much of your mental and physical energy", were not well comprehended by 5 respondents the difficulties were beyond word difficult or vague concepts but the comprehension of the

question intent. Although some of the respondents had difficulties with the meaning of some word/terms (e.g., anxious, physician, concrete goals), overall they were able to comprehend the intent of the questions with an exception for few questions. Of the main items that influenced the missing values figure, "feeling constantly burnout by constant effort to manage diabetes" and "feeling diabetes is taking up too much of your mental and physical energy" were also items that patients found difficult to comprehend. Patients had also problems with the meaning of the word overwhelmed in the item "feeling overwhelmed by your diabetes management". It is possible that patients were uncomfortable to answer the items "feeling constantly concerned with food" and not accepting diabetes hence leaving them unanswered by some patients. Implementing the feedback from respondents on some changes to key words (e.g. doctor for physician, regimen for treatment plan etc.) can improve the strength of the items. In addition, including items covering patients "worrying not getting married or difficulties having children, have trouble getting insulin/testing strips, having to walk long distances to get medical care, feeling discriminated against because of diabetes" would enrich the Zambian version of the PAID.

This study is the first to validate an African version of the PAID. The sample in this study was drawn from three provinces in Zambia including adolescents and adults, type 1 and 2 diabetes mellitus making the sample heterogeneous and generalizable within the Zambian urban context. Secondly, we were able to demonstrate that participants did not employ response style bias instead respondents were able to map responses based on the categories given in the survey and were able to comprehend the question intent. However, the study is not without limitations. First, the sample size was relatively small and drawn from urban settings only. Second, due to the small sample size, we could not conduct a Confirmatory Factor Analysis, which would

have enabled a more rigorous comparison of different factor solutions. Therefore, future studies should work with a bigger sample size and subject the Zambian version of the PAID to Confirmatory Factor Analysis. Thirdly, we cannot rule out the influence of social desirability in the manner participants responded to the scale. In social research participants have the tendency to respond to survey questions in a manner that will be viewed favorable by others [42].

In conclusion, the current study revealed good internal consistency, reliability and validity of the PAID among patients with type 1 and 2 diabetes mellitus in Zambia. Moreover, the majority of our patients demonstrated that they were able to comprehend most questions well and match their responses to the scale categories, although some items may need to be rewritten. The measure has satisfactory psychometric properties to assess individual levels of diabetes specific-distress that qualifies it for diagnostic and clinical use, although some items may need to be clarified and simplified to enhance its comprehensibility. We found a single factor solution to be the best approximation of the data. The existence of a single factor implies that the participants did not make a distinction between clusters of domains or complaints. Rather, diabetes seems to work as a global stressor that comes with multiple complaints. To our knowledge, findings in the current study are the first to highlight the use of the PAID in Zambian patients with diabetes. The study also demonstrated that diabetes-specific emotional distress is very high in Zambian patients compared to patients with diabetes in Western Europe or the USA. These results show that there is a very strong urge to further improve the quality of medical treatment of Zambian people with diabetes, particularly it would be helpful to educate the families. There is need to improve the composition of the health care profession so that the team attending to patients is multi-disciplinary and includes a general health care

practitioner, cardiologist, nutritionist, psychologist, etc. all are currently available in major hospitals but just need to be coordinated to make this possible. There is also need to increase the numbers of qualified people to work with diabetes patients.

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Chapter 5

Diabetes mellitus and co-morbid depression in Zambia[5]

[5] This chapter is based on a published article. Hapunda G, Abubakar A, Pouwer F, van de Vijver F. (2015) Diabetes mellitus and comorbid depression in Zambia. Diabetic Medicine; 32 (6):814-818. doi: 10.1111/dme.12645.

ABSTRACT

Aims: To replicate, in Zambia, a recent global study by the WHO, which reported that the odds of depression were not increased in African people with diabetes, and to explore the sociodemographic and clinical factors associated with depression.

Methods: A total of 773 control subjects and 157 Zambian patients with diabetes completed the Major Depression Inventory and a list of demographic indicators.

Results: Compared with control subjects (mean ± SD Major Depression Inventory score 15.10 ± 9.19), depressive symptoms were significantly more common in patients with diabetes (mean ± sd Major Depression Inventory score 19.12 ± 8.95; $P < 0.001$). ANCOVA showed that having diabetes [$F(1,698) = 16.50$, $P < 0.001$], being female [$F(1,698) = 7.35$, $P < 0.01$] and having low socio-economic status ($F(1,698) = 13.35$, $P < 0.001$) were positive predictors of depression.

Conclusions: Contrary to the WHO study, we found that depression was a common comorbid health problem among Zambian people with diabetes. Clinicians should consider patients' health status, sex and socio-economic status as potential factors predicting depression.

Introduction

Abundant evidence suggests that the prevalence and incidence of depression is elevated in people with Type 1 or Type 2 diabetes [1–4]. Depression in diabetes is not only associated with impaired quality of life [5], but prospective studies have also shown that depression is associated with poor glycemic control, an increased risk of developing microvascular and macrovascular complications and higher mortality rates [6,7].

Only a few studies on diabetes and depression have been conducted on the African continent. In a Nigerian study, in 83 people with diabetes, 25% had an elevated depression score on the Hospital Anxiety Depression Scale [8]. Further two Nigerian studies used a diagnostic psychiatric interview [9,10]. The first was conducted among 200 outpatients with Type 1 or Type 2 diabetes: 30% had a depressive disorder, compared with 9.5% in a control group without diabetes [9]. Agbir et al. [10] found that the prevalence of major depressive disorder was 19.4% in an outpatient diabetes clinic. In another global study, diabetes was associated with a twofold increase in the prevalence of depressive symptoms except in Africa [11].

Little is known about the prevalence of depression in people with diabetes in Zambia. The aim of the present study, therefore, was to address two questions: (1) Do Zambian people with diabetes mellitus have more depressive symptoms than control subjects without diabetes? and (2) Which sociodemographic and clinical variables are associated with depression in patients with diabetes?

Subjects and methods

Study population

Patients with diabetes were recruited from four central hospitals. Healthy adolescent control subjects were recruited from secondary schools and healthy adult control subjects were recruited from various public places within Lusaka. Healthy adolescents gave consent and the head teachers of their schools also gave permission. A total of 930 subjects were included, of whom 773 were healthy subjects and 157 had diabetes (42 adolescents with Type 1 diabetes, 51 adults with Type 1 diabetes and 64 with Type 2 diabetes). Adolescents comprised 72% of the total sample. The demographic characteristics of all study subjects are shown in Table 1 below.

Measurements

Data on age, sex, education level and diabetes type, and a list of the properties and services owned by the families of the study subjects (e.g. car, maid, television), were obtained. The Major Depression Inventory (MDI), a validated, 12-item self-report questionnaire, was used to assess depression [12,13].

Statistical analysis

To establish whether the questionnaire was comparable for the two groups (patients and control subjects), we computed a two-group confirmatory factor analysis, in which we tested invariance of factor loadings and measurement intercepts as tests of metric and scalar invariance, respectively [14]. ANCOVA was used to examine the influence of our predictor variables (healthy status and sex of our subjects) on the mean MDI score, while partialling out the effects of age and socio-economic status.

Ethics

The study was approved by the ethics committee of the School of Humanities and Social Sciences, University of Zambia (reference number IRB: 00006464, IORG: 005376).

Results

The mean ± SD age of the entire study cohort was 23.5 ± 11.73 years, for adults with diabetes it was 47.14 ± 11.21 years, for healthy adults it was 30.09 ± 8.39 years, for adolescents with diabetes it was 15.17 ± 2.11 years and for healthy adolescents it was 16.84 ±1.24 years. Age was significantly different in each group (P < 0.001). Further, for the Major Depression Inventory, Cronbach's α was 0.81, while λ^2 was 0.80. We tested a single factor model for the Major Depression Inventory. The configural invariance (unconstrained) model yielded a good fit, chi-squared test (131, N = 930) = 325.66 (P < 0.001), Tucker–Lewis index = 0.911, comparative fit index = 0.911 and root mean square error of approximation = 0.040.

In addition, we examined the proportions and means of depression in our sample. As Table 1 shows, adults with Type 2 diabetes (26%; mean ± sd MDI score 21.06 ± 7.94) or Type 1 diabetes (27%; mean ± SD MDI score 18.45 ± 9.59) had higher depression scores compared with adult control subjects [9.9%; mean ± sd MDI score 11.45 ± 8.33; $P < 0.001$). Similarly, adolescents with Type 1 diabetes scored higher (27.8%; mean ± SD MDI score 17.53 ± 10.34) than did adolescent control subjects (17.2%; mean ± sd MDI score 16.14 ± 9.20; $P < 0.05$). In general, patients with diabetes had a higher mean MDI score [25.4%; mean ± sd score 19.12 ± 8.95) compared with control subjects (16.3%; 15.10 ± 9.18; $P < 0.001$). Both men and women with diabetes reported more symptoms of depression than did control subjects (Table 1).

Table 1: Demographic and clinical characteristics of the study cohort

Sample composition n (%)						
Healthy sample						773 (80%)
Clinical sample						157(20%)
Type 1 diabetes patients						93(59.2%)
Type 2 diabetes patients						64(40.8%)
Sex *n*(%)						
Males						481 (51.7%)
Females						407 (43.8%)
Missing						42 (4.5%)
Mean age (SD)						23.05(11.73)
Age range						12-68 years
Marital status						
Single						61(23.6%)
Married						164(63.3%)
Widowed						2(0.8%)
Missing						32(12.3%)
	Controls		**with diabetes**			
	adolescents	**adults**	**adolescents**	**adults**		**all Patients**
Education level (n/%)						
Unknown	25(4%)	3(2.1%)	---	54(47%)		
Primary	---	2(1.4%)	14 (33.3%)	10(9%)		
Secondary	629(96%)	36(25%)	28 (66.7%)	29(25%)		
Tertiary	---	103(47%)	---	22(19%)		
Depression categories (n/%)			**Type 1**	**Type 1**	**Type 2**	**Type 1&2**
No to mild depression	369(82.7%)	100(90.1%)	26(72.2%)	54(73%)	38(74.5%)	97(74.6%)
Moderate depression	38(8.5%)	11(9.9%)	6(16.7%)	12(16.2%)	7(13.7%) 19	(14.6%)
Severe depression	39(8.7%)	---	4(11.1%)	8(10.8%)	6(11.8%)	14(10.8%)
Gender aggregated	**Females**	**Males**	**Females**	**Males**		
No to mild depression	220(80.9%)	276(86.8%)	45(68.2%)	52(81.2%)		
Moderate depression	52(19.1%)	42(13.2%)	13(19.7%)	6(9.4%)		
Severe depression	---	---	8(12.1%)	6(9.4%)		

*MDI score range from 0 – 50 and can be categorized no-mild depression (0-24), moderate depression (25-29) and severe depression (30-50)

Table 2: Mean±sd depression scores and ANCOVA results stratified by health status, sex and two covariates

	Controls	**with Diabetes**	**p value**
All	15.10±9.18	19.12±8.95	***
Adolescents: type 1diabetes	16.14±9.20	17.53±10.34	***
Adults: type 1 diabetes	11.45±8.33	18.45±9.59	***
Adults: type 2 diabetes	11.45±8.33	21.06±7.94	***
Females	16.85±9.11	19.53±8.95	*
Males	12.63±9.02	18.70±9.00	***
Independent variables	***F***	***P***	η^2
Having diabetes	16.542	***	0.023
Being female	7.350	**	0.010
Age†	2.360	ns	0.003
Socioeconomic Status†	13.341	***	0.019
Having diabetes *being female	2.075	ns	0.003
R^2 = 0 .080 Adj R^2 = 0. 074			

*= < 0.05; ** = < 0.01; *** = < 0.001; ns =non-significant, † = covariate.

The ANCOVA test showed that, after adjustment for covariates, having diabetes was significantly associated with depression: $F(1,704) = 16.54$ ($P < 0.001$), partial $\eta^2 = 0.02$. The adjusted mean MDI score for those without diabetes was 14.98 compared with 19.20 for those with diabetes. After adjustment for the covariates, the model showed that gender was still statistically significant: $F(1, 704) = 7.35$ ($P < 0.01$), partial $\eta^2 = 0.01$. The adjusted mean MDI score for females was 17.76 compared with 14.36 for males. The corrected model for the between-subjects effect was statistically significant: $F(5,704) = 12.18$ ($P < 0.001$), partial $\eta^2 = 0.08$ and adj$R^2 = 0.074$ account for 7.4% of the total variance in MDI scores. Table 2 shows the results of the ANCOVA test. Within the group with diabetes, MDI scores for women (32%, mean 19.53 ±8.95) and those for men (19%, mean 18.70 ± 9.00) were not significantly different: $t(128) = -0.525$ ($P > 0.05$), 95% CI -3.94 to 2.29.

