A matter of oppression and power struggles:
A qualitative study on local diabetes care and coping mechanisms among diabetics on the isles of Zanzibar

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Abstract

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There is an epidemic of type 2 diabetes worldwide, and particularly sub-Saharan Africa is bearing the brunt. Zanzibar is not exempt, where the literature points out a steadily increasing public health problem. The literature shows that diabetics in sub-Saharan Africa struggle coping with this chronic disease. No study has explored coping among diabetics in Zanzibar, which justifies the current one. This entails the fact that no studies in the region have looked at coping among diabetics in a Muslim society, and especially with regard to Ramadan fasting. The overall objective was to increase understanding of local diabetes care and coping mechanisms among diabetics in Zanzibar. A qualitative methodology was employed; where in-depth interviews were carried out with a heterogeneous group of persons representing useful insights on the topic. The data collection took place in Zanzibar from June to September 2013; which includes the month of Ramadan. The study has found that there is a web of interconnected factors at play. Modern diabetes care as well as awareness and acceptance of the biomedical explanation of the disease is on the rise in this society. Though, there are still constraints, which are related to the multiple explanatory models of sickness still circulating on the isles. This is reinforced by the still limited access to modern diabetes care, as well as continued poor regulation and unempowerment of the traditional sector; leaving the latter to strive for legitimacy, reflected in among others their largely inadequate utilization of biomedical equipment and terminology. This reality can be viewed as a matter of power struggles, using Foucault’s terms. The diabetics move in between; driven by the distinct poverty and the hope for cure. The western, modern way of life is in many ways perceived negatively by the locals; it permeates the society in ways that are hard to cope with. The structural violence is obvious, this social machinery of oppression against the poorest of the world; which is believed to create resistance and reinforce the society’s traditional, largely Islamic based world-view; which, in addition to maintain the existence of the traditional sector; also implies norms that the diabetics struggle with, such as the stigma related to refrain from Ramadan fast. The vicious cycle keep spinning; where disease exacerbation, complications and premature deaths is still the sad fact. The study concludes that continued efforts need to be undertaken to tackle this increasing epidemic in the Zanzibari society, both locally, but equally important through global efforts; where empowerment is a key word.
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Abbreviations

DANIDA: Danish International Development Agency

DAZ: Diabetes Association of Zanzibar

IDF: International Diabetes Federation

IFG: impaired fasting glucose

IGT: impaired glucose tolerance

ILO: International Labor Office

MoH: Ministry of Health Zanzibar

MoHSW: Ministry of Health and Social Welfare Zanzibar

NCD: non-communicable disease

NGO: non-governmental organization

OGTT: oral glucose tolerance test

TDA: Tanzania Diabetes Association

WDF: World Diabetes Foundation

WHO: World Health Organization
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1 Introduction

There is an ongoing and steadily increasing epidemic of type 2 diabetes worldwide, and particularly sub-Saharan Africa is bearing the brunt (IDF, 2013), where the rapid growth of diabetes is related to the nutritional, epidemiological and demographic transitions in the region (Levitt, 2008; IDF, 2013). Zanzibar is not exempt, though the literature from here is limited. An NCD risk factor survey, the first of its kind, was carried out in 2011 by the Zanzibar Ministry of Health with funding from among others WHO; and found moderate, although somewhat uncertain, prevalence rates of diabetes, and alarming prevalence of risk factors for NCDs; pointing that Zanzibar is in an early stage of an NCD epidemic (MoH, 2012). It is also estimated that Zanzibar is facing a significant ageing problem in the future (ILO, 2010). Numbers from hospital registers have showed that diabetes was among the top eleven reported diagnosis in inpatients in Zanzibar (Zanzibar Office of the Chief Government Statistician, 2013).

The literature stresses that diabetics in sub-Saharan Africa struggle coping with this chronic disease; which is related to poverty and limited accessibility to modern health care, as well as to the diverging illness beliefs and medical pluralism still highly existing in the region. No study has explored coping among diabetics in Zanzibar, which highly justifies the current one. This entails the fact that no studies in the region have looked at coping among diabetics in a Muslim society, and especially with regard to Ramadan fasting. The study was partly carried out exactly during the month of Ramadan. The study is further largely based on the notion that a social phenomenon cannot be understood outside its context, which also indicated the need for discovering the area in which the Zanzibari diabetics seek health care. In the light of medical anthropology; part of the study therefore focused on exploring the venues the diabetics use for counseling and care, and the various health care providers’ and other central characters’ perceptions of diabetes and diabetes care. This approach is believed to provide an in-depth comprehensive picture of the lived lives of the Zanzibari diabetics.
1.1 Objectives of the study

The overall objective is to increase understanding of local diabetes care and coping mechanisms among diabetics in Zanzibar.

The data collection revolved around three specific objectives:

- To describe the different venues diabetics use for counseling and care.
- To explore local health care providers’ perceptions of diabetes and diabetes care.
- To investigate coping mechanisms among diabetics and associating factors.

1.2 Structure of the thesis

Including this introductory chapter, there are ten chapters in this thesis. Following this initial chapter; the second chapter provides background information on the research setting, namely Zanzibar. It gives a brief description of Zanzibar’s history, politics, people and demography, as well as its health care system. The third chapter is a comprehensive literature review of the state of art. The first subchapter assesses the evidence base on that type 2 diabetes constitutes a significant current and future public health problem in sub-Saharan Africa including Zanzibar. It includes a description of the pathophysiology, diagnostic criteria and treatment, as well as risk factors for type 2 diabetes; which largely is viewed this in the light of the relevant context. There is a subchapter with the evidence base and recommendations on diabetes and Ramadan fasting. It also looks at the political attention diabetes care in sub-Saharan Africa and Zanzibar has received globally, regionally and locally; and shows a problem area that largely has been neglected, though points out an increasing focus in the field. The second subchapter looks at the literature that exists from sub-Saharan Africa on coping among diabetics, as well as a review of relevant literature from the isles of Zanzibar. The chapter ends with the rationale of the study. The fourth chapter is a description of the theoretical perspectives of the study. It includes a description of how the literature presents the prerequisites for diabetes related self-care and coping, as well as how health, illness and the concept of health care is viewed in the framework of medical pluralism. The fifth chapter is a detailed presentation of the project’s research design and methodologies. It includes ethical considerations, as well as a reflection on the projects’ strengths and weaknesses,
including an account of the role of the researcher and the research assistant. *Chapter six, seven and eight* are dedicated to the findings from this study, where they overall answer respectively each of the specific objectives of the study. The findings are already at this stage discussed in the context of relevant literature. Each chapter is preceded by a summary of the findings of the respective chapter. *Chapter nine* draw upon the material presented in the three previous chapters, and provides an in-depth analysis of the findings, in the light of the theoretical framework chosen for the study. The thesis is finally concluded in *chapter 10*. 
2 A glimpse of Zanzibar

2.1 Its history, politics and people

Zanzibar forms part on the Swahili coast in the Indian Ocean, about 40 km. from Tanzania mainland, and is a semi-autonomous region within the United Republic of Tanzania. It comprises two main islands, Unguja (often referred to as Zanzibar) and Pemba, and a number of sparsely populated islets, the biggest one being Tumbatu. After the 1964 revolution, Zanzibar joined with the then Tanganyika to form the United Republic of Tanzania. Zanzibar elects and maintains its own government and is directly responsible for all nonunion affairs, including health services (MoH, 2012; MoHSW, 2006). Unguja Island covers an area of about 1464 square kilometers and Pemba Island covers an area of about 864 square kilometers. There are five administrative regions, three in Unguja and two in Pemba, which are subdivided into 10 districts. There are 50 constituencies and 289 Shehia, which is the lowest administrative level of the government structure (MoHSW, 2006). Zanzibar town is situated on the island of Unguja. It is divided into Ng’ambo, where the locals live, and Miji Mkongwe, or Stone Town, which used to be the seat of the former sultan of Zanzibar, and is today the city centre with the town’s administration, ministries, banks, children schools and mosques; almost fifty mosques in all. Stone Town is also the centre of the rapid increasing tourist industry; with hotels, guesthouses, cafes, restaurants and shops (Larsen, 2008).
Zanzibar is characterized by its centuries of integration, and the variety of ethnic origin in Zanzibar is striking, with descendants from among others Arabs from Oman, Asians, descendants of former African slaves, citizens originating from Yemen, early immigrants from Persia, as well as indigenous Zanzibari (Bantu peoples); forming a plural society. Swahili is the principal spoken language; and the population is almost entirely Muslim (Larsen, 2008; Bennett, 1978). With early Persian and Arabian influence, the East African coast received the first representatives of the Islamic religion already from the seventh century. Moving on to 1800; Zanzibar had become the principle center for foreign trade along the East African coast; a meeting place for Arabs, Indians and Europeans interested in exchanging their products for those of the African mainland, among others the high scale slave trade, both for export and for domestic labor on the newly established clove plantations on the islands (Larsen, 2008; Bennett, 1978). Around 1840, the Sultan of Muscat and Oman moved his capital to Zanzibar town and established the Zanzibar Sultanate. When the Zanzibari Sultanate became a British protectorate in 1890, the Sultan was still recognized as the legitimate ruler of an Arab state. Encouraged by the Sultan; a period of extensive immigration followed. Gradually, both the free population and the slave population became a part of a sociocultural universe where Islam represented the ideals and values of an encompassing lifestyle (Larsen, 2008). When Zanzibar gained independence from Britain in 1963, the Sultan remained the constitutional monarch of Zanzibar. However, dramatic changes occurred a few months later, with the revolution in January 1964; with the downfall of the Arab State of Zanzibar, where many land and property owners, mainly of Arab descent, were killed or forced to leave the islands (Larsen, 2008; Bennett, 1978). The revolution resulted in a Zanzibari government headed by the Afro-Shirazi Party (ASP), later Chama Cha Mapinduzi (CCM). Shortly after, a signing ceremony created the United Republic
of Tanzania, ending Zanzibar’s 148 days as an independent country. An Africanization process was started in order to fight a system where ethnic origins were claimed to coincide with socioeconomic. Today, the many resent developments, including the tourist industry, have resulted in people being expelled from inherited land or fishing areas in order to secure resorts for tourists and adding to more urban migration. There have also been increased food prices in urban areas, a general decline in trading activities and possibilities, severe employment problems, and a more general feeling that their surroundings are dominated by people who do not follow Zanzibari morality and etiquette (Larsen, 2008). The Zanzibar Strategy for Growth and Reduction of Poverty stressed that there is a feeling among the local communities that it is people from outside Zanzibar that are benefiting from the employment opportunities generated in the tourism industry today, leaving the local community to bear the full brunt of the environmental and cultural costs of tourism (The Revolutionary Government of Zanzibar, 2010:25). All this has caused frustration. Larsen (2008) highlights that within the present political and economic situation, expressions of Islamic fundamentalism have reoccurred, although with relatively limited influence. Parkin (2006: 4) point that the non-Muslim, mainland Union government’s apparent attempt to “Africanize” and de-Islamize Zanzibar, and so make it more likely to conform to central government expectations, is partially echoed in the increasingly bitter political division between supporters of the government party in power, the Chama cha Mapinduzi or CCM (the Revolutionary Party), and those of a party registered in 1992 as the Civic United Front or CUF, where the leaders and followers are characterized as “Arabs”. With the new election coming up in 2015; the situation is colloquially said to be tense, with a question of liberation from mainland at stake. Larsen (2008:31) stresses that the problem of identity remains complex in Zanzibar; as it is historically and politically constituted. She points out different distinctions which apply in Zanzibar culture, such as those between men and women; between different kabila, locally translated into tribe or population; and between humans and the highly present spirits of Zanzibar; masheitani or majini. Within the context of spirit phenomena, Zanzibaris reflect upon and negotiate aspects of their reality. In particular it concerns what it means to be human and the significance of distinctions embedded in kabila and in gender. Zanzibar can be characterized as a sex-segregated society. Distinctions between women and men are essential in this culture; they are defined as psychological opposites, and their different characters, abilities and psychologies complement each other. Hence, the married couple represents the ideal unity. Men, who often have multiple wives, have a duty to support their wives and
children, and the ability to provide is linked to men’s authority over women (Larsen, 2008). Still, Larsen (2008:34) stresses that discourses on gender are frequently contradictory and conflicting. There is among others no shame and quite common with all-female households, as long as the household head is divorced or widowed; and the women often run some kind of small-scale business. Larsen (2008:31) highlights that in relation to *kabila* today, people do emphasize their Zanzibariness, in opposition to the Tanzanian mainland, while at the same time stressing that they are different from each other because they originate from different places outside Zanzibar. Due to a common history of mobility, such an understanding seems to be shared by what is generally seen as the Swahili population on the east African coast. Swahili costal culture is a dynamic synthesis of African, Arabic and Asian ideas and practices within an African historical and cultural context, which is distinctively Swahili. The social organization of perceived cultural differences that is expressed through a focus on *kabila*, refers both to cultural substance expressed through aesthetics and to socioeconomic ideals. Larsen (2008:32) points that Arabness remains an aesthetic ideal. The term ustaraabu, translated to being civilized or refined, denotes being like an Arab. Arabness is associated with Zanzibariness, while bantuness is associated with the mainland. People emphasize their Zanzibariness by referring to their religion, their shared Muslim faith, hospitality, friendliness, etiquette and aesthetics; their way of being in the world (Larsen, 2008).

### 2.1.1 Demography

Zanzibar today has a small but rapidly growing population (the Revolutionary Government of Zanzibar, 2010), is significantly more densely populated than Tanzania mainland (National Bureau of Statistics Tanzania & Office of Chief Government Statistician Zanzibar, 2013), and has a total population of 1,303,569, with respectively 896,721 on the island of Unguja and 406,848 on the island of Pemba. The average household size is 5.1 (Office of the Chief Government Statistician Zanzibar, 2013; National Bureau of Statistics Tanzania & Office of Chief Government Statistician Zanzibar, 2013). The demography of Zanzibar resembles that of many African countries: a youthful population, declining fertility, declining infant and under-5 mortality rates (International Labor Office (ILO), 2010:20). ILO (2010:20) stresses that the population pyramid for Zanzibar shows a significant ageing problem in the future, and also the Revolutionary Government of Zanzibar (2010:23) point that the long-term effect of continuing high population growth in a weak economy could be damaging. The *socio-economic survey of Zanzibar 2013* showed that 44 percent of the population in Zanzibar had
an income below the poverty line, with a per capita income estimated to be USD 638 (Zanzibar Office of the Chief Government Statistician, 2013). Analyzing poverty headcounts by area, two-thirds of poor people live in rural areas, which equates to one-third of the total population of Zanzibar (ILO, 2010). The larger the size of the household and the greater the number of dependents; the more likely you are to be in poverty. There is also a clear differential in the headcount ratio between those in paid employment, like in government, parastatal, or other employment; and farmers, fishers, and the self-employed. Additionally, the higher the educational attainment of a household head, such as attaining a basic education or better, the lower the likelihood of poverty within a household. Zanzibar has relatively high literacy rates, with three quarters of the population aged 15 years and over able to read and write in at least one language (Swahili), and just under 30 per cent of the population also able to read and write in English. Literacy rates are lower in rural areas, particularly for females (ILO, 2010). However, ILO (2010:62) point that around a third of the whole population have no education, and less than 5 per cent of the population have achieved post-school level qualifications; which when relating back to the analysis of educational attainment of household head and poverty, shows that a big challenge remains in increasing the average level of educational attainment, which has a knock-on effect on individual labor market prospects. The Zanzibar economy depends on tourism, commerce, industry and agriculture. In terms of contribution to GDP, agricultural, forestry and fishing activities accounts for about the quarter of the economic activities in Zanzibar while tourism for about half. Only about 15 % of all employed persons are in paid employment (ILO, 2010).

2.2 The health sector

According to the Zanzibar Health Sector Reform Strategic Plan II (MoHSW, 2006:49), the health sector in Zanzibar is financed from three main sources: the government of Zanzibar, development partner contributions, and the public user fees. The government contribution accounted for 29% of spending in the health sector, while development partners accounted for the balance of 71%. The major partners in the health sector, in terms of their financial support, include among others the World Bank, Danida, the African Development Bank, the United States government, and GAVI. Analysis of the government budget indicates that the vast majority of resources are absorbed by health sector wages, salaries and the other allowances; while spending on drugs and supplies is covered by funding from development
partners (MoHSW, 2006). According to ILO (2010:93) vertical priorities of the health care in Zanzibar are infant and child health, maternal and reproductive health, and communicable diseases, such as malaria, HIV/AIDS and tuberculosis. Horizontal priorities are mainly strengthening decentralization of services and improved health care delivery.

The MoHSW (2006:5) highlights that the health system in Zanzibar enjoys a commendable infrastructure compared to other low-income countries in the region, with more than 95% of Zanzibaris living within five kilometers or less of a health facility. It is allegedly carried out a decentralization of responsibility and, to a more limited extent, resources to the district and community levels; through the District Health Management Teams. ILO (2010:66) stresses that the situation is not that positive in terms of distance to the nearest hospital; the mean distance to a hospital in a rural area is 12.8 kilometers. Thus, a proportion of the population has problems accessing health care due to cost or distance of travel. The public sector health infrastructure in Zanzibar is based on a network of first and second line Primary Health Care Units (PHCU) in both urban and rural areas. These refer either to the 30-bed Primary Health Care Centers (PHCC), also known as cottage hospitals, and/or the district hospitals; which in turn are supported by Mnazi Mmoja Hospital in Zanzibar town as the major referral point for the isles (MoHSW, 2006). Thus, Mnazi Mmoja hospital, with a capacity of about 400 beds, caters for specialist tertiary services for the whole country, though as well to provide the majority of the primary and/or secondary care for the North B, Urban, West and Central districts in Unguja, due to inadequate coverage by cottage hospitals and lack of district hospitals in Unguja (MoHSW, 2006). There are four cottage hospitals, two in respectively Unguja and in Pemba, which are intended to provide basic inpatient care in areas distant from other hospital facilities (MoHSW, 2006). There are 100 public first line and 34 second line PHCUs, which provide outpatient services, and with additional services at the second line PHCUs. In addition, there are private health facilities, which are largely concentrated in the urban areas, notably Zanzibar town; i.e. four hospitals and 69 clinics, or so-called dispensaries (Office of the Chief Government Statistician Zanzibar, 2013; MoHSW, 2006). According to the 2013 Socio-Economic Survey, there are 54 assistant medical officers and 130 clinical officers on the isles, 26 medical doctors, and more than 600 nurses of a variety of specializations, with a majority being the common nurse-midwives. This means a number of 1850 patients per doctor (Zanzibar Office of the Chief Government Statistician, 2013).
2.2.1 The traditional sector

The majority of the population in Zanzibar still uses traditional medicine for the treatment of various diseases (MOHSW, 2008; Larsen, 2008; Meier zu Biesen, Dilger & Nienstedt, 2012). It is estimated that today around five hundred traditional healers are working on Unguja, and at least three hundred on Pemba. There are forty-six traditional clinics, such as Islamic herbal clinics, in Zanzibar Town, and sixteen in the rural areas of Unguja (Meier zu Biesen et al, 2012). Meier zu Biesen et al (2012) highlight that due to the continued separation at the institutional level between the traditional- and biomedical sectors, representatives from the World Doctors have since 2005 been initiating a dialogue between a few doctors and healers, as well as training workshops to assist traditional healers in performing their activities in accordance with governmental legislation. Many healers also affiliate themselves with different healer associations (Meier zu Biesen et al, 2012). In 2008, the Ministry of Health and Social Welfare in Zanzibar, with support from WHO, announced a policy aimed at coordinate, regulate and supervise the activities of healers and develop traditional medicine, where the ministry claimed to recognize and advocate for the use of traditional medicine and for incorporating it into the national health system with the objective of ensuring that traditional medicine treatment is done scientifically, rationally and with safety to the Zanzibari community (MoHSW, 2008). The MoHSW (2008: 7) stressed that scientific research is needed to provide additional evidence of its safety and efficacy, and one of the key areas of the policy is therefore to develop methodologies for research and evaluation of traditional medicine. They further highlighted measures such as licensing and register manufacturers, distributors and practitioners of traditional medicine including their premises; providing adequate training for traditional practitioners; as well as to strengthen the Traditional Medicine Unit under the Ministry of Health, whose role is to register, monitor, and control traditional healers’ practices. These measures correspond to the increasing international attention in this field, where among others the recent WHO Traditional Medicine Strategy update exactly aims to support member states in developing proactive policies and implementing action plans that will strengthen the role traditional medicine plays in keeping populations healthy (WHO, 2013a).
3 Literature review

3.1 Type 2 diabetes: an emerging public health problem in sub-Saharan Africa and Zanzibar

The most recent IDF Diabetes Atlas points out a prominent current and future public health problem by calculating that, at present, diabetes affects 382 million people worldwide, with a projected increase by 55% by 2025 (IDF, 2013). Each report from the IDF has highlighted the fact that low- and middle-income countries will bear the brunt of the increase and that Africa will contribute significantly to this rise. 80% of people with diabetes live exactly in low- and middle-income countries (IDF, 2013). The IDF Diabetes Atlas estimated that 20 million people, a regional prevalence of 5.7%; have diabetes in sub-Saharan Africa today, and that this will double by 2025. Some of Africa’s most populous countries have the highest numbers of people with diabetes, including the United Republic of Tanzania (IDF, 2013). This trend is emerging in a region still grappling with high rates of communicable diseases, including the highest global prevalence of HIV, tuberculosis and malaria. With this double burden of disease, diabetes must compete for political attention and financial investments (Hall, Thomsen, Henriksen & Lohse, 2011).

Type 2 diabetes mellitus is the most common type of diabetes, and accounts for more than 90% of diabetes in sub-Saharan Africa (Hall et al, 2011; Levitt, 2008), similar to the global status (IDF, 2013). There is a low prevalence of the other main subtype, type 1 diabetes, in sub-Saharan Africa; where a key factor is the preventable early deaths among children with type 1 diabetes in the region (IDF, 2013). This though, is another problem area and is not a part of this thesis. The rapid growth of type 2 diabetes is associated with economic development, ageing populations, increasing urbanization, dietary changes, reduced physical activity, and changes in other lifestyle patterns. Sub-Saharan Africa is undergoing the fastest rate of urbanization, or westernization, worldwide (IDF, 2013; Mbanya, Motala, Sobngwi, Assah & Enoru, 2010; Levitt, 2008; Hall et al, 2011). In other words; the rapid growth of diabetes is related to the rapid nutritional, epidemiological and demographic transitions in sub-Saharan Africa (Levitt, 2008; IDF, 2013). Variations between urban and rural populations have been frequently observed in studies, with a higher prevalence of type 2 diabetes recorded in urban populations (Hall et al, 2011). This includes among others a Tanzania survey, which
was comparing an urban district of Dar es Salaam and a village in rural Kilimanjaro district, and showed both higher diabetes prevalence and prevalence of overweight in the urban community (Aspray T.J., Mugisi F., Rashid S., Whiting D., Edwards R., Alberti K.J. & Unwin N.C., 2000). The projections that by 2025 70% of Africans will live in cities, with a regional annual urban growth rate of 4.5%; suggest that levels of type 2 diabetes will continue to rise in the region (Hall et al, 2011).

### 3.1.1 Pathophysiology: what is type 2 diabetes mellitus

Diabetes is a chronic metabolic disease that occurs when the body cannot produce enough insulin or cannot use insulin effectively. Insulin is a hormone produced by the beta cells in the pancreas that allows glucose from food to enter the body’s cells where it is converted into energy needed by muscles and tissues to function. A person with diabetes does not absorb glucose properly, and glucose remains circulating in the blood, a condition known as hyperglycaemia, damaging body tissues over time. This damage can lead to disabling and life-threatening health complications (IDF, 2013); as chronic hyperglycemia is associated with long-term damage, dysfunction, and failure of different organs, especially eyes, kidneys, nerves, heart, and blood vessels (Mertig, 2012). Type 2 diabetes usually occurs in adults, but is increasingly also seen in children and adolescents. The metabolic syndrome is the biomedical measurable risks related to developing type 2 diabetes; the components of which include obesity, dyslipidemia (low high-density lipoprotein (HDL) levels and high triglyceride levels), hypertension, and insulin resistance (Mertig, 2012). Having developed type 2 diabetes, the body is able to produce the insulin hormone; but either this is not sufficient or the body is unable to respond to its effects, also known as insulin resistance; leading to a build-up of glucose in the blood. In contrast to people with type 1 diabetes, the majority of those with type 2 diabetes usually do not require daily doses of insulin to survive. Many people are able to manage their condition through a healthy diet and increased physical activity or oral medication. However, if they are unable to regulate their blood glucose levels, they may be prescribed insulin (IDF, 2013). Nutrition therapy for diabetics involves, simplified, a reduced carbohydrate- and fat (especially saturated- and trans fats) intake (IDF, 2012a). WHO & IDF (2006) diagnostic criteria for diabetes are either fasting plasma glucose \( \geq 7.0 \text{mmol/l} \), or 2 hour plasma glucose (venous plasma glucose 2 hours after ingestion of 75g oral glucose load) \( \geq 11.1 \text{mmol/l} \). WHO & IDF (2006:9) though recommend the latter, in form of an oral glucose tolerance test (OGTT), as a diagnostic test for the reasons that fasting
plasma glucose alone fails to diagnose approximately 30% of cases of previously undiagnosed diabetes, and that OGTT is the only means of identifying people with impaired glucose tolerance, IGT. IGT and IFG (impaired fasting glucose), and IGT in particular, are risk factors for type 2 diabetes (IDF, 2013), and especially in populations with low diabetes prevalence they are indicators of an early stage of the diabetes epidemic (Mbanya et al, 2010). IGT diagnostic criteria is fasting plasma glucose <7.0mmol/l and 2 hour plasma glucose ≥7.8 and <11.1mmol/l (WHO & IDF, 2006), in other words higher blood glucose levels after eating (IDF, 2013). IFG is defined as fasting plasma glucose from 6.1 to 6.9mmol/l and (if measured) 2 hour plasma glucose <7.8mmol/l (WHO & IDF, 2006), in other words higher blood glucose after a period of fasting (IDF, 2013).