Discussion

Both adults and adolescents with diabetes reported elevated levels of depression compared with healthy control subjects, and adults with diabetes had higher depression scores compared with adolescents. Approximately one quarter of our sample reported elevated depression levels compared with 39.5% in a study involving a Nigerian adult outpatient cohort with both Type 1 and Type 2 diabetes in Benin City [9]. In that study, 30% of participants had a depressive disorder [9]. In another Nigerian study, the 1-year prevalence of depression was 19.4% [10]. In the present Zambian sample, as in other African countries [9,10], levels of depression were high. In the WHO study [11], the overall odds of depression were not found to be higher for patients with diabetes in Africa. Cultural differences regarding the concept of depression might play a role here. Differences in measuring tools used, poverty levels and comorbid conditions may also explain differences across studies. The results of the present study show that depression is also an important comorbid health problem in African patients with diabetes, and thus are not in line with findings from Mommersteeg et al. [11].

In addition, we found that women and those with a low socio-economic status reported more symptoms of depression. This is in line with a systematic review that provided strong evidence that the occurrence of depression among people with diabetes in low- and middle-income countries is associated with socio-economic status [15]. A lack of mental health services, a lack of insurance coverage and unguaranteed social support for people from communities with low socio-economic status may explain the association between depression and socio-economic status [15]. In addition, as reported by previous studies, our data indicate that females were more depressed than males. The more favorable everyday life conditions of males may explain this difference. In addition, women play many roles which expose them to increased responsibilities [16]. It is also possible that social stigma and discrimination play a role here

and contribute to the development of depression in people with diabetes. According the International Diabetes Federation, stigma is a bigger problem for girls and women, 'who carry a double burden of discrimination because of their health status and the inequalities perpetrated in male-dominated societies' [17].

The present study has some limitations. Firstly, there was the potential for selection bias because we used a non-random sampling technique and the data only represented selected areas of Zambia because of financial and other logistical constraints. Secondly, our study lacks clinical data specific to diabetes and its complications. The self-report measure we used can only measure relative levels of depression; in future, diagnostic interviews would be ideal because they measure absolute levels of depression. Strengths of the study include the use of control subjects in exploring the prevalence rates of depression in our sample. To the best of our knowledge this study is the first to show how common depression is among adolescents and adults with diabetes in Zambia compared with control subjects.

The present results have public health and policy implications; clinicians and policy-makers should pay increasing attention to depression, as the WHO projects that depression will become one of the leading causes of disabilities [18], and because depression appears to be severely underdiagnosed in Zambia, for example, in patients with epilepsy [19]. Furthermore, depression appeared to be a highly recurrent or persistent problem in people with diabetes [20]. Among both adolescent and adult patients in the present study, depression levels were significantly higher. Given the developmental stage of adolescents, depression levels in these patients are of particular concern. Clinicians should discuss the nature, causes and treatment of depression with their patients, especially with adolescents.

In conclusion, the main aim of the present study was to investigate the prevalence of depression among patients with diabetes in Zambia. Contrary to the results of the WHO study, our findings show that depression in patients with diabetes was more common than in a healthy control group. In addition, female gender and low socio-economic status were found to be associated with higher levels of depression. Clinicians should consider these variables when tailoring interventions for individual patients. Policies that directly encourage screening for depression, especially among adolescents, and the development of age-appropriate mental health interventions are warranted in order to promote better mental health in a generation of people with diabetes.

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Chapter 6

Gender, Age and Socioeconomic Status are Associated with Self-Care among People with Diabetes in Zambia[6]

[6] This chapter is based on the following article. Hapunda, G. Abubakar, A. Pouwer, F & van de Vijver, F.J. R. Depression and Self-care: Are Depressive Symptoms are Associated with Suboptimal Diabetes self-care in People with Diabetes in Zambia? Journal of Health Psychology (in press)

ABSTRACT

Aim: Depression is an established risk factor for cardiovascular disease and mortality, and impaired self-care behaviors may play a mediating role. However, depression is a rather heterogeneous construct. We therefore examined the associations between depressive symptoms and different aspects of diabetes self-care in Zambian individuals with diabetes mellitus.

Methods: A total of 157 individuals with diabetes mellitus participated. The sample was drawn from four city hospitals in Zambia. Diabetes self-care was assessed using the Diabetes Self-Care Inventory (SCI) and depression was assessed using the Major Depression Inventory (MDI).

Results: 59% of the sample had type 1 diabetes. Increased appetite was the most endorsed symptom (53%) and trouble sleeping at night was the least endorsed symptom (27%) by our patients. The symptoms "*low in spirit or sad*" ($\beta = -0.226$, $p = < 0.05$) and "*feeling life was not worth living*" ($\beta = 0.235$, $p = < 0.05$) were found to be significantly associated with self-care. The symptom "*lack of energy*" ($\beta = -0.192$, $p = > 0.05$) was marginally associated with self-care. However, these symptoms were no longer significant after controlling for all clinical and demographic variables. In patients with type 1 diabetes, no symptoms were significant. In type 2 diabetes only the symptom "*had bad conscience or feeling guilty*" was associated with better diabetes self-care ($\beta = 0.349$, $p = < 0.05$). Being young and female were significantly associated with poor self-care scores while having a high socioeconomic status was significantly associated with better self-care scores.

Conclusion: Although it was initially hypothesized that depression was associated with diabetes self-care, much of the variance in depression seemed to be explained by demographic characteristics specifically gender, age and SES. Clinicians attending to diabetes patients need to pay attention to these sub-group of patients who are at a high risk of poor self-care.

Introduction

It is estimated that 350 million people worldwide with diabetes have elevated levels of depression [1]. Depression worldwide affects 10-30% of the people with diabetes [2]. A recent survey indicated that globally, individuals with diabetes had increased odds of experiencing an episode of depressive symptoms compared to those without diabetes [3]. Diabetes patients with depression are at increased risk for poor glycemic control and development of cardiovascular complications and have higher mortality rates [2, 4-5]. One of the behavioral mechanisms that may link depression with poor outcomes in diabetes is sub-optimal self-care. In developed countries, patients with comorbid depression and diabetes have been found to have less frequent fruit and vegetable intake, more frequent fat intake, more sedentary behaviors and fewer exercise sessions per week [6-8]. Moreover, smoking was twice as prevalent among depressed than non-depressed diabetes patients [4]. However, studies on the association between depression and self-care in diabetes patients are scarce in the Sub-Saharan African (SSA) context. Nevertheless, studies that have looked at the association between depression and other chronic illness, especially HIV and AIDS, have consistently found that depression is associated with sub-optimal self-care in patients [9-11].

Diabetes care mostly consists of self-care behaviors [12]. After consultations with their health care providers, patients are responsible for their diabetes care 24 hours per day. Optimal outcomes in diabetes require diligent daily self-care [4]. Diabetes self-care consists of proper use of medication (insulin or oral medication, correct timing/correct doses), counting of carbohydrates, a healthy diet (e.g., low in saturated fat, low in salt, high in vegetables/fruits, and moderate alcohol intake), being physically active, monitoring of blood glucose levels, proper foot care, and refraining from smoking, among others [13]. Since comorbid depression in people with diabetes has been associated with poor glycemic control in developed countries

[2, 5] and that people with both disorders rarely participate in recommended health behaviors mentioned above [6-8], the relationship between self-care behaviors and depression remains a very important, yet hardly explored area of research in SSA.

Major depressive disorder is a medical illness that affects feelings, thoughts and behaviors. Depression results in persistent feelings of sadness and loss of interest in previously enjoyed activities [14]. Depression is a heterogeneous construct with an interrelated set of diverse symptoms mostly derived from Western studies; depression is often comorbid with diabetes, which warrants research on the link between depression and diabetes self-care. In this study we attempt to examine the applicability of this link in a non-Western context. To date, the diagnosis of depression is based on the frequency and severity of a set of symptoms. For the diagnosis of major depression, 5 symptoms out of 9 (which include depressed mood or diminished interest in daily activities) are required. These symptoms include depressed mood or irritability, decreased interest or pleasure, change in appetite (increased or reduced appetite), change in sleep (hypersomnia or insomnia), change in activity (psychomotor agitation or psychomotor retardation), fatigue or loss of energy, guilt/worthlessness, diminished concentration, and suicidal ideation [15]. As a result, a considerable number of different combinations of symptoms is possible.

A recent study conducted among Dutch patients showed that particularly depressed mood, sleeping difficulties, appetite problems and suicidal ideation were significantly related with higher glycated hemoglobin (HbA_{1C}) in patients with type 1 or 2 diabetes mellitus (TIDM/T2DM) [15]. Research has shown that anhedonia (loss of interest or loss of pleasure) is related to sub-optimal glycemic control (a product of self-care) in patients with T2D [16]. Identifying symptoms that are particularly associated with diabetes self-care may prove

important for clinical practice. Particularly, depression management improves patient's quality of life and patients' ability to achieve and maintain diabetes self-care goals. Therefore, the aim of the present study is to explore the associations between specific symptoms of depression with diabetes self-care in Zambian individuals with diabetes.

Methods

Design

This study employed a cross-sectional design. We assessed the link between the independent variable of interest (e.g., depressive symptoms, type of diabetes, age, sex, SES and body mass index) and the dependent variable, diabetes self-care [17].

Study sample

The study sample comprised of outpatients with either T1DM or T2DM from major urban hospitals in Lusaka, Ndola, Kitwe and Livingstone. The T1DM or T2DM diagnosis was based on what was indicated on the patients' hospital record cards and their verbal confirmation. Patients were invited to participate in the study if they were at least 12 years old and were diagnosed at least 6 months before the study. In total 157 patients signed the informed consent form and were recruited over a one-year period. Assent was obtained from younger patients below 18 years old. Their guardian consented for them to participate in the study. Table 1 shows the demographic characteristics of the participants.

Table 1: Demographic characteristics of 157 participants (12-68 years) with type 1 and type 2 diabetes

Sex, n (%)	
Females	80 (51%)
Age, mean (SD)	39±17
Age range	12-68 years
Developmental stage n (%)	
Adolescents	42 (27%)
Adults	115 (73%)
Educational levels n (%)	
Adolescents (42)	
5-7th Grade (Primary school)	14 (31%)
8-12th Grade (Secondary school)	16 (38%)
Missing	14 (31%)
Adults (115)	
Primary education	10 (9%)
Secondary education	29 (25%)
Tertiary education	22 (19%)
Missing	54 (47%)
Marital status (Adults/115) n (%)	
Single	6 (5%)
Married	80 (70%)
Missing	29 (25%)

Measures

Demographic variables. Information on age, sex, education level, properties and services owned by families of participants and diabetes type was obtained.

Diabetes Self-care. The 13-item Diabetes Self-Care Inventory (SCI) is a self-report measure used to assess patients' perceptions of their adherence to diabetes self-care recommendations over the past month. Individuals rate themselves on a 5-point Likert scale that indicates how well they followed recommendations for self-care during the past month (i.e., 1 = "never do it" to 5 = "always do this as recommended, without fail") on several items including *glucose testing, administering correct insulin dose, eating the proper foods; sticking to meal plan and exercising regularly*. Individual items can be studied, while an overall adherence score is

derived using the average of the items 1, 2, 5, 7, 8 and 13; these items cover areas that are linked to better metabolic control [18]. The item "wearing a medic alert ID" was dropped because it did not apply to Zambian patients. Higher scores on the scale indicate good diabetes self-care. The SCI shows good reliability, with values of the Cronbach's alpha of 0.84 for T1DM and 0.85 for T2DM [19]. In the current study Cronbach's alpha was 0.71 and Lambda2 was 0.74.