The most common symptoms of hyperglycemia are frequent urination of pale, diluted urine; thirst from the loss of body fluids in the urine; and hunger for sugars. Other symptoms may be headache, sleepiness or difficulties concentrating; visual disturbances; dry or flushed skin from dehydration; and general malaise. Both physical and psychological stress increases the blood sugar. When illness or other stressors increase blood sugars to22.2 mmol/l or higher, ketoacidosis can occur. When the body does not have enough insulin to move glucose into cells for energy, the cells turn to fat to provide needed fuel. The metabolism of fat produces fatty acids and ketones that accumulate in the blood and affect the brain, producing symptoms of hyperglycemia, in addition to shortness of breath, fruity smelling breath, and nausea and vomiting. The kidneys try to eliminate ketones and glucose, giving rise to ketonuria and glucosuria. If diabetic ketoacidosis persists, the client may collapse into a coma (Mertig, 2012). Opposite of hyperglycemia, is hypoglycemia. Anyone with diabetes, especially when taking insulin or secretagogue drugs (oral drugs that make the pancreas increase its production of insulin), can experience low blood sugar. If the intake of carbohydrates does not match the amount of insulin injected or produced by the pancreas as a result of an oral antidiabetic agent, blood sugar will drop. Symptoms of hypoglycemia vary, but may include tremors; sweating, pale skin; dizziness, feeling faint, headache; excessive hunger, especially for carbohydrates; sudden atypical change in behavior and mood; difficulties paying attention, confusion, sleepiness; visual disturbances, dilated pupils; increased heart and respiratory rates; and seizures and coma. Some of the symptoms are very similar to those of hyperglycemia, and it is therefore important to confirm these symptoms with glucose monitoring. In order to prevent brain cell damage, hypoglycemia should be treated immediately with an amount of sugary foods (Mertig, 2012).
3.1.2 The shortage of prevalence estimates

Data from diabetes prevalence surveys is still scarce in sub-Saharan Africa (Hall et al, 2011, Levitt, 2008; IDF, 2013), and certain countries are prominently represented in this field of research, which includes Tanzania (Hall et al, 2011, Levitt, 2008). Some African countries have carried out population surveys with the assistance of the WHO STEP-wise approach to chronic disease risk factor surveillance program (STEPS) (Hall et al, 2011; Levitt, 2008; Mbanya et al, 2010). Levitt (2008) points that the STEPS program is beginning to rectify the small number of epidemiological studies on diabetes in sub-Saharan Africa (Levitt, 2008).

During fieldwork, the researcher got hold of the National Non-Communicable Risk Factor Survey 2011, carried out by the Ministry of Health Zanzibar, with funding from WHO and DANIDA. The survey-tool was adapted from the STEPS program and was the first of its kind; no survey on NCDs and risk factors has previously been undertaken in Zanzibar (MoH, 2012); though numbers from hospital registers have showed that diabetes was among the top eleven reported diagnosis in inpatients, the last registration being from 2011 (Zanzibar Office of the Chief Government Statistician, 2013). There is also a more than 20 year old report pointing diabetes to become a disease of major public health importance in Zanzibar, among others accounting for up to 4% of all hospital disease-specific deaths at the referral hospital, Mnasi Mmoja (Makame & Tull, 1993). Though previous random screening exercises carried out in Zanzibar estimated the prevalence of diabetes being 7%, the results from the survey showed a prevalence rate of diabetes of 3.7% (MoH, 2012). This is lower that the Africa regional prevalence estimates as described earlier. Also when comparing to the prevalence on Tanzania mainland, the Zanzibar numbers are smaller: A STEPS survey from Tanzania showed a prevalence rate of diabetes of 9.1% (WHO, 2012), similar to the IDF (2013) estimates of 9.9%. This survey used the same diagnostic criteria as the one from Zanzibar. The Zanzibar prevalence of IFG being 2.8% (MoH, 2012) is also relatively low, compared to the Tanzania STEPS survey (WHO, 2012) with an IFG prevalence of 10.6%. The prevalence rates from Zanzibar are thereby relatively low or moderate. That said; the Zanzibar STEPS survey not using OGTT as a diagnostic test (MoH, 2012) has most likely excluded a certain proportion of people with IGT. To repeat, Mbanya et al (2010) stated exactly that in populations with low diabetes prevalence, IGT is an indicator of an early stage of the diabetes epidemic. They further point that prevalence estimates from sub-Saharan Africa in general depend to a great extent on the method of diagnosis used in a study, where the prevalence is lower when only fasting plasma glucose results were used than when an OGTT was used.
(Mbanya et al, 2010). IDF (2013:40) points that the majority of people estimated to have IGT live in low- and middle income countries, and 29.7 million people (a regional prevalence of 7.3 %) are estimated to have IGT in sub-Saharan Africa (IDF, 2013). These precautions can be transferable in terms of Zanzibar. Also the alarming prevalence of risk factors for diabetes in Zanzibar, which will be elaborated on below, indicates exactly this. Additionally, the majority of the study population had never previously had their blood sugar measured (MoH, 2012), which also indicates an uncertain number of undiagnosed diabetes in the society.

### 3.1.3 The high prevalence of risk factors for type 2 diabetes in Zanzibar

Type 2 diabetes is as already mentioned largely associated with the rapid nutritional, epidemiological and demographic transitions in sub-Saharan Africa (Levitt, 2008; IDF, 2013). The major risk factors for diabetes in sub-Saharan Africa are similar to those in other regions of the world, whether this refers to the modifiable risk factors, such as urbanization, obesity, poor diet, physical inactivity, or those that are not mutable, such as increasing age, family history of diabetes, and ethnicity (i.e. genetic components) (Levitt , 2008; Mbanya et al, 2010; IDF, 2013). Regarding the not mutable factors, there is especially highlighted that disease frequency in sub-Saharan Africa is higher in migrant Asian–Indians or in populations of mixed ancestry than in indigenous African communities (Mbanya et al, 2010). Such a mixed ethnic background characterizes exactly the Zanzibari population. Additionally, a well-known risk factor for diabetes that among others Levitt (2008) highlights; is the association between stunting in early life and the increased risk for obesity, diabetes and other chronic diseases in adults. Undernutrition is a common problem in children of the region. In 2009 the prevalence of low birth weight in Zanzibar was 4.9 %; which is indicating that also the coming generation is at risk (MoH, 2012).

The NCD risk factor survey firstly showed evidence of poor diet among the Zanzibaris; they found what they characterize as a surprisingly low intake of fruits and vegetables of an average of 1.7 servings per day, considering the size of the agriculture in Zanzibar (MoH, 2012). A large proportion, 28.7 %, had no daily intake of fruits and vegetables. There was a small difference in fruit and vegetable consumption between urban and rural populations; with a slightly higher prevalence of consumption in rural areas. 82.9 % of the population used cooking oil rich in saturated fats; herby palm oil or coconut. The survey pointed that
availability and cost of fat- and carbohydrate rich foods such as chips, French fries and fried chapatti against especially the cost of fresh vegetables might be a contributing factor to the dietary lifestyle found (MoH, 2012). This was supported by a mixed method study, where the quantitative part is a secondary analysis from the STEPS survey; which similarly interpreted that the low consumption can be explained by the low availability and high price of fruits and vegetables (Keller, de Courten & Dræbel, 2012). They highlighted that people from urban areas were more likely to have electricity, running water, an electric cooker, and a fridge, *and*, oppositely to the STEPS survey, that people from urban areas had a more diverse diet and ate more fruits and vegetables, than people from rural areas (Keller et al, 2012). Further; the prevalence of obesity turned out to be high, but also to vary largely depending on using BMI or waist-hip ratio (WHR) as an indicator: Obesity measured as BMI <30 was found to be 7.7 % among men and 20.9 % among women; compared to the one determined by waist-hip ratio, which was found to be 33 % among men and 72.6 % among women. As the survey points; waist circumference and waist-to-hip ratio is a more exact risk prediction of metabolic risk than BMI. Prevalence of obesity was significantly higher in urban areas. The prevalence of hypertension was also high; with an overall prevalence of 33 % (MoH, 2012). The MoHSW (2006:35) has previously pointed that attempts to control changes in local dietary patterns and obesity are constrained by the popular cultural perception that obesity is associated with wealth. There was oppositely to these numbers, found a high prevalence of 82.4 % having moderate or high levels of exercise. This was explained by work in Zanzibar still being very labor intensive, such as fishing, farming and construction; as well as active transportation such as walking or cycling. Though, the level of physical activity clearly differed with higher proportions among men than women; and also between urban and rural areas, with a clearly lowest proportion in Zanzibar town (MoH, 2012). 7.3 % of the population was smoking, with a significant gender difference between men with 14.6 %, and women with 0.7 %. Alcohol consumption was low, with 90.8 % reporting to never have consumed alcohol; again with a significant gender difference of 96.8 % among women against 84.2 % among men. The low consumption of alcohol was interpreted as related to the population confessing to Islam which prohibits the use of alcohol (MoH, 2012). All in all; the results showed an overall prevalence of raised combined risk of NCDs (three or more of the risk factors smoking, insufficient intake of fruits and vegetables, sedentary lifestyle, overweight/obesity and raised BP) to be high, 24.2 %; with slightly higher prevalence in urban than in rural areas (MoH, 2012). Considering these results, with among others high prevalence of obesity especially in urban
areas; nutritional and demographic transitions are clearly evident, and diabetes and other NCDs on the rise is more than likely, despite the relatively low or moderate prevalence rates of diabetes showed in this survey. Also the MoH (2012) interpreted exactly the results as Zanzibar being in the early stage of an NCD epidemic.

3.1.4 Morbidity and mortality: consequences of high rates of undiagnosed and poorly controlled diabetes

The rate of undiagnosed diabetes is estimated being high in sub-Saharan Africa (Hall et al, 2011; Levitt, 2008; IDF, 2013); IDF (2013:56) points at least 63%. Individuals who are unaware they have the disorder are at very high risk of chronic complications. Therefore, the rate of diabetes-related morbidity and mortality in this region could grow substantially (Hall et al, 2011; Levitt, 2008). The type 2 diabetes prevalence surveys from sub-Saharan Africa which has recorded proportions of previously undiagnosed diabetes among participants who attended screening programs found very high levels, with fewer than 50% knowing they have diabetes (Hall et al, 2011; Mbanya et al, 2010). Also the Zanzibar NCD survey found that 82% had never measured their blood sugar, and among the group of those who measured, 10% had diabetes, compared to the overall prevalence of 3.7% (MoH, 2012); which as mentioned earlier indicates an uncertain number of undiagnosed diabetics in the society. Also low levels of adequate glucose control in diagnosed diabetics have been reported in several African prevalence studies (Hall et al, 2011; Mbanya et al, 2010). Microvascular complications are reported to be far more common than macrovascular diseases. The high prevalence of microvascular complications owes exactly to the poor levels of glycemic control so commonly noted in the region (Levitt, 2008; Mbanya et al, 2010). Foot complications and nephropathy are prime examples of the morbidity and often premature mortality associated with these complications. Furthermore, these complications are found early in the course of the disease, as diagnosis of diabetes exactly is often delayed (Levitt, 2008).

IDF (2013) points that only 8.6% of all deaths in the Africa Region can be attributed to diabetes, though also stresses that a staggering 76.4% of those deaths occurred in people under the age of 60. Hall et al (2011) and Levitt (2008) highlight that mortality due to diabetes has been poorly documented in the region; where two out of three studies were conducted almost twenty years ago, though which all showed high mortality proportions. A survey from 1990 investigating mortality among diabetes patients in Muhimbili Medical
Centre in Dar es Salaam, Tanzania; showed five year survival rates of 60% for patients with diabetes requiring insulin and 82% for those not requiring insulin (McLarty Kinabo & Swai, 1990). Levitt (2008) stresses that it is a difficult task to ascertain the true extent of mortality due to diabetes because most mortality statistics are based on the recorded underlying cause of death on death certificates, and in the case of diabetes, the associated renal or cardiovascular diseases are commonly documented, rather than diabetes itself. Additionally, even such data are rare in sub-Saharan Africa. Hall et al (2011) similarly highlight that a consideration of diabetes being a component cause of several other important and often lethal diseases is crucial; both non-communicable diseases such as cardiovascular disease and renal disease, and communicable diseases such as pneumonia, bacteremia and tuberculosis, which have considerable impacts on morbidity and mortality in the region. Though, this has been notably absent from the literature (Hall et al, 2011).

3.1.5 Diabetes and Ramadan fasting

No literature or measures in relation to diabetes and Ramadan fasting are found from Zanzibar, though the health care workers who participated in the study highlighted one specific guideline which they made use of in relation to Ramadan. These set of recommendations, as it was found to be, had its starting point at an international conference on diabetes and Ramadan in Casablanca in 2005. It emphasizes that fasting is associated with multiple risks for diabetics, such as hypoglycemia, hyperglycemia and diabetic ketoacidosis. It highlights that counseling must be provided and that the management plan must be highly individualized, due to the different patients’ clinical picture and treatment regime prior to Ramadan. Patients may be at higher or lower risk for fasting-related complications depending on the number and extent of their risk factors. Conditions are associated with “very high,” “high,” “moderate,” and “low” risk (see table on page 19) (Al-Arouj, Assaad-Khalil, Buse, Fahdil, Fahmy, Hafez, Hassanein, Ibrahim, Kendall, Kishawi, Al-Madani, Nakhi, Tayeb & Thomas, 2010). The recommendations were among others prompted by the EPIDIAR study; a population-based, retrospective, transversal survey conducted in 13 countries with Muslim populations. This study showed that large proportions of diabetic subjects fast during Ramadan, and also that severe hypoglycemic episodes were being significantly more frequent during Ramadan compared with other months (Salti, Benard, Detournay, Bianchi-Biscay, Brigand, Voinet & Jabbar, 2004). A review on diabetes and Ramadan pointed out that there are contradictory findings whether Ramadan fasting alters biochemical parameters in patients.
with type 2 diabetes (Benaji, Mounib, Roky, Aadil, Houti, Moussamih, Maliki, Gressier & El Ghomari, 2006). The review concluded that Ramadan fasting is acceptable for well-balanced type 2 patients conscious of their disease and compliant with their diet and drug intake. However, if patients with diabetes wish to fast, it is necessary to advise them to undertake glycaemia control several times a day, to prevent hypoglycemia risks during daytime fasting or hyperglycemia during the night (Benaji et al, 2006:7).

**Categories of risk in patients with type 1 or type 2 diabetes who fast during Ramadan**

**Very high risk**
- Severe hypoglycemia within the 3 months prior to Ramadan
- A history of recurrent hypoglycemia
- Hypoglycemia unawareness
- Sustained poor glycemic control
- Ketoacidosis within the 3 months prior to Ramadan
- Type 1 diabetes
- Acute illness
- Hyperosmolar hyperglycemic coma within the previous 3 months
- Performing intense physical labor
- Pregnancy
- Chronic dialysis

**High risk**
- Moderate hyperglycemia (average blood glucose 150–300 mg/dl or A1C 7.5–9.0%)
- Renal insufficiency
- Advanced macrovascular complications
- Living alone and treated with insulin or sulfonylureas
- Patients with comorbid conditions that present additional risk factors
- Old age with ill health
- Treatment with drugs that may affect mentation

**Moderate risk**
- Well-controlled diabetes treated with short-acting insulin secretagogues

**Low risk**
- Well-controlled diabetes treated with lifestyle therapy, metformin, acarbose, thiazolidinediones, and/or incretin-based therapies in otherwise healthy patients
3.1.6 Financial burden

The costs associated with diabetes include increased use of health services, productivity loss and disability; and imposes a large economic burden on individuals and families, national health systems, and countries (Mbanya et al, 2010; IDF, 2013). The earlier a person is diagnosed and management of diabetes begins, the better the chances of preventing harmful and costly complications. The need to diagnose and provide appropriate care to people with diabetes is therefore urgent (IDF, 2013). Only 20% of global health expenditure on diabetes was made in low- and middle-income countries, where 80% of people with diabetes live. On average, the estimated health spending due to diabetes was USD 5621 per person with diabetes in high-income countries, compared to USD 50-500 in most countries in sub-Saharan Africa. Africa region has a health expenditure on diabetes being the lowest of any of the IDF Regions; around 4 billion in 2013. Thus, a two-fold increase in diabetes prevalence without a corresponding increase in spending will almost certainly have a very negative impact on rates of complications and death for people with diabetes in Africa (IDF, 2013). Hall et al (2011) point to studies from year 2000 which have estimated the direct cost of treating diabetes ranging from USD 2302 to USD 3207 per person. Even at this level of direct cost, there is a significant discrepancy between the cost and available expenditure, as estimated by IDF (2013).

With limited national funding, individual patients and their families in sub-Saharan Africa may have to spend significant proportions of their income on treatment for diabetes, a level of expenditure that may not be sustainable or affordable (Hall et al, 2011; IDF, 2013). The burden of type 2 diabetes is disproportionately borne by people of working age. Reducing the economic activity of this group through disease and disability affects both household and national economies. Diabetes therefore not only imposes considerable costs of treatment on families, it also hinders their ability to pay for this treatment through the loss of income of the diabetic member. Due to the cost of diabetes, including the cost of the complications and the many diseases where diabetes in an underlying factor, it is critical for policymakers to highlight the importance of introducing early and cost effective interventions for both primary and secondary prevention. (Hall et al, 2011; Mbanya et al, 2010).
3.1.7 Political attention

Globally

IDF (2013:88) highlights the last years’ significant progress in building global political recognition for diabetes and other NCDs on the global health agenda. The UN Resolution 61/225 on World Diabetes Day in 2006, the UN Political Declaration adopted at the UN High-Level Meeting on NCDs in 2011 and the UN Conference on Sustainable Development in 2012 all acknowledged that the burden of diabetes and other NCDs are one of the major challenges to development in the 21st century, especially for developing countries; and needs to be addressed on a global scale (IDF, 2007; United Nations, 2011; United Nations, 2012). Highlighted were among others the recognition that NCDs worldwide largely can be prevented and controlled through international collaboration and multi-sectorial action by all UN Member States and other relevant stakeholders at local, national, regional, and global levels. The UN Political Declaration on NCDs listed specific commitments; which were related to reducing risk factors and create health-promoting environments; to strengthen health systems towards the provision of equitable, universal coverage and promote affordable access to prevention, treatment, care and support; to establish or strengthen multi-sectorial national policies for the prevention and control of NCDs; to promote and support research and development; as well as to strengthen country-level surveillance and monitoring systems (United Nations, 2011). The WHO following developed a Global Action Plan for the prevention and control of NCDs, as requested by the 66th World Health Assembly in May 2013 (WHO, 2013b). It is building on the previous 2008–2013 WHO action plan for NCDs, and its aim is to operationalize the commitments of the UN Political Declaration on NSDs. Its objectives thereby correspond to the recognitions and commitments listed above (WHO, 2013b). Still, IDF (2013:56) points that investment, research and health systems are slow to respond to the burden diabetes represents to sub-Saharan Africa, and remain focused primarily on infectious diseases. Hall et al (2011) point that establishing timely and effective integrated diabetes programs in the region requires a shift in current public health priorities, and that this requires a much better evidence base; both to highlight the scale of the problem and the areas for intervention. Most African countries do not have national diabetes programs capable of handling the increased numbers of diabetes patients. Health-care systems in most African countries are state-funded and priority is given to the unfinished agenda of communicable diseases, or acute and not chronic care. Consequently this gives high financial
costs of treatment, particularly insulin; limited availability of diagnostic tools, treatment and glucose monitoring equipment; lack of guidelines and policies for diabetes care; healthcare facilities not easily accessible in all areas; few education programs for both patients and staff; and a low awareness of diabetes among healthcare professionals (Hall et al, 2011; Levitt, 2008; Mbanya et al, 2010). That said; it is also highlighted that diabetes and other NCDs are achieving increasing political attention in sub-Saharan Africa, with various regional meetings, initiatives and programs that has been initiated recent years (Levitt, 2008; Hall et al, 2011).

In sub-Saharan Africa

In 2006, the Diabetes Declaration and Strategy for Africa was announced, and called among others for the establishment of a network of key-people in each country to facilitate communication and coordination. It also urged countries to provide epidemiological baseline data, and to undertake the WHO NCD Risk Factor survey for those who did not have adequate evidence base. Central in the declaration was also the concept of empowerment, empowerment of individuals, families and communities; that patient education as the basis for optimal self-management is an essential component of effective diabetes care, and that this only can be achieved by educating the health workforce (IDF Africa, WHO Afro & the African Union, 2006). The Africa Diabetes Care Initiative was a follow-up to the latter; where the goal was to identify feasible and sustainable strategies for diabetes self-management in real-world primary care and community settings (IDF Africa Region, 2010). This initiative intended to provide a stimulus for support to upscale primary and community care, but additionally emphasized that each country or community should establish a health facility that would function as a “Diabetes Centre of Excellence” within patient-centered prevention, treatment, clinical research and education (IDF Africa Region, 2010). Additionally, The IDF Africa Action Plan, which was an implementation of the UN Resolution 61/225 on World Diabetes Day in 2006 (IDF Africa Region, 2008); established a Task Force on National Diabetes Policy and Action with the three aims; to identify countries with diabetes programs and facilitate activities; to assist in the development of national programs where none exist; and to develop a framework for implementing a National Diabetes Policy. Also here were the primary healthcare and community interventions mentioned as central key areas. Capacity building at primary care level was intended to involve among others nurses, doctors, technicians, community health workers, diabetes educators, and people with diabetes. The
primary health care units should all have available a minimum package of care. Partners in community actions to educate and inform populations were suggested to be among others the media, faith-based organizations, formal and informal groups, traditional healers, and activities around World Diabetes Day (IDF Africa Region, 2008). Lastly, one should mention the Sub Saharan Africa Diabetes Conversation project which was launched in 2011, and is also implemented in Tanzania. This is a program revolving around diabetes group education (IDF, 2012b).

In Zanzibar

Makame (1993) pointed that the Diabetes Association of Zanzibar (DAZ) was founded in 1986, and that it according to him had played a major role in promoting diabetes education and in improving diabetes health care on the islands. Moving towards present times, Ramaiya (2006) describes that Tanzania Diabetes Association (TDA) in 2004 established, simultaneously as establishing diabetes clinics on the mainland; eight diabetes clinics in Zanzibar and Pemba, with financial support from the WDF and Novo Nordisk. The diabetes clinics were distributed in one referral hospital and two cottage hospitals in Unguja, and in three district hospitals and two cottage hospitals in Pemba. In addition to establishing the clinics, training for health care professionals were provided, together with a starter kit of equipment for each of the clinics. Ramaiya (2006:1) highlighted that prior to this; specialist diabetes services were only available at the main referral hospital on the islands of Zanzibar and Pemba. In the Zanzibar Health Sector Reform Strategic Plan II, the MOHSW (2006:35) recognized the growing importance of NCDs in the overall disease burden; with an increase particularly in diabetes and hypertension being seen in the health facilities recent years. It was highlighted that a NCD Unit was created within the MOHSW in 2002 to help address the problem, and an integrated NCD policy, program and guidelines were among the core interventions on the agenda. One of the main targets was to establish the missing baseline data on the burden of disease and the main risk factors, which was then achieved by the NCD Risk Factor Survey from 2011. Other targets were among others to increase community awareness on NCDs, to establishment an effective surveillance system on NCDs, and to integrate prevention and management of the most common NCDs in all PHCCs and hospitals, and in selected second line PHCUs, by 2010. They confirmed that currently, services were only provided at referral facilities through eight special clinics throughout the Isles (MOHSW, 2006). As a response to the findings from the NCD Risk Factor Survey, the MoH (2011)
stressed a continued focus on education for behavior change, as well as using the primary level as an entry point for care and early detection of NCDs; as the NCD Strategic Plan was only partially achieved. Further, the MoH (2011:8) highlighted the plan of formalizing an NCD unit to reflect the priority of this issue; which indicates that the NCD unit was delayed in relation to its declared commencement in 2002.
3.2 Coping among the diabetics: the evidence base

Firstly, recognizing that no similar study like this, related to an exploration of local diabetes care and coping among diabetics, has been found from the isles of Zanzibar; reflects the need for taking a look at the evidence base generated in the rest of sub-Saharan Africa. Some research has been published regarding this topic in the region, both quantitative, in form of cross-sectional surveys, and qualitative studies. A few of them were carried out in Dar es Salaam, the closest city to Zanzibar when crossing over to Tanzania mainland. The quantitative surveys have assessed various factors which influence self-care among diabetics, and they have given the prevalence estimates of these factors. The overarching results point out limited access to modern health care and treatment, combined with poverty, as the main factors which negatively influence diabetics’ self-care in the region. Though, all the surveys sampled their participants through diabetes clinics, which is also among the limitations of these studies, in terms of a selection bias; as diabetics attending health care might not be representative for the general diabetic population. This is among the indications that other factors might not have been accounted for through these surveys. There are also limitations of quantitative surveys in order to assess a topic which largely is a matter of experiences and perceptions of lived, everyday lives. This is where the qualitative studies are essential, and provide in-depth, contextualized, narrated data; which have found that, in addition to financial constraints; there are also diverging illness beliefs and medical pluralism that still pervades the region and influence the diabetics’ coping. At the end, we will return to Zanzibar and look at the evidence base from there that the researcher believes is relevant to the study.

3.2.1 Evidence from sub-Saharan Africa

Poverty and inaccessible biomedical health care

The quantitative surveys on this topic largely found financial difficulties as the main obstacle to self-care. Among them was one cross-sectional study which assessed self-care practices and psychosocial distress among people with type 2 diabetes in Dar es Salaam, Tanzania (Mosha & Rashidi, 2009). Limiting factors found were among others the majority of the respondents in the study having low incomes that could barely meet the costs of the basic needs; 70.2 % had primary and no formal education; and the majority of the diabetics lived in
households with an average family size of more than 7 people, which this was considered crucial due to the indication of the amount of resources required to take care of the family members. Additionally, a high cost of glucose testing was found, as well as unaffordable medication, though to a minority of the population (29.8%). Consequences were blood glucose testing practice among the study subjects being very low; a small amount of the population not using the recommended medication due to lack of money to buy prescribed drugs; as well as difficulties following a proper diet. The study also showed that the respondents with low income had significantly higher diabetes related distress than those with high incomes (Mosha & Rashidi, 2009). Another quantitative study did a comparison of self-care and perceived educational needs in adult Tanzanian and Swedish diabetic patients, where the Tanzanian sample was collected through the diabetes outpatient clinic at Muhimbili Medical Centre in Dar es Salaam (Smide, Ekman & Wikblad, 2002). Also here the Tanzanian diabetes patients reported being suffering from the lack of drugs and equipment. None of the Tanzanians monitored their own blood glucose, and they had poor glycemic control as detected by the survey (Smide et al, 2002). Moving to one of Tanzania’s neighbor countries, also a cross-sectional survey from Uganda, with the aim of describing illness beliefs and diabetes self-care behaviors of Ugandan adults with type 2 diabetes (Baumann, Opio, Otim, Olson & Ellison, 2010), found that the major barrier hindering self-care was economic; most patients could not afford to consistently take drugs, the cost of transportation to clinics for regular visits, the cost of glucose monitoring, and the cost of appropriate food. Few did home glucose monitoring. Blood pressure, blood glucose, and anthropometric measurements indicated that the majority of participants had poor metabolic and blood pressure control. Also a quantitative study from Ethiopia, where the aim of the study was to identify predictors of self-care behaviors among patients with diabetes (Ayele, Tesfa, Abebe, Tilahun & Girma, 2012); found among others low income as one of the obstacles to self-care, as well as that individuals with elementary educational status were more likely to perform self-care than those unable to read and write. On the other hand; diabetic patients with very high income were 0.2 times less likely to perform self-care than with less income, which was interpreted as high income patients may have riskier life style than low income respondents (Ayele et al, 2012).