Depression. We used the symptoms from the Major Depression Inventory (MDI), a 12-item self-report questionnaire used to assess depression. Items of the MDI ask the patient to rate how long in the past two weeks each of the depressive symptoms was present on a six point scale ranging from 0 "not at all" to 5 "all time" on items such as *have you felt low in spirit or sad, have you felt less self-confident, have you suffered from reduced appetite etc.*? The instrument can be used to measure severity of depression with a score range from 0 - 50. According to the manual (based on Western norms), an MDI total score between 0-24 indicates "no depression to mild depression", 25-29 "moderate depression" and 30-50 "severe depression". Items 8 and 10 are divided into two sub-items, a and b. Only the highest scores of item 8 and 10 (either a or b) are included in the statistical analysis. This self-report measure contains the ten ICD-10 symptoms of depression and is identical with the DSM-IV symptoms apart from one that relates to low self-esteem [20]. The symptoms for major depressive disorder covered in this measure include (i) depressed mood, (ii) decreased interest, (iii) increased and reduced in appetite, (iv) changes in sleep pattern, (v) changes in daily activities interests, (vi) loss of energy, (vii) feeling of worthlessness and (viii) diminished concentration. The symptom "suicidal ideation" is not part of this measure. In the current study, each symptom was scored as present if the chosen response was "slightly more than half the time", "most of the time", or "all the time". Previous studies using the MDI showed higher values of Cronbach's alpha of

0.89 [35] and 0.94 [20]. In the current study, the value of Cronbach's Alpha was 0.79 and the value of Lambda2 was 0.80.

Statistical analyses

Linear regression analyses were conducted for each individual depressive symptom as assessed by the MDI. This was done in order to test their associations with diabetes self-care behaviors. Since T1DM and T2DM have different etiology and management styles, we also ran separate regression analyses for each type of diabetes. Using a hierarchical approach, we adjusted our linear regression models for the following potentially confounding variables: sex, age, socioeconomic status (SES), type of diabetes and BMI. All analyses were conducted with SPSS version 16.0. *P*-values < 0.05 were considered as statistically significant.

Results

Demographic data

Table 1 shows the demographic characteristics of the sample. Of the 157 participants, 80 were females (51%). Mean age was 39±17 years, with ages ranging from 12 - 68 years. Of the total sample, 115 (73%) were adults. About 25% of the adults sample had secondary education. About 69% of the adolescents were school-going and the rest had not indicated their education level. Most of the adult subjects (80%) were married. Table 2 shows that a total of 93 subjects were classified as having T1DM (59%) in the medical charts and 58 had T2DM (37%). The type of diabetes for 6 patients could not be determined because the clinical record cards for these patients were not available at the time data was collected. In the total sample the mean body mass index (BMI) was 25±5 kg/m^2. The mean BMI was 22±4 kg/m^2 for adolescents and 27±5 kg/m^2 for adults. The BMI for males was 25±5 kg/m^2 and for females 26±5 kg/m^2.

Table 2: clinical characteristics of the participants (n =157)

Type of diabetes	n	%
Type 1	93/157	59
Type 2	58 /157	37
Missing	6 /157	4
BMI mean (SD)		25 (5) kg/m^2
Males		25 (5) kg/m^2
Females		26 (5) kg/m^2
Adolescents		22 (4) kg/m^2
Adults		27 (5) kg/m^2
SCI score		19.52±6.06
Min vs. Max		9 - 32
Table 2 continue		
MDI score		19.12±8.95

Self-care activities

	Self-care level		
	Below average	**Average**	**Above average**
1. Glucose testing	92 (60.5%)	17(11.2%)	43(28.3%)
2. Glucose recording	93(62%)	11(74%)	45(30.2%)
3. Ketone testing	99(79.8%)	6(4.8%)	19(15.3%)
4. Administering correct insulin dose	10(8.8%)	16(14.2%)	87(77%)
5. Administering insulin at right time	11(9.7%)	14(12.4%)	88(43.6%)
6. Adjusting insulin intake based on sugar…	43(39.1%)	19(17.3%)	48(43.6%)
7. Eating proper food; stick to meal plan	16(10.3%)	21 (13.5%)	119(76.3%)
8. Eat meals on time	28(18.2%)	26(16.9%)	100(64.9%)
9. Eating regular snacks	86(57%)	22(14.6%)	43(28.5%)
10. Carrying quick-acting sugar to treat…	83(56.1%)	21(14.2%)	44(29.7%)
11. Coming for appointments/review	10(6.5%)	13(8.4%)	132(85.2%)
12. Exercise regularly	48(31.4%)	26(17%)	79(51.6%)
13. Exercise strenuously*	103(70.5%)	10(6.8%)	33(22.6%)

Below average (“never do it” and “sometimes follow recommendations”), average (“ follow recommendations 50% of the time”), above average (“usually do as recommended; occasional lapses” and “ do as recommended without fail”), *better if below average.

Proportions of depression and self-care

Based on the cutoff of the measure, 74.6% of our patients had no to mild depression, 14.6% had moderate depression and 10.8% had severe depression. Table 2 shows that the most endorsed symptom of depression was *increased appetite* (53%), followed by *low in spirit or sad* (46%), *feeling restless* (39%), *lack of energy* (38%), *difficulties concentrating* (37%), *feeling subdued* (36%), *feeling life was not worth living* (34%), *feeling less confident* (32%), *loss of interest in daily activities, feeling guilty,* and *reduced appetite* each at 31%, and *trouble*

sleeping at 27%. The mean depression score was 19.94±8.95. A *t*-test analysis revealed that there was no statistical difference between adults and adolescents with diabetes on self-care scores (t = 0.21, df =155, p >.05). The majority of patients scored above the midpoint of the self-care scale (19.52±6.06). The majority of patients reported glucose testing (60.5%), glucose testing (62%), ketone testing (79.8%); eating regular snacks (57%) and carrying quick-acting sugar to treat reactions (56%) as major problems related to required self-care activities.

The association between depressive symptoms and diabetes self-care

Our results showed no association between total diabetes self-care and the composite score of the Major Depression Inventory (β = 0.080, p > 0.05). We then conducted 12 linear regression analyses to study the associations between diabetes self-care and the 12 individual depression symptoms of the MDI while controlling for demographic characteristics. Linear regression analyses showed a small, negative correlation between diabetes self-care and the symptoms "*low in spirit or sad*" (β = -0.226, p = < 0.05) and positive correlations with "*feeling life was not worth living*" (β = 0.235, p = < 0.05) and *"less self-confident"* (β = 0.201), p = < 0.05 (Table 3). These associations remained significant even after applying Bonferroni correction except for the symptom "feeling life was not worth living". There was no association between the 12 symptoms of depression and diabetes self-care in patients with T1DM. In patients with T2DM, only the symptom "having a bad conscience or feeling guilty" was positively and significantly associated with diabetes self-care.

We found that being younger (β = -0.239, p = <.05), being female (β = -.196, p = < .01), and type 2 diabetes (β = -0.211, p = <.01) were the demographic characteristics that were associated with poor self-care. Having high SES (β = 0.224, p = < .01) was associated with better self-care. BMI was not associated with self-care (β = 0.035, p = >.05).

Table 3: Standardized regression coefficients from 12 separate liner regression analyses for the association of each MDI items and diabetes self-care (n = 157).

	Model 1		model 2		model 3		model 4		model 5	
	B	*p*	β	*p*	β	*p*	β	*p*	β	*p*
MDI 1: low in spirit	-.226	*	-.164	ns	-.162	ns	-.146	ns	-.151	ns
MDI 2: lost interest	-.028	ns	.012	ns	.036	ns	.036	ns	.039	ns
MD1 3: lack of energy	-.133	ns	-.172	ns	-.144	ns	-.192	†	-.192	†
MDI 4: less self-confident	.201	ns	.177	ns	.178	ns	.137	ns	.137	ns
MDI 5: feeling guilt	-.053	ns	-.069	ns	-.086	ns	-.077	ns	-.078	ns
MDI 6: life no worth living	.235	*	.213	*	.188	*	.174	ns	.170	ns
MDI 7: diff. concentrating	-.044	ns	-.010	ns	.019	ns	.055	ns	.056	ns
MDI 8a: very restless	-.043	ns	.031	ns	.016	ns	.011	ns	.012	ns
MDI 8b: felt subdued	-.002	ns	.048	ns	.069	ns	.106	ns	.107	ns
MDI 9: trouble sleeping	-.068	ns	-.045	ns	.002	ns	.025	ns	.028	ns
MDI 10a: reduced appetite	.119	ns	.090	ns	.098	ns	.109	ns	.117	ns
MDI 10b: increased appetite	.142	ns	.126	ns	.110	ns	.112	ns	.120	ns
R^2 (Adj R^2)	.14 (.04)		.27 (.16)		.30 (.18)		.36 (.25)		.36 (.24)	

Model 1: unadjusted

Model 2: adjusted for sex, age

Model 3: adjusted for sex, age, SES

Model 4: adjusted for sex, age, SES, type of diabetes

Model 5: adjusted for sex, age, SES, type of diabetes, BMI

* = >.05, ns = non significant, † = marginally significance

Table 4: Standardized regression coefficients from 12 separate liner regression analyses for the association of each MDI items and diabetes self-care in type 1 diabetes patients.

	Model 1		model 2		model 3		model 4		model 5	
MDI1: low in spirit	13	ns	.09	ns	.10	ns	.11	ns	.11	ns
MDI2: lost interest	.06	ns	.02	ns	.02	ns	.02	ns	.01	ns
MDI3: lack of energy	.08	ns	.07	ns	.05	ns	.04	ns	.02	ns
MDI4: less self-confident	.06	ns	.04	ns	.03	ns	.04	ns	.04	ns
MDI5: feeling guilty	-.10	ns	-.09	ns	-.09	ns	-.08	ns	-.08	ns
MDI6: life not worth-living	.05	ns	.04	ns	.03	ns	.04	ns	.05	ns
MDI7: diff. concentrating	-.04	ns	-.05	ns	-.04	ns	-.07	ns	.-07	ns
MDI8a: very restless	.10	ns	.13	ns	.13	ns	.15	ns	.15	ns
MDI8b: felt subdued	.-.09	ns	-.11	ns	-.09	ns	-.09	ns	-.09	ns
MDI9: trouble sleeping	.11	ns	.13	ns	.14	ns	.11	ns	.10	ns
MDI10a: reduced appetite	-.20	ns	-.19	ns	-.19	ns	-.20	ns	-.21	ns
MDI10b: increased appetite	.06	ns	.09	ns	.10	ns	.12	ns	.11	ns
R^2 (adj R^2)	.11 (-.02)		.14 (-.01)		.14 (-.02)		.15 (-.02)		.15 (-.03)	

Model 1: unadjusted

Model 2: adjusted for sex

Model 3 adjusted for sex and age

Model 4: adjusted for sex, age and SES

Model 5: adjusted for sex, age, SES, and BMI

Table 5: Standardized regression coefficients from 12 separate liner regression analyses for the association of each MDI items and diabetes self-care in type 2 diabetes patients.

	Model 1		model 2		model 3		model 4		model 5	
MDI1: low in spirit	.17	ns	.18	ns	.16	ns	.16	ns	.13	ns
MDI2: lost interest	-.13	ns	-.20	ns	-.09	ns	-.17	ns	-.14	ns
MDI3: lack of energy	.08	ns	.05	ns	.10	ns	.09	ns	.07	ns
MDI4: less self-confident	.06	ns	.04	ns	.04	ns	.09	ns	.07	ns
MDI5: feeling guilty	.32	*	.32	*	.34	*	.36*		.35	*
MDI6: life not worth-living	-.23	ns	-.26	ns	-.24	ns	-.20	ns	-.22	ns
MDI7: difficult concentrating	-.02	ns	-.01	ns	-.01	ns	-.00	ns	-.01	ns
MDI8a: very restless	-.02	ns	-.00	ns	-.02	ns	-.04	ns	-.02	ns
MDI8b: felt subdued	-.15	ns	-.14	ns	-.16	ns	-.20	ns	-.18	ns
MDI9: trouble sleeping	-.02	ns	-.02	ns	-.01	ns	-.05	ns	-.03	ns
MDI 10a: reduced appetite	-.16	ns	-.16	ns	-.20	ns	-.18	ns	-.13	ns
MDI 10b: increased appetite	.22	ns	.20	ns	.22	ns	.15	ns	.20	ns
R^2 (adj R^2)	.28 (.09)		.29 (.08)		.20 (.07)		.38 (.15)		.38 (.14)	

Model 1: unadjusted

Model 2: adjusted for sex

Model 3 adjusted for sex and age

Model 4: adjusted for sex, age and SES

Model 5: adjusted for sex, age, SES, and BMI

Discussion

The aim of the present study was to explore the associations between individual depressive symptoms and diabetes self-care behaviors. Our initial results revealed that only two cognitive-affect symptoms and one somatic symptom of depression showed small associations with diabetes self-care even after Bonferroni correction except for the symptom "*feeling life was not worth living*". The size of these associations decreased after statistical adjustment for potential confounders. However, in one unadjusted model (i.e., not correcting for age, sex and SES) we found that the symptom "*feeling low in spirit or sad*" was associated with poor diabetes self-care, whereas "*feeling life was not worth living*" was associated with better diabetes self-care behaviors. The symptom "*feeling life was not worth living*" remained significant even after controlling for age, sex and SES but not significant after Bonferroni correction. The symptom "*lack of energy or strength*" was marginally associated with poor diabetes self-care only after controlling for confounding variables. Our results suggest that "*feeling sad*" and to a lesser extent "*lack of energy*" were linked with poor diabetes self-care behaviors. The association was observed for the former symptom only when considered with age, sex and SES of the patients. One explanation for these associations could be that these two depression symptoms interfere with memory, but perhaps also contribute to a lower motivation and decreased ability of a person to adhere to self-care activities. *Feeling low in spirit or sad* is a commonly (74%) used phrase to mean depression in Zambia [21]. Other symptoms such as "thinking too much" and "having a heavy heart" are cultural metaphors for fear and grief equivalent to those found in Zimbabwe [22-23].

The composite score and other individual depressive symptoms were not significantly associated with diabetes self-care. Interestingly, the ICD-10 requires any two of the following core symptoms to be present; "*depressed mood (dysphoria)", "loss of interest or pleasure*

(anhedonia)" and "*decreased energy"* in order to be considered a depressive episode. The two core symptoms of depression, as defined in the DSM-IV, are "*depressed mood*" and "*loss of interest or pleasure*" [24]. Our results showed that two of these ICD-10 core symptoms were associated with diabetes self-care, namely *"low spirit"* and "*lack of energy"*. To some extent our findings support those of Van Tilburg *et al* who reported that variations in depressive mood were associated with differences in glycemic control (a critical outcome of self-care) among patients with type 1 diabetes [25]. This study, like ours, addressed the association between depressive mood and self-care although van Tilburg *et al* only focused on glycemic control, a critical outcome of self-care. Moreover, depressive mood disorders have been found to be higher in individuals with diabetes relative to those without diabetes, according to the World Mental Health Survey among community samples of adults across 17 countries including: Europe, the Americas, the Middle East, Africa, Asia and the South Pacific [26].

The symptom "*increased appetite"* was the most endorsed item of the depression scale. Interestingly, polyphagia (to eat more) is common in patients with type 1 diabetes and is often caused by hypoglycemia and severe depression or stress [27]. However, this was not the case with our findings. In short-term human intervention studies, ingestion of high glycemic index (GI) foods increased hunger and lowered satiety. Literature shows that the consumption of high GI meals induces a sequence of hormonal and metabolic changes that promote excessive food intake [28]. As such, increased hunger and food intake is an attempt to restore energy homeostasis which could explain why the majority of patients endorsed increased appetite.

The findings of this study may explain the importance of using individual depressive symptoms rather than depression composite scores when measuring diabetes constructs such as self-care. By using composite scores we may miss important information about differential links between

individual depressive symptoms and diabetes self-care. Thus, the association between depressive symptoms and self-care should not be restricted to the composite score. In our study the composite score was not significantly associated with self-care. In the Sub-Saharan African context, the conceptualization of depression and what it means is still unclear perhaps due to linguistic and psychological equivalence limitations (there is no word for "depression" in most Zambian languages, it is often expressed in a sentence; equivalent words are anxiety and fear). For instance, a study involving qualitative interviews among 139 women from a low income compound in Zambia identified symptoms of depression to include headache, unhappiness, disturbed sleeping patterns (problems of the mind), problems in making ends meet (worries and poverty), feeling of fragility and instability (mood swings), various supernatural causes, either bad fortune or because they thought they might be victims of an evil spell (Satan, God's work) and high blood pressure (a symptom commonly said to have been caused by poverty, worries and problems of the mind) [21]. Like most other Sub-Saharan African countries, multiple somatic rather than cognitive and emotional complaints (symptoms), such as headaches and fatigue (related to the heart and head), are the main presentation of depression [22]. Therefore, it is important to understand culture-specific terminologies used by patients to mean depression especially that most Sub-Saharan African countries including Zambia have no direct equivalent term for depression but anxiety [22]. Until the conceptualization of depression is clear, focusing on individual symptoms and their relationship with self-care may prove to be important rather than the association with depression composite scores.

Like other studies, our participants' age, gender, SES and type of diabetes were significantly associated with self-care, moreover these background variables seem to moderate the relationship between depressive symptoms and self-care behaviors [29]. Being young was negatively associated with self-care. We speculate that being young was negatively associated

with self-care because young people often experience conflict of priorities that negatively affect their self-care behaviors. Young people often forget to adhere to their regimen because they engage in many competing activities, feel embarrassed in the presence of their peers and are less inclined to engage in self-care behaviors compared to adults. These results must be interpreted with caution because other studies suggest that older people have elevated depression which may interfere with their diabetes self-care behaviors compared to young ones [30]. Being female was negatively associated with self-care. Females are more likely to be depressed than men [3]. Moreover, we did find that female patients had higher depression scores than men in the current study, which is in line with results from the literature. We speculate that because women are more depressed then male patients and have more responsibilities (managing homes) than men, their self-care was sub-optimal. We also found that high socio-economic status was positively associated with self-care. Although socio-economic status is a proxy for a wide variety of factors, these results could suggest that individuals with high SES have readily available money to buy healthy food, required medication and engage in social activities that do not side track them from self-care activities compared to patients with low SES. Having T2DM was also associated with problems with self-care.

The strength of the present study is that we used individual items of the MDI, which are based on the DSM-IV and the ICD-10 symptoms of major depression [20]. Limitations of the study are that we do not know the refusal rate, therefore there might have been a selection-bias but is it difficult to estimate how big this selection bias was. The sample size was also small due to recruitment difficulties; as a consequence, probability sampling could not be used. Due to the limited sample size, we could not analyze our data separately for adolescents and adults, which could have led to a better insight into possible differences between the groups.

Interpretation of these results should be done with caution mainly because of the small sample size and the statistical analyses at item level, even when applying a Bonferroni correction. In addition, we were unable to screen for other illnesses, such as HIV, which could have a confounding effect on our results. Finally, we cannot rule out a possible overestimation of self-care activities and underestimation of depressive episodes by our respondents due to social desirability often found in self-report measures. Moreover, the self-care inventory and the major depression inventory have no norms, yet still the former was not validated for the Zambian sample. However, in its form the SCI had items that were tapping into common self-care activities except for one which was dropped "wearing a medic alert ID" because no subjects who participated in the study had any. This measure can be made more robust by adding items like "receiving reminders from family/friends to take medication" and "accessing medical essentials e.g. syringes".

Conclusions

Although it was initially hypothesized that depression was associated with diabetes self-care, much of the variance seems to be explained by demographic characteristics specifically gender, age and SES. Therefore, clinicians need to screen and treat individual depressive symptoms in patients with diabetes, especially in women, young people and patients from low SES. Given the lack of manpower in cognitive behavioral therapy (CBT) in Zambian hospitals, in the meantime we recommend the use of anti-depressants in treating depression which have not only been found to be effective in treating depression [31-33], but are free and readily available in Zambian major hospitals. Specifically, if drugs are to be prescribed, we recommend the use of fluoxetine anti-depressants which have been found to be associated with improved glycemic control [35]. Not only is depression management meaningful from the perspective of a patient's quality of life, it may also appear to have beneficial implications for patients' ability to achieve

and maintain diabetes self-care goals [31]. In addition to depression treatment, patients with diabetes ought to be helped to optimize self-care by enhancing self-efficacy, healthy eating, physical activities, monitoring of blood sugar, and compliance to medication, good problem solving skills, healthy coping skills and risk reduction behaviors [13]. Therefore, interventions should simultaneously address depression symptoms and self-care skills to achieve optimal diabetes outcomes. Future studies should aim to identify Zambian symptoms of depression based on a large representative sample and examine their association with diabetes self-care.

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Part 3

Thesis Integration: Discussion and Conclusion

Chapter 7

General Discussion and Conclusion

Introduction

This thesis examined psychosocial functioning in individuals with diabetes mellitus and also how psychosocial issues are associated with emotional wellbeing of patients in Sub-Saharan Africa (SSA), notably Zambia. The main goal was to understand diabetes in SSA and Zambia and also to identify psychosocial issues surrounding diabetes and how they relate with each other. To achieve this goal, the thesis addressed two themes: (1.) understanding the emotional factors associated with diabetes in Sub-Saharan Africa and/or Zambia (this is described in part one of the thesis) and (2.) psychosocial functioning in people with diabetes in Zambia in part two of the thesis. The following questions were addressed:

1. What is the prevalence of diabetes in children in SSA, what are the consequences and risk factors for diabetes and what does diabetes care look like in SSA?
2. What are the sources of stress, the ways of coping with stress, the perceived quality of care and the quality of life as experienced by Zambian adolescents living with type 1 diabetes?
3. Does the Zambian version of the Problem Areas in Diabetes (PAID) have sound psychometric properties and what are the levels of diabetes-specific emotional distress in people with diabetes in Zambia?
4. How common is co-morbid depression in individuals with diabetes in Zambia?
5. What is the association between symptoms of depression with diabetes self-care in individuals with diabetes?

Although scientific evidence should guide and inform health care providers, policy makers and more importantly people with diabetes, published data on diabetes mellitus in Africa remain scarce [1]. Therefore, part 1 of the thesis aimed to increase our understanding of the prevalence and consequences of diabetes in SSA and Zambia by summarizing the literature. The first

questions addressed under this part were: What is the prevalence of diabetes in children? What are the consequences and risk factors for diabetes and what is the quality of diabetes care in SSA? This question was addressed in chapter 2 of the thesis using a narrative review of the literature on diabetes. This literature review revealed that many incidence studies have excluded children, due to lack of comprehensive statistics on children. A few studies suggested that the prevalence of diabetes in general is on the increase in the region. The causes of diabetes were similar with other regions but the peak age for the onset of diabetes and consequences of diabetes seemed to differ from other regions. Given that there were little data on diabetes in children and adolescents, particularly data relating to psychosocial issues affecting young people with diabetes in SSA, chapter 3 addressed the question: What are the sources of stress, ways of coping with stress, perceived quality of care and quality of life as experienced by Zambian adolescents living with type 1 diabetes mellitus (T1DM) from the viewpoints of the adolescents themselves, their caregivers and their health care providers? A qualitative design was used to address these questions. Results using thematic content analysis suggested that stress was common among adolescents with diabetes and their immediate family members. Various coping strategies were employed although some strategies were maladaptive such as avoiding injecting themselves with insulin. Quality of life and diabetes health care were suboptimal. The results of this study suggested that psychosocial issues affecting patients worldwide also affect patients in Zambia. Socioeconomic issues, such as poor health care and non-availability of medical essentials and other psychosocial issues, such as restricted lifestyle choices, should be incorporated in treatment models.

Part 2 of the present thesis aimed at examining psychosocial functioning in people with diabetes in Zambia. This part of the thesis was necessary because little is known about psychosocial issues associated with diabetes mellitus in the Zambian context. One of the

reasons for the lack of information on psychosocial functioning and dynamics in individual with diabetes is a dearth of good, validated measurement tools. Therefore, the third question of the thesis addressed in chapter 4 was: Does the Zambian version of the Problem Areas in Diabetes (PAID) have sound psychometric properties and what are the levels of diabetes-specific emotional distress in people with diabetes in Zambia? Using Exploratory Factor Analysis, results revealed that a one factor model was suitable for the Zambian version of the PAID, consistent with other validation studies done elsewhere [2-4] but not with others [46-49]. Cognitive interviews on the content of the PAID items showed that participants were able to comprehend the questions but some participants faced some challenges with the meaning of some words such as "anxious" and "physician". Diabetes-specific emotional problems were common in individuals with diabetes. These results suggest that the PAID is a good measure that clinicians and researchers in the area of diabetes can use. Given that diabetes-specific emotional problems are common in individuals with diabetes, there is need for a combined effort by different stakeholders to implement intervention programs aimed at reducing diabetes-specific distress in individuals with diabetes in Zambia.