One qualitative study (Kolling, Winkley & von Deden, 2010) did a triangulated methods approach to diabetes management among urban poor type 2 diabetics, again in Dar es Salaam, Tanzania; where the research was centered on Kleinmans’ category of the popular
sector, which refers to the treatment that takes place outside of the sphere of the biomedical health care system. Kolling et al (2010:3) point that due to the network of diabetes clinics recently established throughout Tanzania, a considerable increased number of people now access affordable diabetes treatment and health education. Still, it is not optimal; the clinics were overcrowded and understaffed, and at the time of data collection there was a national wide shortage of the normally subsidized insulin for more than two years, and there was also an issue with the supply of oral medication. This meant that people needed to buy the medicine at private pharmacies where it was still available, but at a high cost; which resulted in many of the informants not taking their medicine regularly, because they were unable to purchase it. One qualitative study from both a rural and an urban part of Cameroon based on triangulated methods over a period of two years, had the objective to explore the cultural aspect of compliance, its underlying principles and how these cultural aspects can be used to improve patient centered care for diabetes in Cameroon (Awah, Unwin & Phillimore, 2008). They also found that financial considerations were among the major deterrent to following the biomedical path; many patients lacked the money to purchase the medicines prescribed at diabetes clinics. Thus, dietary and medical non-compliance partly occurred systematically, as a result of these constraining factors (Awah et al, 2008).

Kolling et al (2010) highlight the aspect of kinship; that living with diabetes very much is a family matter in the African context, and people's self-care practices have to be seen as a collective praxis. Family circumstances, where poverty was the fundamental life condition; make continual prioritizations crucial for the patients’ illness actions, and make the dynamics of illness action discontinuous (Kolling et al, 2010). Mosha & Rashidis’ (2009) survey on the other side found a high level of social support among the study population, which was associated with higher level of self-care. Also Baumann et al (2010) found the majority of participants reporting high levels of family and peer social support. One survey from south-Africa investigated exactly the effects of social support on among others metabolic control and blood pressure control (Westaway, Seager, Rheeder & Van Zyl, 2005), and found that patients with lower levels of social support had poorer health than patients with higher levels of social support. Particularly the effect on blood pressure control was evident, which was interpreted as blood pressure being more stress-sensitive than metabolic control. Westaway et al (2005) suggest that the high prevalence of diabetes mellitus in black South Africans, usually considered being the result of diet and other lifestyle changes, may be exacerbated by a breakdown of the traditional social support system, which is rapidly eroded by urbanization.
and other lifestyle changes. Lastly, one semi-structured interview study from Uganda aimed to explore healthcare-seeking behavior among diabetics, with particular attention to possible gender influence (Hjelm & Atwine, 2011); and found dissimilarities between males and females in access to economic resources, severity of disease and health awareness. In a society with male dominance, women depend on free government hospitals as men control the money and thus have easier access to private health care. The risk of a switch between different care givers is then greater in women, entailing a risk of interrupting compliance and glycemic control, negatively affecting health (Hjelm & Atwine, 2001).

**Diverging illness beliefs**

The quantitative surveys on this topic have showed varied results regarding the diabetics’ knowledge of the disease and relevant self-care. The Baumann et al (2010) survey showed that the majority of Ugandan adults with diabetes had adequate knowledge of the disease, where it was viewed as a serious, chronic illness that requires the need to be active, eat healthy, and take medications. 83.8%/a majority of the participants reported having attended a diabetes education class at the clinic. Though, Baumann et al (2010:7) highlight comments from participants that emerged after the completion of the questionnaire, such as “Will I be cured?”, including many revealing that they stopped taking medications when feeling better; which the researchers interpreted as inconsistencies in the diabetics’ illness beliefs. The survey from Ethiopia also found that knowledge of the respondents about diabetes was very high accounting (94.7%); however, majority of them still did not follow the recommended self-care practices. This was associated with among others high perceived barriers of self-care and less perceived severity of the disease and its complications (Ayele et al, 2012). Smide et al (2002) contradictory found lack of knowledge among the participants relevant for self-management, such as the interaction between food, insulin and physical activities, and what to do in case of hypoglycemia. Though, the Tanzanian diabetics had knowledge of hyperglycemia, which the researchers interpreted as reflecting the necessity of knowing what to do when no drugs were available (Smide et al, 2002). Also Awah et al’s (2008:6) qualitative approach found a lack of basic knowledge about diabetes and diabetes risk factors amongst Cameroonian diabetics being evident. The study’s overall finding was that the cultural pressures on patients are responsible for patients’ partial acceptance of and adherence to prescriptions. The biomedical care offered treatment packages that were socially inappropriate and therefore rejected or modified for most of the time by people with diabetes.
They highlight that compliance is a biomedical idiom underpinned by certain biomedical assumptions and values, which made sense only to the health care provider. The accusation of being noncompliant could easily sound senseless to patients, as they took it for granted that the causes of diabetes had a wider scope than biomedical health care providers understood. The ultimate aim of virtually all diabetes patients at the point of diagnosis, and indeed afterwards, was still to be cured, so that when one talked of treatment it was equated with curing and not management. Skepticism about the efficacy of biomedicine and what clinics can offer still run deep, although some Cameroonianians were coming to terms with the fact that diabetes is not a curable disease (Awah et al, 2008). Several other qualitative studies found the same pattern related to the desire for a cure among diabetics. De-Graft Aikins’ (2005) qualitative, longitudinal study with triangulated methods among diabetics from urban and rural areas of Ghana, found contradictory to the latter that most participants privileged biomedicine over other health systems, and biomedical explanations of the disease were legitimate; but the psychosocial impact of diabetes and the high cost of biomedical care drove cure seeking and medical inaction. Thus, although participants understood and stressed that diabetes was incurable, there was an underlying hope for a cure, a desire to overcome disruption to body-self (De-Graft Aikins, 2005). Also Kolling et al (2010) found the hoping for a cure evident among their participants in Dar es Salaam. Additionally, one focus group-and semi-structured interview study from eastern Ghana aiming to explore why patients with diabetes use traditional medicine for the treatment of diabetes (Rutebemberwa, Lubega, Katureebe, Oundo, Kiweewa & Mukanga, 2013), also found the belief in a cure for diabetes being prominent in the community. We will get back to issue this in the medical pluralism subchapter.

Lastly, some of the studies have touched upon aspects of stigma related to diabetes in the respective communities. Baumann et al (2010) found that participants reported significant negative psychosocial outcomes associated with having diabetes; where a high percentage reported feeling worried, overwhelmed, and sad or depressed. This was interpreted as diabetes carrying a stigma that one has a deficiency. The study shows that more men than women reported interference with sexual functioning. Baumann et al (2010:8) relate this to the high value of fertility in most African cultures, including Ugandan, and that this dysfunction presents a significant psychosocial issue for sexually active men. Two qualitative studies highlighted the stigma attached to AIDS to actions relating to diabetes treatment. Awah et al (2008) found that the advice to lose weight was something that most diabetes patients found
instinctively difficult to follow, because of the fear of being thought of having AIDS. This was actually even going beyond AIDS, due to obesity and overweight in the past and still today is taken as a sign of good health, wealth and vitality in Cameroon (Awah et al, 2008). De-Graft Aikins’ (2005) found that in rural Ghanaian communities; uncontrolled diabetes symptoms, i.e. weight loss, were misconstrued as AIDS, which was highly stigmatized. Also Levitt (2008) highlighted in his review the stigma attached to the syndrome of weight loss and wasting associated with HIV/AIDS in Africa. Additionally, he stressed that cultural perceptions may hinder measures to reduce rates of obesity. In many African communities, a larger body size may be associated with affluence, health, attractiveness and happiness. However, some evidence indicates that cultural perceptions of body size may be changing, and that women may be willing to reduce their body size for improved health and social reasons (Levitt, 2008). Baumann et al’s (2010) survey revealed that over half of the participants reported typical activities of daily living as their regular exercise; which the researchers interpret as not surprising, due to activities such as jogging or swimming not being the cultural norm in Uganda. Cultural beliefs were also reported in relation to food choices; that “food is not food” unless it is the typical Ugandan carbohydrate-rich diet.

Medical pluralism

As already touched upon; a third major topic identified in the literature review, was the considerable presence of medical pluralism in the African diabetic populations. Levitt (2008) highlighted in his review that any African populations still regard alternative healing systems as the primary source of healthcare or, alternatively, consult both. Mosha & Rashidi’s (2009) survey from Dar es Salaam was the one quantitative survey found that was mapping the use of non-conventional medicine among diabetics, and showed that the majority of the subjects (51.9%) reported to have tried non-conventional medication such as traditional herbs to treat their conditions. Only a small proportion of the subjects (12.4%) pointed they were still using some traditional herbs/supplement to treat their condition (Mosha & Rashidi, 2009). Kolling et al (2010) stress that in Tanzania the medical sector is pluralistic, with biomedical health care systems and ethnomedical health clinics existing side by side offering different explanatory models, a term coined by Kleinman, concerning the causes of diabetes and means of effective treatment. Healers offer a cure, and low cost treatment; which provide an attractive alternative to the prospect of lifelong biomedical treatment. Additionally, the herbal medicine was often brought to the participants by relatives. Ethnomedical treatment often
relieves people short-term; physically by easing the symptoms and psychologically by imposing the mentioned hope of a cure. Also Awah et al (2008) found two competing regimes of treating diabetes, biomedical therapy on the one hand and traditional medicine on the other hand; two regimes which were equally valued in these communities of Cameroon. People often adopted other medical treatments in combination with biomedicine and believed that the combination would be more effective in curing diabetes. Health care providers complained how many diabetics returned to the clinic in conditions worse than the previous appointment because their blood sugar remained high, as a result of the combination of treatment (Awah et al, 2008). De-Graft Aikins (2005) centered her study precisely on the concept of healer shopping, which is defined as the use of a second healer without referral from the first for a single episode of illness, and point it out as the primary and dominant response for chronically ill people in Africa. The diabetics’ cure seeking constituted healer shopping across biomedical, ethnomedical, and faith healing systems. Medical inaction constituted passive disengagement from medical management and active engagement with faith healing, i.e. witchcraft and sorcery. Different choices depended on people’s socioeconomic status and access to these pluralistic services, as well as on whether participants hoped for a cure in terms of a biomedical breakthrough or believed in a (Christian) spiritual cure for diabetes. Medical inaction was most prominent among low income and rural people, as the consequences of living with diabetes were more severe, and they had least access to biomedical and regulated ethnomedical services and could not afford recommended foods. Most participants also distinguished between legitimate spiritual action, occurring within the Christian sphere, and illegitimate spiritual action within the traditional religious sphere; and they were more likely to seek faith healing rather than traditional religious healing (De-Graft Aikins, 2005). Kolling et al (2010) contradictory to the latter found that most people with diabetes seemed to value biomedical treatment, but experienced difficulties engaging continuously in treatment due to geographical and financial constraints as well as poor physical health. When placed in a position of financial hardship, the long-term future was blurred to most of the informants and unpredictable which led them to make decisions concerning their health based on immediate opportunities and obstacles; and ethno medicine was tried at least once for hope of cure, or even to assuage other family members (Kolling et al, 2010). Rutebemberwa et al’s (2013) study showed that diabetics used traditional treatment due to hospital treatment being both geographically inaccessible and costly and even often out of stock. Traditional treatment was easily accessible, as herbalists lived within the
community, where they aggressively promoted herbs in public places. Diabetics were told by the traditional healers that traditional herbs can cure diabetes. Also the diabetics’ social network often encouraged them to seek care from traditional healers, telling them that the illness will cure (Rutebemberwa et al, 2013). Hjelm & Atwine (2001), similar to Kolling et al (2010), used Kleinmans model to give analytical categories, and found, contradictory, that help with health problems primarily was sought from the professional sector. As already mentioned, women were more likely to use the free-of-charge public services, while men more often turned to private for-profit clinics; due to dissimilarities in access to economic resources. In a few cases, particularly among women, traditional healers were consulted; mainly in case of failed healthcare or complications. Otherwise traditional treatment was found not being used as many did not believe in it, found it too expensive, or feared the risk of worsening their disease.

### 3.2.2 Diverging illness beliefs and medical pluralism in Zanzibar

Makame (1993) described more than 20 years ago; that some of the major problems confronting diabetes care in Zanzibar included among others ignorance about the cause of diabetes and poor management. Since then, no studies on exploring diabetes care or coping among diabetics have been reported from the islands of Zanzibar. Though, there have been studies carried out in Zanzibar assessing a variety of patient groups’ health-related behavior, as well as describing the highly existing pluralistic health care in this society. They have similarly found that coping with disease in Zanzibar is a complex matter which implies a person’s constant assessment of nature and causes of disease, of choices and of consequences; within the context of among others diverging explanatory models of health and illness, a highly present traditional sector which people still strongly relate to, as well as a modern health care of relatively limited accessibility. The researcher believes that the line can be drawn between these studies, and the current one.