According to the World Health Organization, depression is one of the major leading causes of disability in the world [5]. In people with diabetes, depression increases risk of poor glycemic control, the development of diabetes complications, low adherence to treatment, poor quality of life, higher health-care utilization and cost, loss of productivity, increased disability and increased mortality rates [6-7]. Given the documented consequences of diabetes and co-morbid depression, chapter 5 addressed the question: how common is co-morbid depression in individuals with diabetes in Zambia? The study results revealed that, although a global WHO study showed that the odds of depression were not increased in African people with diabetes [6], our study found that depression was more common in individuals with diabetes compared

to healthy controls. Our findings are in line with other studies that demonstrate that depression is common in individual with diabetes [8-9] and there is need to diagnose and treat depression in people with diabetes.

There is evidence that depression relates with negative self-care behaviors, such as infrequent fruit and vegetable intake, frequent saturated fat intake, more sedentary lifestyle and fewer exercise sessions per week than non-depressive diabetes people [10]. This research and the previous study support the thesis that depression is common in people with diabetes. Chapter 6 addressed the question: what is the association between symptoms of depression and diabetes self-care behaviors in individuals with diabetes? The results revealed that depression was indeed associated with less optimal diabetes self-care behaviors, yet most of the variance in self-care was explained by socio-demographic characteristics and having type 2 diabetes. These results suggest that depressive symptoms may exacerbate poor diabetes self-care in people with diabetes especially when patients are young, female, poor and have type 2 diabetes.

Different Perspectives and Their Integration

There seems to be a sharp increase in the prevalence of diabetes. In the 1990s, diabetes was seen as a rare medical condition in Africa [11]. The recent International Diabetes Federation atlas estimated that about 22 million people in SSA are living with diabetes [12]. Although the prevalence of diabetes is increasing in SSA, the prevalence rate of 5.1% is still lower compared to 9.7% in the Middle East and North Africa, 7.9% in Europe, 8.3% South-East Asia, Western Pacific 8.5%, North America and Caribbean 11.4% and South America 8.1% [12]. These differences may be due to poor diabetes case record keeping and misdiagnosis (undiagnosed diabetes cases are estimated at 13 million plus in SSA) [12]. In addition, some persons who develop T1DM and live in rural areas of SSA never get insulin therefore they may die before

their conditions are registered. As a result, the prevalence rate may seem lower than in other regions.

The fact that research on diabetes in SSA is relatively scarce compared to developed countries, probably has negative effects for the people with diabetes in SSA, because many policy makers and clinicians still think diabetes is a rare disease and misunderstand its clinical characteristics. As of 2010, there were only 84 published studies on diabetes in SSA [13]. Most of these studies were epidemiological in design and may not have had a complete picture of the extent of diabetes prevalence because most cases of diabetes remain undiagnosed. Studies on children with diabetes especially with T1DM are almost not available and there are claims that there is evidence of T2DM in overweight African children. There is a sharp difference between SSA and Western countries in terms of availability of data on the prevalence, incidence of diabetes and psychosocial challenges that are faced by people with diabetes. There are three main reasons for these differences: 1. Sub-Saharan African countries face a large burden of communicable diseases such as malaria and HIV/AIDS, consequently both the international community and local stakeholders including researchers have focused their attention on the communicable conditions at the expense of non-communicable ones such as diabetes. 2. SSA is characterized by a lack of resources that are essential in the process of identification and treatment of diabetes. 3. Policy guidelines on diabetes are either weak or nonexistent in most SSA countries. In addition, Africa is now just experiencing a demographic transition. Due to changes in lifestyle, people are becoming more sedentary, having a higher access to refined food, so the threat or burden of diseases like diabetes is really now emerging as a serious problem while in the past this was less of an issue.These factors among others are probably the main drivers of the current status on what is currently known about diabetes in SSA.

There seem to be interethnic differences in the onset of diabetes and diabetes-related complications. Generally, the peak age of diabetes onset in African patients seems to be delayed compared to other ethnic groups. For instance, a study in South Africa demonstrated that the peak age of the onset for type 1 diabetes in Africans was at 22-23 years with early peak between the age 14-17 years later than white counterparts whose peak age was between 12 and 13 years [14]. Environmental factors and social determinants could explain the variations for diabetes onset across different ethnic groups (see Appendix 1). Comorbidity such as depression [6-7] is common in diabetes patients. However, compared with developed nations, African people with diabetes also tend to be infected with illness such as malaria and HIV and AIDS [15-17]. Diabetes is often misdiagnosed as HIV and malaria [18]. Lack of diagnostic tools and trained health care providers are the factors behind misdiagnosis of diabetes in SSA. Another observation is that life expectancy in SSA children with diabetes is shorter compared to other regions of the world. On average, a child with diabetes only lives as short as 5 years and sometimes 1 year depending on the region [19-20], meaning quality of life is lower and life expectancy is shorter in children with diabetes compared to healthy children in SSA. Again, lack of resources, medical essentials and lack of proper skills among health care providers could explain this disparity with the west.

Stress in adolescents in Zambia often stems from lack of physical and social support systems. Access to health facilities and medical commodities are the number one source of stress in the young people with diabetes and their families. It seems as if some of the adolescents do not to have necessary social support from their communities and families. Consequently, many adolescents living with diabetes in Zambia face numerous hurdles. The situation is made even more difficult because some adolescents with diabetes appear to use maladaptive coping strategies. Coping with stress is needed to achieve or maintain a healthy mental and physical

wellbeing of the adolescent with diabetes. Yet, mental health services to help adolescents develop adaptive coping strategies were either weak or nonexistent. It was interesting to note that stigma in people with diabetes is perpetuated by different mediums and the cause of stigma seemed to differ across cultures. In Australia, stigma was found to be perpetuated by media, friends, health care professionals and teachers who often had a notion that diabetes was a self-inflicted condition and stigmatization often took the form of negative social judgments and exclusions from activities [21]. In Iran, persons with T1D were reported to be stigmatized as miserable humans, rejected marriage candidates and were deprived of a normal life because they were equated to disabled people who could not enjoy life [22]. In Zambia it was negative social judgment and exclusion from activities like in Iran because it was believed diabetes was a contagious disease and that it negatively affected the reproductive system of female patients [44]. While in Australia it is seen as a self-inflicted disease carrying a negative connotation, in Zambia, type 2 diabetes is perceived as a disease for the rich "opulence" and a disease that separates the rich from the poor.

Worrying about diabetes, treatment barriers, diabetes symptoms, poor communication and family burden seem to be the major factors that contribute to a poor Quality of Life (QoL) children with diabetes elsewhere [23]. Our study showed similar findings; additionally, limited sense of independence and low social participation were the main issues that seemed to affect QoL in the adolescents. These topics (sense of independence and social participation) are developmental issues that are extra important for adolescents.

Interestingly, contrary to the earlier global WHO study which showed that the odds of depression were not increased in African people with diabetes [6], we found that depression and diabetes specific emotional distress were common in people with diabetes in Zambia.

Social and cultural factors could explain the prevalence of depression. People with depression, as explained in Chapter 3, are often stigmatized and face a lot of financial burdens associated with diabetes management. Cultural variations in the conceptualization of depression and differences in measurement tools (questionnaire vs. diagnostic interviews) may further explain why the WHO study did not find increased odds of depression in people with diabetes in Africa. Furthermore, the WHO study did not use data from Zambia. In addition, it was interesting and clinically relevant to learn that two depressive symptoms were associated with less optimal diabetes self-care although much of the variance was explained by socio-demographic characteristics of the participants. There are two implications for these results: (1.) depression symptoms may have a stronger association with self-care behaviors in females and type 2 diabetes people. (2.) It is important to critically assess the reliability and validity of depression measures in different groups of people with diabetes and across cultures and nations for the screening of diabetes to be effective in Africa. More importantly, indigenous measures especially diagnostic interviews must be developed for proper assessment of depression.

Potential Pathways that Link Emotional Stress and Diabetes Mellitus

Emotional stress was a dominant variable throughout this thesis. Therefore, a description of the potential pathways that link emotional stress and diabetes mellitus is warranted. The literature suggests behavioral and bio-physiological mechanisms as the two main pathways that explain the link between emotional stresses especially depression and the development of diabetes mellitus [24]. Below is a review of such studies.

Behavioral pathway that links stress, the development of diabetes and diabetes outcomes

The associations between emotional stress, the development of type 2 diabetes and diabetes outcomes are complex. The onset of diabetes itself, the strict diabetes self-care regime, the

challenging diabetes self-care activities and the development of hypoglycemic events or the long-term complications of diabetes can be sources of stress. Different emotional reactions especially depression and anxiety have been associated with unhealthy lifestyle and poor self-care behaviors in the general population [25, 26] but also in people with diabetes [27]. Unhealthy lifestyle behaviors, such as eating excess calories, low exercise, smoking and alcohol abuse, are all leading risk factors for the development of type 2 diabetes [24]. Not only does emotional stress, particularly depression, lead to the risk of developing diabetes, but also impair a range of self-care activities such as adherence to the prescribed treatment (testing blood glucose levels, adjusting insulin, physical inactivity and/or poor dieting) [28]. All these poor self-care factors may exacerbate the risk of developing poor glycemic control and diabetes complications.

Bio-Physiological Pathway

Chronic stress is an important risk factor for depression. Both chronic stress and depression are related to a number of bio-physiological changes that may lead to increased risk of developing type 2 diabetes or complications of diabetes. Studies have demonstrated that chronic stress and depression are often characterized by long term activation of the hypothalamic-pituitary-adrenal axis and the sympathetic nervous system, all related to the development of abdominal obesity [24]. Therefore, it appears that depression moderates this relationship and may explain why depression or chronic stress increase the risk of developing type 2 diabetes [29]. Another potential pathway in which biological mechanisms may predispose depression towards the development of diabetes involves HPA-axis hyperactivity and sympathetic nervous system (SNS) activation. Specifically, depression has been associated with HPA-axis hyperactivity and enhanced SNS activity resulting in excessive cortisol exposure, catecholamines and interleukin-6, all biological reactions that bring about insulin resistance [30]. In addition, the

HPA axis, SNS and inflammatory responses are connected such that activation of the HPA axis results in simultaneous activation of SNS. Then SNS activation stimulates releases of interleukin (IL)-6, activating the inflammatory cascade and increasing cytokine release [30]. As a result, these integrated biological systems can enhance insulin resistance which leads to the development of type 2 diabetes or worsening of glycemic and metabolic outcomes in individuals with already established diabetes. The above mentioned pathway is illustrated graphically in Appendix 2.

There is also evidence that inflammatory mechanisms are involved in depression [31]. The rise in the concentration of cytokins and glucocorticids particularly cortisol, in response to chronic stress and depression contribute to behavioral changes associated with depression [24, 31]. A meta-analysis has shown that depression is related to increased levels of pro-inflammatory markers [32]. Inflammatory processes may be common antecedents of stress vulnerability, depression and type 2 diabetes, which can develop in parallel or in succession [24]. In another study, inflammatory processes were shown to play a role in the development of type 2 diabetes [45].

Although the above outlined potential pathways indicate the association between psychophysiological factors and diabetes, little is known about the mechanisms by which psychological issues such as depression and chronic stress increase the risk of the development of type 2 diabetes. In addition little is known on the intricate relationship between the aforementioned psychosocial or bio-physiological factors and the risk of developing type 1 diabetes.

Psychosocial perspective on diabetes in Zambia

To be able to address psychosocial issues affecting Zambian patients with diabetes, treatment must be first made available and patients should be screened for depression and other psychological issues and then document different information relating to diabetes. One of the biggest challenges of managing diabetes in Zambia and in SSA in general, is lack of a good surveillance system that feeds into the national health system to provide trends and to measure exposure (e.g. risks factors and social determinants), outcomes (e.g., morbidity and mortality), and health system capacity and response to diabetes management and care [51]. Providing data on trends and exposure will probably not only improve treatment and prevention of such cases but also help allocation of resources to high prevalent trends and exposures. It is also important for clinicians to begin to educate patients on not only physical complications of diabetes, but also psychosocial complications associated with diabetes. Health care providers, the diabetes association, health policy makers and perhaps also the pharmaceutical industry should join forces to empower the people with diabetes and their family with more knowledge about diabetes management, and make sure that they have the self-care tools they need. The studies in this thesis have shown high a incidence of psychosocial problems associated with diabetes such as stress, depression, stigma and discrimination, family support, access to essential commodities and resources to meet certain demands of diabetes such as food. It is expected that these psychosocial problems will increase and even complicate diabetes screening, treatment and care in Zambia especially with the rapid urbanization which will have impact on prevention, management and treatment of diabetes especially among the poor and slum dwellers. Urban growth rate in Zambia was 4.2% in the 2000-2010 census from 1.5% in 1990-2000 period [55]. With this increase, diabetes inequities will rise due to comorbidities associated with an aging population and other environmental agents such as viruses that may play a role in the development of T1DM, the proliferation of slums and poverty which

accompany urbanization [51]. Moreover Sub Saharan African consumers are increasingly aspiring for fast food choices and Zambia is among the top fast food establishment destination [52]. Consequently, urbanization and its consequences on diabetes may increase the risk of stress and depression which will exacerbate diabetes care. The development of stress and depression associated with urbanization may also led to the development of diabetes. The circle is a vicious one which may also led to other psychosocial problems such as increase in treatment cost, discrimination, and poor quality of life among others.

Psychological needs are often attended to if immediate physiological needs are met. I propose the application of Maslow's hierarchy of need theory to some of the psychosocial problems affecting patients with diabetes in Zambia. The application of Maslow's theory is useful in this case because a robust health system firstly has to focus on prevention and medical treatment of diabetes and its complications and then on the negative psychosocial factors affecting people with diabetes [53]. Most psychosocial issues are as result of challenges meeting basic needs. Lack of insulin for example may be worrisome for patients which may contribute to stress and other psychosocial problems. The theory argues that basic needs are to be met for the satisfaction of higher needs to be sought [54].

Physiological needs

Physiological needs are the physical requirements for human survival. If these requirements are not met, the human body cannot function properly and will ultimately fail [54]. Physiological needs are thought to be the most important; they should be met first. In relation to type 1 diabetes, insulin, proper diet and food, absence of other potentially life threatening illness such as HIV and AIDS and resources to meet basic requirements are important physiological needs. For type 2 diabetes, in addition to a proper and healthy diet, absence of

life threatening disease such as cardiovascular disease, access to health facilities, patients need education that aids survival [53]. For both type 1 and 2 diabetes policies that support provision of care and access to insulin and oral medication, and blood glucose measures in case of insulin treatment are useful, this can be accomplished with government subsidies, for example and help from international organizations such as International Diabetes Federation, International Insulin Federation and the World Health Organization [53]. In Zambia, this remains a formidable task for patients, policy makers and clinicians. As discussed in chapter 1 and 3, most patients still cannot afford physical requirements needed to survive with diabetes. It's either patients cannot afford to buy essential medical commodities such as insulin for type 1 diabetes patients or cannot afford a proper diet recommended for diabetes patients especially among type 2 diabetes patients. Moreover in Chapter 4, 40% of participants reported feeling deprived of food and meals. Access to medical facilities that can diagnose and manage diabetes is still a big challenge given that only big hospitals have specialized manpower to handle such disorders. This adds pressure to an already strained family on transport costs to such facilities. Coupled with the above challenges this leads to increased risks of misdiagnoses and late detection of diabetes. It is not surprising why the life expectancy of diabetes patients in Zambia is low (11.2 years for those aged 0-14 years and 16.7 years for those aged 15 years and above) [18].

Safety needs

If physical needs are relatively satisfied, the individual seeks safety needs at the individual, family or community level which often dominate behavior. For patients with diabetes safety and security needs should cover personal security, financial security, health and well-being security to able to satisfy safety needs. For individuals with type 1 and 2 diabetes (those who use insulin) this means they must engage constantly in testing their blood glucose levels and

seeking helpful diabetes related information that can increase their safety. According to Beran information and education on diabetes can be a source of safety and can protect patients from potentially life threatening consequences of diabetes [53]. In addition, particularly for type 2 diabetes, proper diet and exercising are protective factors. At the family and community level, interest must be developed by family members, peers and schools teachers for example to identify signs of hyperglycemia and hypoglycemia in order to help patients when they encounter such episodes. In Zambia, there is need to improve safety needs of patients' especially through education to patients and family members. It was dreadful for example to learn that family members gave life threatening advice to young people with diabetes to stop injecting themselves with insulin and evidence that some adolescents engaged in maladaptive strategies of coping such as avoiding injecting themselves with insulin.

Belonging needs

After physiological and safety needs are fulfilled, the third level of human needs is interpersonal and involves feelings of belongingness. In terms of diabetes care and management, a conducive working relationship between a health care provider and a patients is a very important need. Patients need to few valued and cared for not only by health care providers but also by family members, peers, spouses, classmates and so on. Patients everyday experiences should make them feel they belong to a caring and loving family or community, free of discrimination and stigma. If patients feel they have adapted and are part of the wider community they will also be open about their condition adding even more support from peers and community members [53]. Moreover, many patients are susceptible to social anxiety, stress, and depression. Therefore, a strong sense of belonging can be a buffer to such psychosocial experiences. In Zambia, sensitization and education programs on diabetes for patients and also family members will be required in order to increase not only the sense of

belonging of diabetes patients but also a fast track to help improve their self-esteem needs. In Chapter 3, stigmatization and discrimination were found to be common among people with diabetes. Peers discriminated their friends with diabetes because they felt diabetes was a contagious disease and society had belief that diabetes patients were not reproductively fit and had low status value in romantic relationship especially among girls; all these factors have potential to decrease a sense of belonging of a person. Moreover, in Chapter 4, 48% of patients reported that they felt friends or family members were not supportive of their diabetes management efforts. 37% reported experiencing uncomfortable interactions around diabetes with family or friends and 40% felt alone with diabetes. 41% felt they were not satisfied with their diabetes physician suggesting they had bad experiences in their relationship with their health care providers.

Self-esteem needs

Once a person's belonging needs are met, a person strives to meet self-esteem needs. Human beings have a need for self-respect, need to be accepted and to be valued by others. From the diabetes perspective, people with diabetes need to feel accepted and valued by others, despite their condition. Patients with diabetes also need high self-efficacy, motivation and self-confidence especially to manage their diabetes. Meeting this need is often challenging especially to children and adolescents. Psychological imbalance such as discrimination, depression and denial (not accepting diagnosis of diabetes) can be a bottleneck for a person to obtain high levels of self-respect and esteem. Deprivation of these self-esteem needs may lead to an inferiority complex, weakness, and helplessness which in turn may affect diabetes care. In general, in Zambian patients, there is need to improve self-esteem. For instance 58% of participants in Chapter 4 reported feeling guilty when they got off track with their diabetes management. In addition, in Chapter 3, most young patients reported limited sense of

independence due to strict monitoring from parents or guardians. It is also likely that many patients' self-esteem was dampened following stigma and discrimination they faced due to their diabetes. As alluded to earlier, psychological imbalances such as depression, stress and diabetes specific distress, all found to be common among patients with diabetes in this thesis can hinder a person from obtaining a higher level of self-esteem or self-respect.

Self-Actualization need

This level of need is the highest in the hierarchy and refers to what a person's full potential is and the realization of that potential. According to Beran the person that describes "diabetes as something positive" do this in that they not only accept their intrinsic situation, but also help others and in some cases push the limits in terms of achievements (e.g. athletics) to a level that most cannot achieve [53]. This level is best summarized by Abraham Maslow's' own word "what a man can be, he must be" [54]. Zambian patients must be molded into feeling that they can be the person that they want to be, and achieve whatever they want to achieve. Doubts in adaption in future roles e.g. work and romantic relationships reported in chapter 3 must be spelt out through education and providing role models who have diabetes and have made high achievement in life. Winnie Mandela, Tom Hanks, Randy Jackson, Larry King and Halle Berry all have type 2 diabetes. Jack Cultler, a Chicago Bears quarterback, and the Singer Nick Jonas have type 1 diabetes. The actress, Salma Heyek, had gestational diabetes. Models like these can help push young people with diabetes to achieve their self-actualization needs.

Methodological Considerations

The studies presented in this thesis have several strengths and limitations. This section reviews and discusses some of the limitations that run through the studies presented in this thesis.

Study Designs

The studies included in this thesis were a narrative literature review (chapter 2), a qualitative study (chapter 3) and cross-sectional studies (chapter 4-6). Triangulating different designs enhanced the validity and credibility of the findings by comparing information obtained from different data collection methods; document reviews, interviews and cross-sectional data (questionnaires). Document review and interviews enabled collection of vast and rich information which would have not been possible using questionnaires. Cross-sectional designs are especially useful when testing different age groups, gender groups and type of diabetes as was the case with the studies described in this thesis. This enabled the thesis to obtain a wealth of information on group differences across age, sex, diabetes type and SES groups. However, the results of the cross-sectional data presented in the thesis should be interpreted with caution because of the small sample size used across the studies and the item-level (detailed) analyses, which would require cross-validation. The nature of the designs in this thesis does not allow to draw causal inferences from our studies. Randomized control designs can give more insight into the cause and effect of the variables covered in the studies. In addition, observational data such as those covered in the thesis involving mostly cross-sectional studies are likely to be confounded by other variables. Although potential confounders were controlled in the analyses, other confounders, such as duration of diabetes, self-efficacy of a patient, HbA_{1c} levels and other biological markers, were not taken into account. Further, data on participation refusal rate were not available. As a result, it is not possible to estimate to what extent selection bias may have occurred. Persons who refuse to participate in a study may have important information that could not have been obtained from others. Participation refusal and non-response may increase uncertainty about the results and threaten the generalizability of the results especially that the sample size was very small in all the studies due to difficulties in accessing patients with diabetes.

Measurement

The tools of data collection used in this thesis were interviews and self-report measures. The use of mixed methods in this thesis strengthened the validity of findings and recommendations, as a mixed methods approach is useful to broaden and deepen our understanding of psychosocial processes involved in diabetes mellitus. However, both techniques may suffer from bias resulting from social desirability which can increase measurement error. Social desirability occurs when participants aim to answer questions in a manner that will be viewed favorably by others. It can result in over-reporting "good behavior" and under-reporting "bad" or undesirable behavior. Further, physiological measures of diabetes such as HbA_{1c} levels were not used in the current studies because such data were not accessible at the time of data collection due to ethical and resource restrictions. Combining self-report and physiological measures can give more accuracy in the measured attributes. In addition, although these measures were validated, there were no established norms to be used as a benchmark for comparison with other studies in the same area.

Assessment of our key variables

The main psychological constructs that were used in this thesis were stress, diabetes-specific distress, self-care and depression. These terms were used in a general manner. For instance, the meaning of depression included depressive episode, depressive disorder and depressive symptoms. In addition, we only used self-report measures instead of diagnostic interviews seen as a gold standard for assessing depression. Evidence suggests that these two ways of assessing depression can produce different results. For example, 70% of diabetes patients with elevated self-reported depressive symptom scores do not meet diagnostic criteria for major depression disorder on the basis of a structured clinical interview [33]. The implication for this limitation is that bias towards underreporting as well as stronger agreement associated with self-report

measures could have threatened the validity of the study results. To improve on the validity of the study results, participants were: 1.) Instructed to be as honest as they could when answering items on scales; 2.) Items on scales were both positively and negatively worded to counter response set; 3.) Standardized measures with a strong reliability index were used to collect data.

Practical and Clinical Implications

This thesis provides results that have several implications for research and clinical practice. The studies presented in the thesis demonstrate an intricate relationship between psychosocial factors and diabetes mellitus. Psychosocial issues have been documented to affect quality of life in people with diabetes and the potential benefits of including skilled psychosocial support services in the multidisciplinary program of diabetes care have been suggested [34]. Thus, identification and treatment of psychological issues affecting people with diabetes seem warranted in order to improve the quality of life and outcomes of these patients.