After fieldwork, the researcher became aware of a large collaborative, mixed method research project that had been carried out in Zanzibar in 2011/2012. This project was based on the assumption that there is a strong need to create a platform for collaboration between traditional healers, biomedical doctors, and government representatives. One of its goals was to understand patients’ health-related behavior in order to supplement and promote better
health care for patients; and it focused among others on the current situation of traditional healers in Zanzibar, and the composition and limitations of the public health sector (Meier zu Biesen et al, 2012). Firstly, Meier zu Biesen et al (2012:46) point that although the MoH sets ethical norms and standards for healers in order to regulate their practices, cooperation between biomedical and traditional practitioners on equal terms is still in its infancy. The data confirmed that there is no lack of enthusiasm on the side of traditional healers to collaborate with doctors. However biomedical doctors seemed to be less enthusiastic about cooperation with healers. There seemed to be uncertainty about whether some of the diagnostic and/or curative techniques used by healers should even be permissible at all. The claim for empirical truth, and the need for the proper documentation and scientific validation of healers’ remedies; were issues frequently expressed by doctors and government representatives. In the opinion of doctors, the incorrect treatment of chronic diseases and surgical interventions are practices that traditional healers should desist from, and considerable delays were recognized in the treatment of patients suffering from everything from malaria, HIV/AIDS, cancer, stroke, diabetes, asthma, to diarrhea. According to doctors, traditional healers speak about diseases and cures in biomedical terms without sufficient biomedical understanding. During research it was observed that healers seemed to have incorporated biomedical language, techniques and diagnostic tools, such as plasma glucose test, into their own practice (Meier zu Biesen et al, 2012). Meier zu Biesen et al (2012:8) consider the appropriation of biomedical language and the diagnosis of disorders using biomedical terminology to leave traditional healers vulnerable to scrutiny by biomedical practitioners. Further, Meier zu Biesen et al (2012:26) reveal that treatment of chronic diseases such as hypertension, stroke, and/or diabetes was something all the healers dealt with. Healers associated the increase of heart problems and/or diabetes with stress, lack of physical activity, and unbalanced diet. High blood pressure could be understood as pressure caused by a spirit who is bothering the patient from inside. In addition of providing special herbal remedies and infusions, the patients who suffered from a stroke or diabetes were also told to rest and modify their lifestyle. Great emphasis was put on the type, characteristics, and nutrition value of different foods and beverages. Consequently, healthy dietary practices emerged as a distinct field of medical knowledge among the healers. Young & Ali (2005:6), who carried out a qualitative study in Pemba on maternal anemia; point that a diet of nutritious food is the most clearly delineated commonality between traditional and biomedical cures of anemia.
Meier zu Biesen et al (2012) point that therapy seeking in Zanzibar is part of a process that involves social, cultural, and psychological factors, as well as financial burdens. Patients often go through long and desperate episodes of searching for relief, which implies both involvement in spiritual rituals as well as the admission to biomedical health care facilities; neither of which are a guarantee for success. While almost all patients had used biomedical treatment, the majority had also used traditional medicine at least once in their lives. A key factor for patients delaying or interrupting biomedical treatment was the difficulty in complying with lifelong medications as required for chronic diseases such as diabetes and HIV/AIDS. The Zanzibar Traditional and Alternative Medicine Policy Act stresses that the usage of traditional medicine is in line with the lack of drugs in the public sector and the high prices in the private sector (MOHSW, 2008). Though the results indicate that people paid less for their consultation with traditional health care services compared to the hospital, Meier zu Biesen et al (2012:47) point that cost alone was not the major criterion for selecting health services; the social context of its delivery seemed to be equally important. The patients’ perceptions of quality of care were crucial, and healers were judged as being more patient-centered. Additionally, the perception of efficacy was a critical determinant of treatment choices, as many of the patients sought help from healers after biomedical treatments had been perceived to have failed. Patients knew exactly where to seek help; their choices were not haphazard. They particularly preferred to treat diseases that are considered incurable by biomedical specialists, such as diabetes and HIV/AIDS, with traditional medicine. Patients were reluctant to make use of the hospital unless their condition became critical. The biomedical sector seemed to be chosen for its professionalism in case of emergencies, for the conducting of laboratory tests, and/or for the treatment of serious diseases. Also the treatment of diseases regarded as an affliction or those associated with witchcraft and/or attacks by spirits were reserved for traditional healers. Beckmann (2012) showed with three case studies how HIV-positive in Zanzibar struggle to make decisions in an environment characterized by deep uncertainties about the nature and causes of HIV/AIDS. It was highlighted that treatment literacy played a relatively minor role in predicting the success or failure of anti-retroviral treatment in Zanzibar; rather, concerns revolved around questions of control and agency, limiting structural factors, and alternative aetiologies in the context of medical pluralism. Traditional healers were offering a cure, which was what the patients were really hoping for. Much trust was invested in the prospect that a cure will be found one day, either through biomedicine or traditional healers (Beckmann, 2012).
Meier zu Biesen et al (2012) describe that separating bodily symptoms from social, cultural, and symbolic effects is particularly problematic in Zanzibar, since the concepts of health and illness are more broadly defined and intertwined with social and cultural conditions. The association of cultural and moral processes, especially witchcraft, is still seen as an important factor contributing to disease and life problems in Zanzibar. There is a clear distinction in disease causation between “illness brought by God”, “illness brought by man” and “illnesses caused by spirits” in the Zanzibari society. Illnesses of man are those brought by sorcery or different sorts of dawa, such as an evil eye, used by others in order to inflict harm. Dawa is the Kiswahili term for medicine, but it has a wide range of meanings, especially within Islamic theological discourse. Furthermore, an important category in the Zanzibari context are “illnesses caused by spirits”, known as majini or masheitani, a category with a great variety in terms of the kind and nature of illness. In Zanzibar, spirit beings are recognized in orthodox Islamic doctrine and form part of the Islamic cosmology. Lastly, the causality of “illnesses of God” is close to the English term “natural” regarding its implications, and they happen with no moral cause (Feierman, 1981; Giles, 1999; Larson, 2008; Mackenrodt, 2011; referred to in Meier zu Biesen et al, 2012:11). Meier zu Biesen et al (2012:11) point that differences in terms of notions of disease causation between doctors and healers can best be shown by describing the management of HIV/ AIDS. Healers in Zanzibar differentiate between HIV/AIDS that is “caused by God”, also explained as an “ordinary HIV-infection” communicated via sexual transmission; and HIV/AIDS that is not caused by a virus but by the “environment”, and thus related to witchcraft. The latter is said to be only treatable by healers, as they are able to manipulate the devil that has bewitched the ailing person. Also Beckmann (2012:14) point that in an environment where AIDS equals adultery and immorality, and the victims face stigmatization even by those closest to them, witchcraft explanation requires an analysis of the whole network of social relations and thus deflects blame away from the individual, placing responsibility on the larger group. Though, the prominent perception among religious leaders and the general population was found to be that AIDS is a divine retribution for increasing immorality, embedding the pandemic in a local Muslim discourse on the erosion of Zanzibar’s culture. In fact, the framing of AIDS as incurable led many to question whether it was a disease at all, since the Quran states that there is a cure for every disease. In Zanzibar there is a belief that the Quran is the ultimate medicine and source of scientific knowledge, and is supported by the belief that God can cure any disease. Therefore, many argued, AIDS had to be a direct punishment from God; which made it highly
stigmatized (Beckmann, 2012:4). An older case study from Watamu, coastal Kenya (Beckerleg, 1994), supports that Swahili medicine is pluralistic and offer sufferers a choice of therapies based on competing theories and religious ideologies. The study showed an adherence to a particular religious, Islamic based medicine which explained illness being attributed to nonmystical causes. Beckerleg (1994:2) describes that Islamic medicine is humorally constituted; where notions of hot and cold, balance, movement, and blockage forms the basis of many Swahili notions of the body and of illness. Beckerleg (1994:11) explains that numerous Swahili practitioners make up their own medicines, based on recipes given in Arab language textbooks or compounds they have developed themselves. The raw materials are sold in medicine shops of great uniformity, found in all Swahili towns. Most of the products are of plant origin; some are local roots and herbs, but the majority is imported from India, and many are known by Indian names as well as by Arabic and Swahili terms.

There is, however, considerable overlap between the literate Arab-based medicine and home remedies. Non-literate herbalists use a mixture of imported medicines sold in shops and plant material gathered in the bush or from the seashore (Beckerleg, 1994). Young & Ali (2005:6) found in their study from Pemba that among traditional treatment, it was reported using both local herbs and crystal-like substances that dissolves in water, obtained in Oman. Meier zu Biesen et al (2012:23) point that understanding Zanzibar’s healing practices implies an awareness of the so-called dawa ya suna, which forms part of Swahili traditional medicine practiced by a healer or religious leader. This religious healing, where healers access the word of God, is manifested through the Quran; often supplemented by herbal remedies. The word suna, literally meaning “good tradition”, has a strong link to the Prophet Muhammad and refers to medicine he used, things he did, and blessings he gave. Reading and writing Quran verses are essential pillars of suna medicine (Larsen, 2008, referred to in Meier zu Biesen et al, 2012). In the context of suna, diseases and/or epidemics are explained as a punishment from God or trial (Meier zu Biesen et al, 2012). Beckmann (2012) found that in Zanzibar, religious and moral concerns pose additional hurdles to the sick person. Fasting during Ramadan, for example, is an important religious requirement and a highly respected social activity, but interferes with the strictly time-bound treatment regimes among the HIV-positives. While the sick are exempted from fasting in Islamic doctrine, HIV-positive people on treatment face competing messages about their status. Many are eager to take part in the collective experience of Ramadan, others are worried about having to explain why they do not
fast. As a result, clinic staff report altering biomedical parameters and rising opportunistic infections during and after Ramadan in the islands (Beckmann, 2012).

3.2.3 Rationale of the study

Having this comprehensive literature review in mind, it is clear that Zanzibar, similar to the rest of sub-Saharan Africa, is facing an emerging diabetes epidemic that for long has been a neglected field on the political agenda. This literature review has shown that there is a web of factors influencing coping among diabetics in sub-Saharan Africa; both poverty and other socio-economic factors, limited access to modern health care, as well as diverging illness beliefs, where the occurrence of medical pluralism is a highly existing reality, with traditional health sectors side by side with the modern health care. Also relevant literature from the isles of Zanzibar reveals a society with multiple explanatory models of health and illness, which are largely rooted in an Islamic theological discourse; and with plural “experts” in the field of health, who are being equally consulted by the majority of the population. Some also found that patients in Zanzibar particularly prefer to treat diseases that are considered incurable by biomedical specialists, such as diabetes, with traditional medicine. This is the starting point of moving into a field which is largely unexplored; namely local diabetes care and coping among diabetics on the isles of Zanzibar. Also the fact that no previous study in the Africa region seemingly has investigated coping among diabetics in a Muslim society, and particularly in relation to Ramadan fasting, highly justifies this study, which partly was carried out exactly during this month. The UN Political Declaration on NCDs listed among their specific commitments for relevant stakeholders to promote and support research in this field (United Nations, 2011). Still, IDF (2013) points that research is slow to respond to the burden diabetes represents to sub-Saharan Africa, and remain focused primarily on infectious diseases. Mbanya et al’s (2010) review on diabetes in sub-Saharan Africa, stresses exactly that anthropological perspectives are needed to elucidate the causes, prevention, and control of diabetes, especially in Africa, where health outcomes are highly dependent on cultural variables. In-depth qualitative research will complement findings of quantitative epidemiological research (Mbanya et al, 2010). A qualitative, anthropological approach is exactly what has been applied in this study, and this takes us to the next chapter; the theoretical foundations of the project.
4 Theoretical perspectives

Diabetes self-management education

During project planning, it was largely made use of theory revolving around the concept of diabetes self-management education (DSME). According to IDF (2012a:22), it is widely accepted that diabetes education is an important component of care for type 2 diabetes patients. Type 2 diabetes is a lifestyle disease that requires the person living with the disease to self-manage and make numerous daily decisions regarding food, activity and medications. It also necessitates that the person has to be proficient in a number of self-care skills, like blood glucose monitoring, foot examination and taking medications (IDF, 2012a). *Self-management* refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (IDF, 2012a). Effective diabetes-related *coping* involves identifying factors contributing to current and near-future glycemic status (i.e. life stress or physical stress), having the knowledge and skills to evaluate the circumstances and respond appropriately, implementing a new treatment strategy or behavior, and having access and willingness to use a health care professional or support person who can help solve problems and collaborate in a treatment decision (American Diabetes Association (ADA), 2012). DSME is defined as the ongoing process of facilitating the knowledge, skill and ability necessary for diabetes self-care (IDF, 2012a; ADA, 2012). Promoting knowledge is not enough and effective educational strategies require attention to behavior change. Diabetes self-management education is considered successful when patients are able to translate the information and skills into behavior change (IDF, 2012a), and the concept itself is largely derived from theories on behavior change (American Diabetes Association, 2012). Though the literature on diabetes education highlights the importance of taking account of culture, ethnicity and psychosocial issues; this concept is also largely developed and applied on the basis of western and biomedical contexts and discourses; and with an evidence base from western societies. Therefore, the researcher since the initial stages considered it essential to additionally apply theories of medical anthropology, with the emphasis that a society’s health-care system cannot be studied in isolation from other aspects of that society, especially its social, religious, political and economic organization (Helman, 2007).
Medical anthropology and the work of Kleinman

Particularly the work of Arthur Kleinman was assessed. According to Kleinman (1980:72), a key axiom in medical anthropology is the dichotomy between two aspects of sickness; disease and illness. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability. Both the meaning given to symptoms and a person’s emotional response to them are influenced by his or her own background and personality, as well as the cultural, social and economic context in which the symptoms appear. Illness is the shaping of disease into behavior and experience (Helman, 2007; Kleinman, 1980). Disease on the other side is what the practitioners have been trained to see through the theoretical lenses of their particular form of practice. The practitioner too has been socialized into a particular collective experience of illness (Kleinman, 1988). Kleinmans’ explanatory model describes the notions, held by both patients and practitioners, about an episode of sickness and its treatment that are employed by all those engaged in the clinical process. They offer explanations of sickness and treatment to guide choices among available therapies and therapists and to cast personal and social meaning on the experience of sickness. They provide explanations of five main questions: (1) aethology (cause of condition), (2) time and mode of onset of symptoms, (3) pathophysiology, (4) course of sickness (including degree of severity), and (5) treatment (Kleinman, 1980: 105)

This brings us to health-care pluralism and Kleinman’s three overlapping and interconnected sectors of health care; the popular sector, the folk sector and the professional sector. The professional sector comprises the organized, legally sanctioned healing professions, normally modern Western medicine or bio-medicine (Helman, 2007; Kleinman, 1988). The practitioners of scientific medicine form the only group of healers whose positions are upheld by law, and they have the power to question and examine their patients, and label them, sometimes permanently, as ill or incurable, a label that may conflict with the patient’s perspective. Modern Western medicine is unique in the increasingly important role, both practical and symbolic, played by technology in both its diagnosis and treatment. In modern medicine, the machine is an intrinsic part of almost every doctor-patient interaction, and in many non-industrialized societies, even the simple syringe is seen as being the very embodiment of modern Western medical science (Helman, 2007). Helman (2007:123) stresses that the medical perspective assumes that diseases are uniform in form, progress and content, and that they will have recurring identity. This perspective does not include the
social, cultural and psychological dimensions of ill health, and the context in which they appear. Bio-medicine can be regarded as the ethno medicine of the Western, industrialized world, and it is important to realize that for all its power and prestige, Western biomedicine provides only a small proportion of health care in most parts of the world (Helman, 2007).