Identifying emotional problems in patients

Chapter 3 through chapter 5 identified several psychosocial issues affecting people with diabetes. Among them were adaptation problems vis-à-vis managing diabetes, worrying about the future especially regarding adjusting in adult roles, such as job demands and finding romantic partners, worrying about low sugar reactions, worrying about the future and possible health complications, getting anxious when they got off track with diabetes management and feeling that diabetes was taking up too much of the mental and physical energy. Consequently, there is need to identify emotional problems that affect people with diabetes using reliable and valid measures. Chapter 4 and 5 demonstrated that the PAID and MDI were reliable measures. Therefore, physicians, diabetes nurse specialists, psychologists and other health care

practitioners can use the PAID and MDI to assess diabetes-specific distress and depression in Zambia. These measures may be useful especially that evidence shows that only 25% of emotional stress is identified in clinical practice among people with diabetes [35]. Moreover, the America Diabetes Association global guidelines for T2DM recommend that an assessment of the patient's psychological and social situation should be included as an ongoing part of the medical management of diabetes [36].

Identifying psychosocial problems affecting people with diabetes require clinicians and other health care practitioners to be able to recognize such problems and attend to them. There is need to educate health care providers on recognizing and detecting psychosocial issues such as depression and emotional stress [37]. The effectiveness of educating healthcare providers to recognize depression for example was tested in a randomized trial and it was found that education was well received by participants (healthcare providers), 80% of whom thought it would change their management of patients with depression [48].

Treatment of diabetes-specific stress and depression

There is evidence that Cognitive Behavioral Therapy (CBT) and antidepressants are effective in reducing levels of depression in people with diabetes [39-40]. After reviewing four published and completed randomized controlled trails testing psychosocial therapy for depression in diabetes, two controlled pilot studies of group CBT and two unpublished RCTS on CBT and additionally five systematic reviews/meta-analyses assessing the effectiveness of psychosocial treatment of depression in diabetes, the conclusion was that psychosocial interventions, particularly CBT, are effective in improving depression in patients with diabetes [40]. Additionally, results showed that psychosocial interventions were effective when used in combination with pharmacotherapy. Another review involving 17 studies, six employing

psychosocial interventions, eight pharmacological studies and three collaborative care interventions, concluded that CBT and antidepressants (including serotonin re-uptake inhibitors–SSRIs, nortryptyline and buproprion) examined separately or in collaborative care approach are effective in treating depression in patients with diabetes [39]. Therefore, there is a need to train health care providers in CBT and combine CBT with other less costly community-based interventions such as peer support intervention.

The effectiveness of current treatments for depression and diabetes-specific distress should not be overestimated, since a considerable percentage of depressed patients do not respond to treatment [37]. For instance, about 45% of the intervention group still had significant depression symptoms 12 months after the intervention and some had recurrence of depression [41]. In addition, most psychosocial intervention studies on depression have focused on adult populations; there is little evidence on their effectiveness in children and adolescents. Lastly the effectiveness and efficacy of these programs have hardly been tested in SSA context. Therefore, RCT should be employed to evaluate the effectiveness of such interventions in the Zambian context. Additionally, cultural appropriateness and contextual effectiveness of such interventions (especially given the constrained resources) need to be evaluated. More importantly, mental health services should be promoted and encouraged to patients with chronic illnesses in Zambia. Currently, mental health services are weak or non-available in most health institutions in Zambia with exception for those relating to HIV and AIDS and these are often donor driven.

Recommendation for Future research

The thesis established a number of gaps that may require future research to advance the field of psychosocial functioning and diabetes in Zambia and elsewhere. In this section, recommendations for some areas that may require future research are suggested.

Review of diabetes literature in SSA showed that epidemiological data on diabetes is lacking and sometimes inaccurate especially among children. In order to advance our understanding of the impact of and on psychosocial functioning, there is need for more epidemiological studies to establish the incidence and prevalence of diabetes and prospective studies on common psychosocial issues affecting people with diabetes especially children will be needed. At the time only two studies in Africa examined psychological problems specifically depression, in people with diabetes [8-9]. The dearth of epidemiological and psychosocial data on diabetes is a bottleneck to the provision of quality care for children affected with diabetes in Zambia and other similar settings. Therefore, in the future there is a need to invest in large-scale studies to provide an adequate evidence base for developing intervention programs for people living with diabetes in Zambia.

Chapter four of the thesis demonstrated that the PAID had good psychometric properties for assessing diabetes-specific distress. This preliminary evaluation indicated the PAID provides an initial, useful measure for assessing diabetes-specific distress. However, there is a need to establish the latent structure of the PAID using confirmatory factor analysis in future studies. In addition, the PAID will need to be adapted and enriched to cover other diabetes specific-emotional items such as worrying about finding romantic partners, worrying about being able to adapt and fit well at work or future occupations and other stigmatization associated with diabetes because these were some of the common diabetes-specific emotional distress that were

reported in the qualitative study in chapter 3. Further in chapter five, a self-report measure (MDI) showed that depression was common in patients with diabetes. As noted earlier, self-report measures for depressive symptoms and structured interviews based on MDD diagnostic criteria tap into different constructs that have independent association with diabetes. Due to logistical reasons (e.g., time restrictions, financial resources and adequate access to clinicians who can carry out the clinical interview) I used a self-report questionnaire. Future studies should use both self-report and structured interviews to assess depression in patients with diabetes. Moreover, the gold standard for a research on depression is the structural clinical interview that uses the DSM IV criteria for illness [42]. In addition, using individual depressive symptoms was more effective than using composite scores of self-report measures when investigating the association between depression and diabetes self-care. Future research should examine this relationship using diagnostic clinical interviews. It will also be interesting to examine the relationship between individual depressive symptoms with other diabetes-specific areas such as fear for hypoglycemia and glycemic control.

Test scores obtained in different cultural populations cannot be interpreted in the same way across studies [43]. Therefore, cross-cultural variations in the conceptualization of depression and other psychosocial issues will need further research in the future in order to draw valid conclusions and formulate effective treatment plans. Differences in sociocultural backgrounds between African nations and Western nations may influence the assessment of depression as we know it and measured by most questionnaires and interviews. For example, painful heart, fear of witchcraft, worry about poverty are all symptoms of depression in Zambian low SES communities which may differ in high SES communities and yet still for developed countries [50]. Furthermore, norms must be established for the measures that were used in the studies in order to come up with conclusive comparisons with findings elsewhere.

Given the bidirectional relationship between diabetes and depression, policy makers, patients and family members can all play a role in minimizing the implications of this relationship. Zambian Policy makers should develop policies that encourage and prioritize screening and treatment of both diabetes and psychosocial issues especially depression affecting people with diabetes. This direction will over time have a trickledown effect on Zambian health care providers' capacities and mandate to screen, treat and educate patients on the two disorders. If patients are educated about the two disorders and there is a deliberate policy to screen and then treat depression in diabetes patients, patients may put in more effort to buffer depression including other psychosocial issues affecting people with diabetes and improve self-care activities.

Although the etiology and management of type 1 and 2 diabetes are different, there are no major differences in the way depression affects Zambian patients with diabetes whether they are young (adolescents) or old (adults). However, young patients seemed to have poorer self-care scores compared to adults which in itself may increase symptoms of depression. Therefore clinicians should pay even more attention to young patients and females: the former seemed to score high on depression compare to male counterparts. Age and type of diabetes did not predict diabetes specific distress either although depression did predict diabetes-specific distress. This data has implications in clinical care of Zambian patients; all patients should be treated (young or older, with type 1 or type 2 diabetes) that are susceptible to depression particularly women who seemed to score even high scores than men. At the family level, there is need for increased family support regardless of age or type of diabetes although women and girls should be given more support since they are more vulnerability to depression.

Conclusion

The present thesis showed that diabetes is increasingly affecting a lot of people in Zambia and in SSA. Many people in Zambia with diabetes seem to register high levels of psychological problems especially depression and diabetes specific distress compared to other countries. Methodological issue in differences in socio-cultural expressions of depression may explain differences in the results observed in the thesis with those of the developed world. For instance, the study on depression in chapter 5 showed major differences in results with those reported in Denmark, USA and Nigeria because of different measurement tools (MDI vs Beck depression inventory for example) used for depression in the reported studies. Socioeconomic factors may also explain results in chapter 4 on diabetes-specific distress that differ with those of countries like USA, Sweden, Norway Netherland. These countries have strong economies, easy access to diabetes care, support from nurses, and easy access to oral medication, insulin and blood glucose measurement material, which may explain why Zambian patients reported high distress in comparison to the aforementioned countries. Health authorities and policy makers in developing countries face the challenge of improving health. In particular, clinicians and other stakeholders should concentrate on improving diagnosis, improve care and sensitizing the communities on prevention measures. Lack of health care resources, stress and stigmatization, poor health care and inadequate advice by family and friends, due to a lack of knowledge are common problems in Zambian adolescents with diabetes which health facilities should incorporate in care. Health care professionals must also be concerned with the mental health of diabetes patients' particularly diabetes-specific emotional stress, depression and the potential negative effects of depression on medical outcomes and diabetes self-care. Clinicians need to register and treat individual depressive symptoms in patients with diabetes, especially in women, young people and patients from low SES. In addition to depression treatment, patients with diabetes ought to be helped to optimize self-care by enhancing self-efficacy, healthy

eating, physical activities, monitoring of blood sugar and compliance to medication, good problem solving skills, healthy coping skills and risk reduction behaviors. Mental health services, particularly problem-focused therapy, could help reduce levels of depression and improve the quality of life of patients. Therefore, interventions should simultaneously address depression symptoms, emotional problems and self-care skills to achieve optimal diabetes outcomes. In all, there is need to make treatment accessible and improve the quality of medical treatment of patients.

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Chapter 8

Thesis Summary

Thesis Summary

There is an increase in the incidence of diabetes in Africa. A review of literature showed evidence of increased risk of several psychosocial problems including depression, anxiety and distress among others among individuals with diabetes (Chapter 2). Although there is abundant evidence in developed nations, little is known about the psychosocial issues affecting people with diabetes in Zambia. Therefore, the aim of this research was to examine psychosocial dynamics and functioning in individual with diabetes.

Given the lack of research on diabetes in Zambia, it was important to understand diabetes in adolescents and how it affects their everyday experiences. Therefore, chapter 3, using structured interview explored stress, stress coping strategies, quality of care and life of adolescents with diabetes among 10 adolescents, 8 caregivers and 4 health practitioners. Results showed that diabetes had a huge impact on adolescents such that they had to make lifestyle adjustments in order not only manage the disease but also fit in with their healthy peers at school or at home. The adjustments they made include those involving diet and participating in activities they previously engaged in such as those requiring them to stay away from home for a long time. Adolescents experienced diabetes-related stress a result of the challenging routine of insulin administration, cost and access to required food and transport cost or laborious travel to the hospital. Others mentioned worrying about the future as the major stressor among adolescents with diabetes. Adolescents also mentioned experiencing stigma and discrimination in social context at home and at school. In addition to the aforementioned distressing issues, there was a common view among the participants that distance to hospitals, cost of food, medicine and other medical essentials were the major barriers to quality health care. In order to deal with these issues participants mentioned that adolescents employed different coping strategies such as spiritual and social support strategies. These findings

indicate the need to improve diabetes care especially making health services available and easily accessible. There is also need to recognize and identify psychosocial issues and intervene in order to improve the quality of life of adolescents with diabetes.

The aim of chapter 4 was to test the validity and reliability of the Problem Areas in Diabetes (PAID). A total of 157 Zambian people with diabetes completed the PAID and other self-report measures. Exploratory factor analysis showed that a one-factor solution was the best interpretable solution. Internal consistency of the Zambian version of the PAID was 0.90 and stable cross the types of diabetes. Diabetes-specific emotional problems were common, with problem endorsements ranging from 22% – 61% across PAID items. The PAID showed low to moderate associations with the Self-Care Inventory, Hypoglycemia Fear Survey and the Major Depression Inventory. Cognitive interviews showed that participants were able to comprehend question intent while a few participants faced some challenges with the meaning of words such as "anxious" and "physician" and with comprehension of some items. The Zambian version of the PAID is a reliable and valid measure to assess diabetes-specific distress. Zambian people with diabetes expressed high levels of diabetes-specific distress; yet some items may need to be simplified or clarified to enhance comprehensibility. Policy makers, clinicians, researchers and people with diabetes need to combine forces to find ways to reduce the high levels of diabetes-specific emotional distress in Zambians living with diabetes.

The aim of chapter 5 was to explore how common depression is in individuals with diabetes and examine factors associated with depression in our sample. A total sample of 930 participants comprising of 773 healthy controls and 157 individuals with diabetes completed a set of demographic questions and the Major Depression Inventory (MDI). Results revealed that depression was more common in people with diabetes compared to healthy controls. Further

females were more likely to report depression than males. Within individuals with diabetes, there was no significance difference between those with type 1 and type 2 diabetes. Thus, despite the different etiologies of the two types of diabetes, the observed differences in depression were not significant, suggesting a need to consider both types of diabetes prone to depression. The observed levels of diabetes in Zambia were often high compared to other nations in the West and in Africa particularly Nigeria. Gender and socioeconomic status were found to be associated with reported depression in our subjects.

Finally, in chapter 6 we examined the association between depressive symptoms as measured by the MDI and self-care using the self-care inventory in individuals with diabetes. 157 people with diabetes completed the two measures. Out of 12 depressive symptoms from the MDI, we found that the symptoms "*low in spirit or sad*" and "*feeling life was not worth living*" were significantly associated with self-care. The symptom "*lack of energy*" was only marginally associated with self-care and did not remain significant after applying Bonferroni correction. However, much of the variance observed between the association of depression and self-care was accounted for by demographic characteristics such as the patient's age, sex, socioeconomic status and diabetes type which were significantly associated with self-care. Clinicians should identify individual symptoms of depression most affecting patients especially among woman and patients from low SES and intervene in order to improve self-care behaviors and quality of life of the patients.

In conclusion, the present thesis demonstrated that diabetes is a growing problem in Sub-Saharan Africa, including Zambia. Pertinent problems affecting people with diabetes include comorbid conditions, such as HIV, malaria, macrovascular and microvascular complications. Mental health issues are also common among people with diabetes, particularly depression and

stress. Lack of resources complicates identification and treatment of diabetes in SSA and Zambia.

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To my wife and family thanks you for your support and encouragement. I dedicate this work to you, my daughter, late parents and siblings. Cheers!

List of Publications

A. Manuscripts and articles included in thesis

1. Hapunda G, Abubakar A, Pouwer F, van de Vijver F. Validity and reliability of the Zambian version of the problem areas in diabetes scale (PAID) in diabetes patients: A triangulation with cognitive interviews. Submitted manuscript.
2. Hapunda G, Abubakar A, Pouwer F, van de Vijver F. Gender, Age and Socioeconomic Status are Associated with Self-Care among people with diabetes in Zambia. *Journal of Health Psychology*. In press.
3. Hapunda G, Pouwer F. *Diabetes in Sub-Saharan African Children: Risks, Care and Challenges.* In A. Abubakar & F. van de Vijver. Applied Developmental Science for Sub-Saharan Africa. New York: Springer. Accepted book chapter.
4. Hapunda G, Abubakar A, van de Vijver F, Pouwer F. Living with type 1 diabetes is challenging for Zambian adolescents: qualitative data on stress, coping with stress and quality of care and life. *BMC Endocrine Disorder* 2015. Doi.10.1186/s12962-615-0013-6.
5. Hapunda G, Abubakar A, Pouwer F, van de Vijver F. Diabetes mellitus and comorbid depression in Zambia. *Diabetic Medicine* 2015; 32 (6):814-818. doi: 10.1111/dme.12645.

B. Other manuscripts

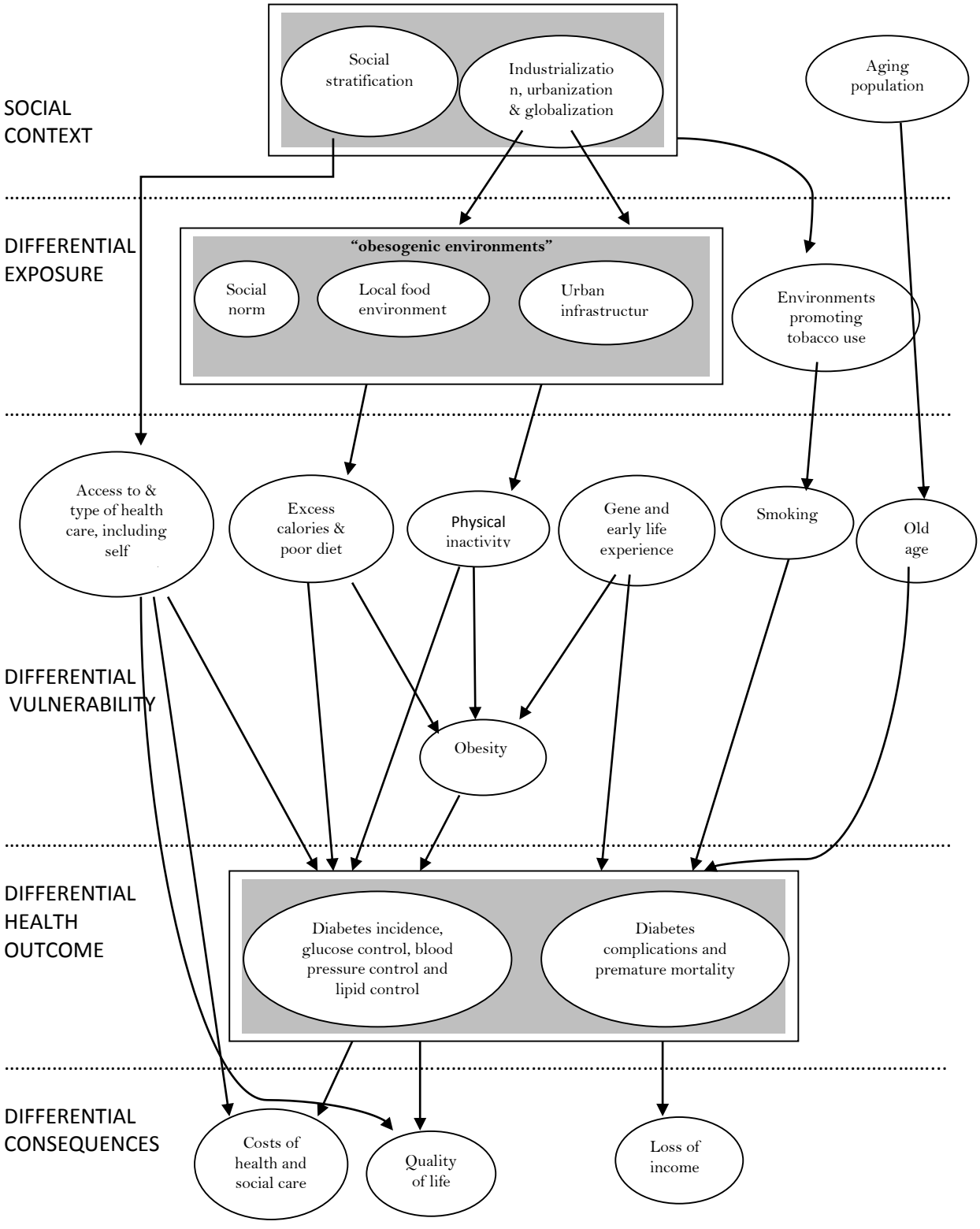
1. Adams BG, Abubakar A, van de Vijver F, de Bruin GP, Arasa J, Fomba E, Gillath O, Hapunda G, Looh La J, Mazrui L, Murugami M. Ethnic identity in emerging adults in Sub-Saharan Africa and the USA, and its association with psychological wellbeing. *Journal of Community & Applied Social Psychology*, 2015. Doi.10.1002/casp.2247.
2. Hapunda G, Sichimba F. *Experimental Psychology*. In AA Mogaji. International Handbook of the Discipline of Psychology. Accepted book chapter.
3. Hapunda G. Application of attachment theory in pediatric health.Saarbrücken: Lambert Academic Publishing. 2011 (ISBN 978-3-8465-9423-0)

About the Author

Given Hapunda was born on 31st January 1981 in Mkushi, Zambia. After he graduated from secondary school at Sikalongo in Choma, Zambia, he obtained his Bachelor degree in Psychology and English at the University of Zambia, Zambia. Upon his completion of his bachelor degree, he was awarded a Staff Development Fellowship (SDF) at the University of Zambia. Subsequently, from 2007-2009 he was awarded a study grant to follow a master degree in Child and Adolescents Psychology under a joint programme between the University of Zambia and Leiden University, The Netherlands. Upon completion he joined the teaching staff in the department of psychology at the University of Zambia. From 2010 to 2011 he participated in a pre-doctorial research capacity programme in South Africa under the South Africa Netherlands Programme for Alternative Development (SANDAP). In August 2010, he started his PhD project at Tilburg University, Netherlands. His research focused on psychosocial functioning in individuals with diabetes in Zambia.

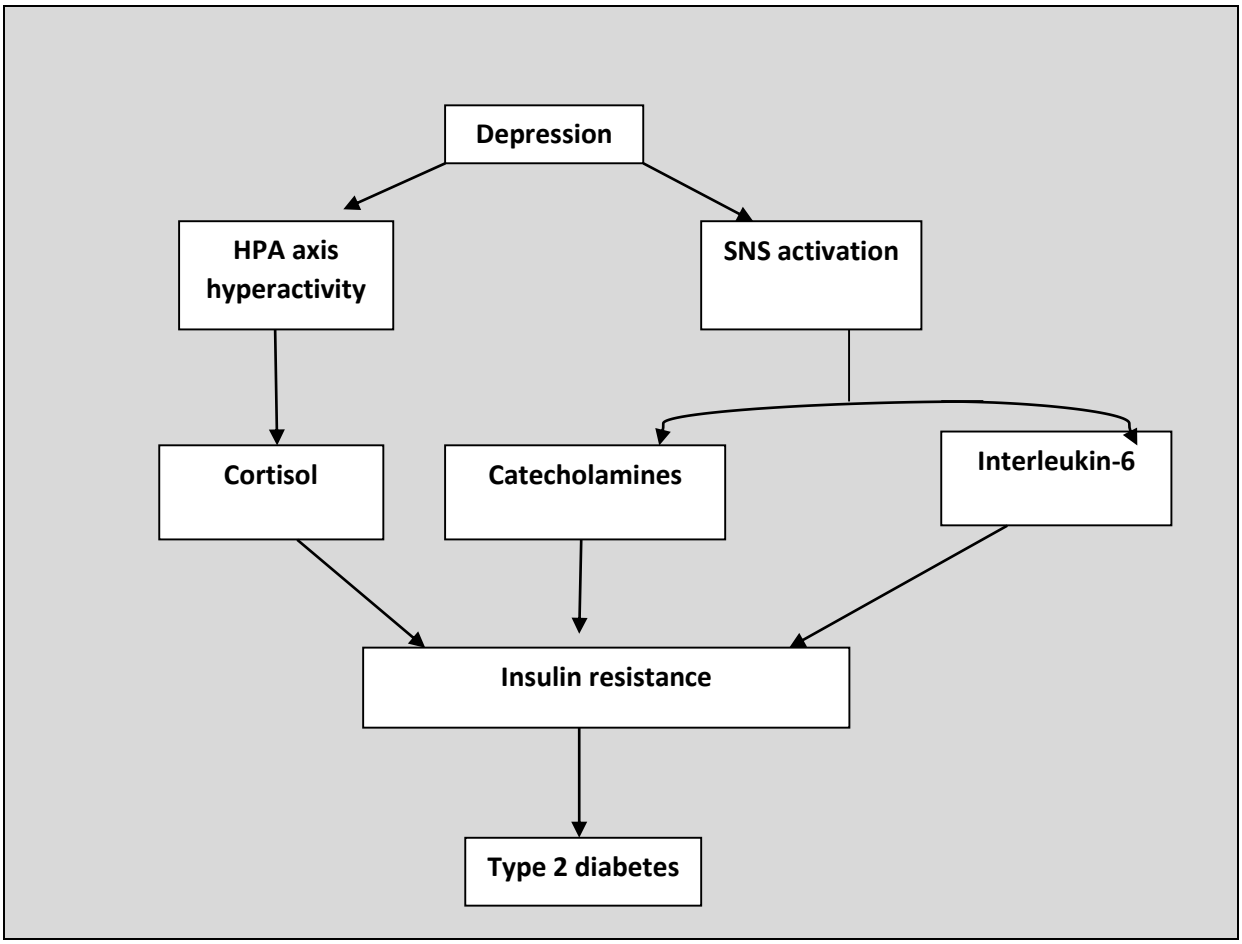
Appendices

Appendix 1: The social determinants of consequences of type 2 diabetes



Source: Equity, social determinants and public health programs, World Health Organization, Geneva, 2010

Appendix 2: The Bio-Physiological Pathway of Depression



Source: Champaneri et al., 2010