The popular sector is the lay, non-professional, non-specialist domain of society, where ill health is first recognized and defined and health-care activities initiated (Helman, 2007; Kleinman, 1988). This sector is made up of a series of informal and unpaid healing relationships of variable duration, which occur within the sufferer’s own social network, particularly the family (Helman, 2007). In the folk sector, which is especially large in non-industrialized societies; a wide variety of non-professionalized and usually non-institutionalized specialists, with individuals specialized in forms of healing that is either sacred or secular, or both, occupies an intermediate position between the popular and professional sectors (Kleinman, 1988; Helman, 2007). Most folk healers share and reinforce the basic cultural values and world-view of the communities in which they live, including beliefs about the origin, significance and treatment of ill health. Their approach is usually a holistic one, dealing with all aspects of the patient’s life, including relationships with other people, with the natural environment and with supernatural forces, as well as any physical or emotional symptoms (Helman, 2007). Helman (2007:85) highlights a group of healers which are seen in many Third World countries nowadays, namely the untrained injectionists; who administer biomedical medicines and injections. These modern would-be folk healers are able to acquire their healing knowledge from books, correspondence courses, or the internet.

Finally; one need to highlight that ill people, in any society, move freely between the popular, folk or professional and back again, often using all three sectors at once, especially when treatment in one sector fails to relieve physical discomfort and emotional distress. People make choices, not only between different types of healer, but also between diagnoses and advise that makes sense to them and those that do not. These choices are influenced by the context in which they are made, including the types of helper actually available, whether payment for their services has to be made, whether the patient can afford to pay for these services, and the explanatory model that the sick person uses to explain the origin of ill health (Helman, 2007).
Foucault and the concept of power-knowledge

After fieldwork, the researcher dug increasingly into the work of the postmodern theorist Michel Foucault, which emerged as a useful tool to address the complex realities encompassing diabetes care and coping among diabetics in Zanzibar. Especially one of his fundamental concepts; *power-knowledge*, has been applied. Foucault (1980:133) suggests that *truth* is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extend it; a regime of truth. Knowledge and truth, like everything else, have a history; one which is closely related to the way in which operations and relations of power have been transformed over the last centuries. Knowledge and truth are not essential and ahistorical, but are produced by epistemes and, at the same time, hold that episteme together. Foucault’s concept of epistemes –periods of history organized around, and explicable in terms of, specific world-views and discourses – shows that the way in which people make sense of their world depends on an order of reason and sets of discursive formations that do not translate from one to another. They are the grounds on which we base everything, so we more or less take them for granted. Foucault argues that there is no true state of existence, since our understandings of ourselves and our lives are always filtered through the ideas, discourses and institutions that constitute society. He problematizes the question of truth, and wants to show the extent to which it is an effect of the work of discourses and institutions, rather than being absolute or essential (Danaher, Schirato & Webb, 2000). Thus for Foucault, one of the most significant forces shaping our experience is language, or in other words discourses. *Discourses* can be understood as language in action; they are the windows which allow us to make sense of and see things. These discursive windows or explanations shape our understanding of ourselves, and our capacity to distinguish the valuable from the valueless, the true from false, and the right from wrong. Discursive formations are defined as much by what lies outside them as what lies within. The discursive formation of science for instance is also defined in relation to areas from which it distinguishes itself (Danaher et al, 2000). Danaher et al (2000:36) point that Foucault’s work on discourse has implications for understanding the operations of institutions. Public institutions draw their authority from their capacity to *speak the truth*. Foucault (1980:93) states that in any society, there are manifold relations of power which permeate, characterize and constitute the social body, and these relations of power cannot themselves be established, consolidated nor implemented without the production, accumulation, circulation and functioning of a discourse. Each society has its regime of truth, its “general politics” of truth.
There can be no possible exercise of power without a certain economy of discourses of truth which operates through and on the basis of this association. We are subjected to the production of truth through power and we cannot exercise power except through the production of truth. There is also a constant *battle for truth*, which is largely about the status of truth and the economic and political role it plays (Foucault, 1980). Dominant disciplines and discourses are the results of power struggles in which they have triumphed over other disciplines and forms of knowledge (Danaher et al, 2000).

Foucault through the concept of power-knowledge goes beyond the conventional view that the development and acquisition of knowledge necessary makes people more powerful, or is “good for them”. Rather, knowledge is something that makes us its subjects, because we make sense of ourselves by referring back to various bodies of knowledge. Discipline and knowledge *make us* certain kinds of people, and disciplinary power accords a person a space within an institution and a rank within a system. Knowledge, or discourses, authorizes and legitimates the exercising of power. Foucault distinguishes his approach from those models that understand power in terms of force imposed from above, by viewing power as a set of forces, or quiet coercions, which establishes positions and ways of behaving that influence people in their everyday lives. He argues that knowledge and truth are produced out of *power struggles*, and they are used to authorize and legitimate the workings of power. Foucault does not think of power as a thing to be owned or held by somebody, but as a ubiquitous and ever-changing flow (Danaher et al, 2000). Power must be analyzed as something which circulates, or rather as something which only functions in the form of a chain. It is never localized here or there, never in anybody’s wealth. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising this power. Individuals are the vehicles of power, not its points of application (Foucault, 1980). The way in which this flow moves around depends on how different groups, institutions and discourses negotiate, relate to and compete with one another. Just as information and knowledge are diffused and multiplied across a culture, so is power. Power is mobile and contingent; it moves through different groups, events, institutions and individuals, but nobody owns it (Danaher et al, 2000). Another important point Foucault makes about power, is that although power acts on people in a non-egalitarian way, at the same time it works on everybody, the dominant as well as the dominated (Danaher et al, 2000:77). Foucault (1980:119) points that what makes power hold good, what makes it accepted, is the fact that it does not only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure,
forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression. Another important point is that power never achieves what it sets out, or claims, to do; as the rules by which some people are produced as normal, and others are excluded, ensures that opposition and resistance are built in effects. Thus, power is never able to completely control things because it always produces resistance. Foucault (1980:97) states that one should try to locate power at the extreme points of its exercise, where it is always less legal in character. He states that there are many different kinds of revolutions, roughly speaking as many kinds as there are possible subversive recodifications of power relations.

The quiet coercions and monitoring gaze, or surveillance, associated with disciplinary forces have become pervasive throughout the social body of modern western cultures. The power of the gaze establishes an “economy of looks” that distributes value throughout the social body, so that the idea of looking, or gazing, is associated with power, knowledge and value. The role of the gaze has for instance played a significant part in the field of health; where biomedicine acts as the most socially and institutionally privileged knowledge of the body. On a wider social level, the gaze is also a mechanism for the monitoring and control of public health (Danaher et al, 2000). Foucault suggests that the judges of normality are everywhere, throughout the social body. The process of distinguishing people is what Foucault calls dividing practices; which work to qualify or disqualify people or practices as fit and proper members of the social order. Modern western societies, and the disciplinary institutions that compromise them, organize their practices through actively producing scandalous identities or subject roles who serve as the other against which normality can be measured. So institutions, and the subject roles they make available, are constantly being judged in terms of their relative normality or abnormality (Danaher et al, 2000).

The work of Foucault is also criticized; for instance are one of the ideas associated with Foucault that people are completely dominated by and subject to power. This usually gets translated into a notion that we are merely the dupes of dominant social groups, never knowing what we do, and therefore unable to resist power (Danaher et al, 2000). Danaher et al (2000:4) though points out that there is actually nothing in Foucault’s work that conforms to this notion, but that this has not stopped it from being one of the truths of Foucaultian theory.
Farmer and the concept of structural violence

Additionally, the study is inspired by the concept of structural violence, which according to Dr. Paul Farmer (2004) describes the social machinery of oppression against the poor. It describes social structures; economic, political, legal, religious, and cultural; that stop individuals, groups, and societies from reaching their full potential (Farmer, Nizeye, Stulac & Keshavjee, 2006). Structural violence is often embedded in longstanding ubiquitous social structures, normalized by stable institutions and regular experience. It is linked very closely to social injustice and the social machinery of oppression (Farmer et al, 2006). Farmer (2004) views oppression as a result of many conditions, not at least the ones that reside in consciousness, which necessarily implies the need to examine the roles played by the erasure of historical memory and other forms of desocialization as enabling conditions of structures that are both “sinful” and ostensibly “nobody’s fault”. Structural violence is violence exerted systematically, indirectly, by everyone who belongs to a certain social order (Farmer, 2004). Farmer (2004) stresses that any thorough understanding of the modern epidemics requires a thorough knowledge of history and political economy; the fact that there are large-scale social and economic structures in which affliction is embedded. A syncretic and properly biosocial anthropology of plagues moves us beyond noting, for example, their strong association with poverty and social inequalities to an understanding of how such inequalities are embodied as differential risk for disease and for adverse outcomes including death, as well as differential access to new diagnostic and therapeutic tools now available to the fortunate few (Farmer, 2004).
5 Methodology

Due to the aim of this study, a qualitative, exploratory approach was applied. A qualitative research is a theoretical and methodological focus on complex relations between personal and social meanings, individual and cultural practices, and the material environment or context (Ulin, Robinson & Tolley, 2005). It is suitable when we want to learn more about the human qualities, such as experiences, perceptions, thoughts, expectations, motives and attitudes (Malterud, 2011). We can ask for the meaning, importance and nuances of events and behavior, and we can strengthen our understanding of why people behave as they do. We can explore dynamic processes such as interaction, development, and wholeness (Malterud, 2011). Sampling methods in qualitative research are based on purpose rather than on statistical probability of selection (Ulin et al, 2005).

The data was collected through in-depth interviews. The time frame the researcher had available for data collection was limited to three months, which made it logical to focus on doing one method well. Also with a mainly self-financed, limited budget available; it was unrealistic taking on too much. Prior to the field work, the researcher considered thoroughly whether or not to triangulate the methods in terms of including also systematic observations. Observation is recommended if you want to see how something happens rather than how people perceive it happening, to gather your own impressions (Ulin et al, 2005). This could have helped to validate interview data that the study participants reported, for instance when it came to their practices. In the end, the researcher decided to exclude this method; mainly due to practical reasons such as time limit. It was a big chance of ending up with too much material, which might have had resulted in superficial analyses (Malterud, 2001). Also, to observe among others clinical settings when not speaking the local language fluently; would be, off course possible, but problematic. There would have been a more or less constant need of an interpreter; which could have turned out more or less successful. Considering the limited time frame for data collection, it would not have taken many obstacles to make things go wrong. If the cooperation with the interpreter for some reason had not turned out well; it would have been critical for especially the results from the observations. The idea was that the interviews with other participants from the community, including the diabetics themselves; would supplement and balance the interview data from the health care providers. The triangulation of participant sample also turned out to be even more prominent than planned, which will be described later. That said, informal observations and conversations were
constantly made and a log was recorded throughout the fieldwork. This turned out to be valuable for the analysis process and the writing of the report. It was also initially planned to conduct a focus group discussion with health care providers at the beginning of the data collection, as focus groups can be valuable to get an overview of the field you are entering. This though proved to be difficult due to practical reasons; the research naturally started up at the diabetes clinic at Mnasi Mmoja, the main referral hospital on the isles, where there were a limited number of health care workers who were simply very busy in their everyday work. Additionally Ramadan started shortly after the start of the field work, and after their working day, the health care workers, like everyone else, were occupied with their obligations related to this holy month. All in all, it was practically difficult to arrange a focus group discussion. Eventually, it also turned out that rich information was adequately gathered through in-depth interviews. This therefore ended up as essentially an in-depth interview-study. The nature of the qualitative interview is the unique interactive approach, differentiating it from the standardized survey interview. In a relaxed and comfortable setting, the conversation is meant to generate empirical data by enabling participants to talk freely (Ulin et al, 2005). Semi-structured interviews were conducted with the participants, which imply the typical qualitative questions, being informal, non-judgmental, and open, with open-ended questions and probes (Ulin et al, 2005).

5.1 The path towards the research objective

This study initially started with objectives aimed at mapping the community’s, with an emphasis on the health care workers’, perceptions on diabetes self-management education, as little research was found on how health care workers perceive training and educating diabetics in self-care in a resource constrained setting such as Zanzibar. Thus; the objectives, with its western terminology and the emphasis on biomedical health care workers, alluded to a largely biomedical approach, although the researcher was aware of the folk- and the popular sector being highly existing in Zanzibar, and also in the planning stages acknowledged and stressed that the sample was going to include different informants from the community, including diabetics; as a heterogeneous sample might highlight variation, or similarities, of the phenomenon (Ulin et al, 2005). Qualitative research though is exactly explorative; the study design is never fixed, there is rather a constant interplay between design and discovery. The investigator is supposed to be in touch with the research process, observing how participants
respond to the topic and examining data for fresh insights that might lead to altering a

As new themes emerged through the process of data collection; it proved to be even more
crucial to include the local diversity of realities revolving around this phenomenon, than the
researcher had foreseen in the planning phase. Thus, the sample naturally evolved to include
almost as many diabetics as health care workers, in addition to a number of informants from
the folk- and popular sector, as well as other key informants. This gave a more accurate
description of the phenomenon, as diabetes, coping and related counseling and care in
Zanzibar is a complex matter in a complex society; anything but an encapsulated, uniform
bio-medical process. The objective was therefore adjusted, where the final objective was to
increase understanding of local diabetes care and coping mechanisms among diabetics in
Zanzibar. The data collection revolved around three specific objectives; to describe the
different venues diabetics use for counseling and care; to explore local health care providers’
perceptions of diabetes and diabetes care; and to investigate coping mechanisms among
diabetics and associating factors.

5.2 The research participants, participant
recruitment, and the research sites

In the research planning the goal was to include a minimum of 15 participants, due to the
limited time frame. In the end, 20 research participants took part in the study, and they
consisted of type 2 diabetics over the age of 18, health care workers, traditional healers, and
other participants from the community somehow involved in diabetes care, or otherwise being
in a position of providing useful insights on the topic. This encompassed what is believed to
be a diverse, heterogeneous group of persons representing the Zanzibari context. Interviewed
were seven both rural and urban type 2 diabetics of different age, sex, occupation and duration
of being diseased. Interviewed were also eight health care providers of different professional
background, age, sex; working in both urban and rural areas of Unguja, in both public and
private sectors. Many of them also had working experience in diabetes care on the island of
Pemba. Their professions included a medical doctor specialized in diabetes, assistant medical
officers and clinical officers, and nurses. One should mention a couple of words about the
clinical officers and assistant medical officers, as they are nonexistent in the west, but quite
common in Zanzibar. These “mini-doctors” had minimum three years of higher education,
just as the nurses; and they basically served as doctors, especially the assistant medical officers; including prescribing medication. According to the 2013 Socio-Economic Survey, there were 54 assistant medical officers and 130 clinical officers in Zanzibar, compared to 26 medical doctors (Zanzibar Office of the Chief Government Statistician, 2013), which is believed to reflect their strong position in the health care. Additionally, it was interviewed two traditional healers, one male and one female, both running their traditional clinics in Zanzibar town; one female relative of a diabetic in the countryside; one imam from Zanzibar town; one diabetes educator (a diabetic himself); one key person (also a diabetic) from the Diabetes Association of Zanzibar (DAZ); and one key person at the NCD unit at the Ministry of Health.

All the participants were recruited from the island of Unguja. In the planning phase it was thought of doing part of the data collection on Pemba, as this could have further triangulated the sample in terms of especially the more remote and rural population of this island. When data collection commenced, it turned out that it out of practical reasons were more productive to remain on Unguja and concentrate on collecting sufficient participants from there. Firstly, participant recruitment in Zanzibar took time. It happened for instance occasionally that you could have a planned an interview with someone, who suddenly did not show up when the time was there. This might be due to various reasons; one is believed to be that a large part of the data collection took place during the holy month of Ramadan, which Zanzibaris are highly dedicated to, and thus influenced their priorities this period. Another experience is that Zanzibaris generally are not that concerned with rigid timeframes and tend to relate loosely to appointments; “pole pole”, take it easy, is frequently used in their vocabulary. That said, “hakuna matata”, no worries, is also a saying in this culture; people are genuinely friendly, helpful and hospitable; and there comes a time for action, eventually. Meaning; that even though recruitment was time-consuming, the variety of participants on Unguja turned out be sufficient, also in terms of triangulation, as you find among others the contrasts between urban and rural parts by remaining only on this island. Additionally, the bureaucracy of applying for various required, and costly, permits also proved to be rather complex and time-consuming. Travelling to collect data in Pemba; there would have been a need for additional governmental permits to access the areas or health facilities concerned. There would also have been a completely new setting, where one had to have formed contacts from scratch; compared to Unguja where the researcher already had a social network, which will be elaborated on later. Also the recruitment techniques of qualitative methodology, such as
snowballing, requires a starting point in terms of contacts; which all takes time to build up. This also includes the role of the research assistant (also further described later), who turned out to be a central part of the data collection process; as she was situated on Unguja. All in all, this resulted in the researcher deciding to remain on the island of Unguja for the data collection.

The data collection had its natural starting point at the diabetes clinic at the only referral hospital in Zanzibar, Mnasi MMOja. It is situated in Zanzibar town on the island of Unguja, and shares its premises with the Ministry of Health including ZAMREC, Zanzibar Medical Research and Ethics Committee. Thus, the researcher obtained the research permissions from ZAMREC simultaneously as obtaining permissions from the hospital management. The researcher also lived in walking distance from these premises. Mnasi MMOja is always crowded with people, both inside the premises and alongside the road outside, where you find provisional little kiosks selling snacks, or ladies basically sitting along the road selling their home-made food. This is aimed for the patients inside of the hospital, whose’ relatives are responsible for providing them with food while being hospitalized. The roads are also hectic, with cars, scooters and dala-dalas, the local minibuses; bringing people to and from town. Inside the hospital premises, the first thing that meets you is a queue of female relatives sitting waiting for visiting hours, with jugs and bowls with food and drink, so to see their respective and provide them with food. Wall to wall with this, on the ground floor, you find the diabetes clinic. In this setting, you found the persons, in terms of health care workers, with highest expertise and knowledge in the field of diabetes care in Zanzibar, thus, a considerable time was spent there on both formal interviews but also on informal conversations and observations, among others of individual consultations and the weekly diabetes group education sessions. Some of these health workers were largely among the key persons in the diabetes care in Zanzibar; they were involved in the politics and planning, and had also been a part of the team carrying out the recently published NCD Risk Factor Survey. Both health care providers and diabetics were recruited through this site; where the researcher and/or the research assistant made contacts in a discreet manner, informed the person orally about the study, and ask if he or she would like to participate. If yes, the person was provided the information sheet; and usually had a few days to consider it thoroughly. The health care workers were interviewed in a room at the clinic according to their own wishes, while diabetics were interviewed either in their own home, or at the researcher’s residence,
whatever suited the participants best. Some of the other key persons in this study were also recruited through snowballing from the diabetes clinic.

During the data collection at Mnasi Mmoja, the researcher got to know about the regular visits the health workers at the diabetes clinic made to the diabetes clinics at the two cottage hospitals in the rural areas north and south of Unguja, and that it was possible to join their transport there. After some struggle, as these visits suddenly were removed from the agenda; the researcher and the assistant joined, not the health workers from the diabetes clinic, but from other fields of the health sector; their transport to the cottage hospital at north. This visit was clarified with the cottage hospital management ahead of it. The diabetes clinic on these premises was open once a week, compressed into a tiny room at the cottage hospital. The waiting area outside was typically full of diabetic patients, men and women mixed in this case. Similar were the circumstances at the cottage hospital south on Unguja, which also was used as a location for data collection. At the northern clinic, both health care workers and diabetics, including a relative of a diabetic, were recruited, while at the southern clinic, only health care workers were recruited. The diabetics were in these cases out of practical reasons interviewed the same day as they got the information about the project and agreed to participate. All the interviews were carried out in a room where you had privacy at the hospital premises, according to the participants’ wishes.

Additionally, there were recruited health care workers through one of the common, small private primary care clinics or so-called dispensaries in town that the assistant knew of. These were approached due to being highly attended by diabetics on everyday basis for check-ups, substantially blood glucose monitoring. There turned out to be small problems recruiting from these facilities; from one potential participant who suddenly had traveled to mainland the day we showed up for a planned interview, to others who were basically not interested in participating. Finally, one assistant medical officer from this clinic was happy to join the research. Also the first traditional healer was recruited through the assistant, who knew of him from before. In turn, he arranged contacts with the other traditional healer who participated in the study. It was also an attempt to recruit diabetics through this healer, which turned out to be more difficult. He told initially that he would gladly put us in contacts with diabetics, but through frequent phone contact this nevertheless proved difficult to arrange. The day of the actual interview at his clinic, there were several admitted patients in the premises. After the interview, the traditional healer showed us around, and gladly offered us to talk to them, as
some of them allegedly were diabetics. These patients though were in fact critically ill; most had recently undergone strokes, seemed cognitively impaired, and lay in bed with indwelling catheters and other relatively advanced biomedical equipment; which the traditional healer and his assistants apparently administered. The fact that these critically ill persons found themselves in a traditional clinic and not in a hospital, made the researcher have the feeling of conducting interviews with them being not ethically sound; thus, this was politely turned down. The second healer also offered to create contacts with diabetics, but this interview was conducted late in the data collection process; so there was found being too little time to follow this up properly. The day we carried out the interview, there was also no diabetic at the traditional clinic to recruit. Additionally, it appeared during the course of data collection how influential the religious leaders, the imams, were on diabetics in this society, especially in the times of Ramadan. Thus, to get an imam’s perceptions on this topic, an imam was recruited through a relative of the researchers’ cohabitant, and this interview was carried out at the researchers’ residence. Most of the other key persons in this study were as mentioned recruited through snowballing. These interviews were conducted respectively in the researchers’ residence with the board member from DAZ, and in a diabetes educators’ village in the countryside, where the shehe (local leader) of the village approved the interview and provided us a meeting room in a small sort of common building. The researcher approached the NCD Unit by seeking the Ministry of Health, where she was kindly provided the right contact information. This interview was carried out at the NCD Unit premises.

5.3 Data collection

The data was collected during a field work period that took place between June 26th and September 20th 2013. The holy month of Ramadan took place within this period, which highly left its mark on in the insights provided by this study. Prior to the data collection, the researcher and the assistant, together with the researchers’ fellow student and her assistant; did interview exercises, including the use of the tape recorder the translation process, and the techniques of the qualitative interview, such as active listing, asking open-ended and not leading questions, and probing and follow-up questions. Both the researcher and the assistant experienced this as a valuable practice ahead of what was coming. There were also spent much time where the researcher elaborated on the research topic, the qualitative methodology, and ethical considerations in relation to research; followed by the assistant giving valuable
feedback. Eventually, the small team got more prepared and synchronized to the task that awaited. As data collection started, every interview was prepared ahead, and they were based on interview guides; which provides flexibility, but also the structure needed to keep track of essential themes and make the data more comparable for analysis. The interview guides were adjusted according to the scheduled informant. (See appendix 1-4 for examples of interview guides.) However, interviews were all in all loosely constructed, and the conversations naturally often spanned beyond the guide; which brought up valuable information. The interviews generally lasted around one and a half hour, with a few exceptions of less than half an hour to almost two hours. It was noticed that exceeding more than one and a half hour, some participants started getting restless, although they never said so explicitly. This applied particularly to the health care workers. Though, this was only limited to very few cases; and most of the interviews were wrapped up before people seemed to start having enough. There was also naturally a variety of how information-rich each and every interview turned out to be; some people eager to talk, others not. Most people though seemed to find it positive and enriching to participate in the interview, and some could have continued the conversation far beyond two hours. This often provided rich, unexpected information, but in those cases it was also valuable with the interview guide to get on the right track when the conversation went too far off the topic. Others seemed to be a little nervous and tense in the beginning of the interview, but always seemed to relax more during the course of it. For those, it was experienced especially important with adequate probing and follow-up questions. All in all, people tended to open up more longer into the interview and seemed more comfortable in the setting; which also made the relatively long sessions valuable after all. The main drawback doing in-depth interviews is that participants might say things that not necessarily reflect the truth; in terms of saying what they think you would like them to say. Though, the diverse sample in this study is believed to have leveled out and balanced that risk. Additionally, the researcher naturally throughout the fieldwork made informal observations of the clinics and hospitals, the traditional healer clinics, and the Zanzibari society in general. This included informal conversations with people and with the research assistant in particular. All this also contributed to a comprehensive understanding of the field. Due to the interviews turning out to be rather lengthy, and as the topics appeared to be sufficiently covered by one interview session; the researcher did not see the need for repeated interviews. Only in one case a repeated interview was carried out, with a key person at the diabetes clinic at Mnasi Mmoja; which was all in the end of the field work with the intention of wrapping it up with some few
final questions. It was emphasized spending time recruiting and conducting interviews with new informants, as this as mentioned turned out to be fairly time-consuming.

All the interviews were tape-recorded, after permission from the participants. Due to data collection largely taking place during Ramadan, the researcher was careful with offering snacks or drinks during interviews conducted this period, as this might have been taken as an insult. Apart from that, snacks or drinks were offered. Either the researcher or the assistant took notes throughout the interview, depending on whether it was conducted in English or in Swahili. For the informants who felt comfortable with carrying out the interview in English, this was done; and the researcher conducted it mainly by herself, while the assistant took notes. However, it often happened that the conversations could switch between English and Swahili, and here the assistant naturally stepped in. For the informants who did not have sufficient English skills, the assistant functioned as a continuous translator between the researcher and the informant; where the researcher asked the question, the assistant translated the question, for then to translate back what the participants had replied. Sometimes this translation could be rather time-consuming, but eventually it was worked out a well-functioning flow of the oral translation, where the assistant became proficient at extracting the main points. All in all, it was apparent how the team work improved during the course of data collection. Both the researcher and the assistant, both being novice researchers; became more and more familiar with each other and the research process; thus, a more functional flow of conversations and cooperation in general was facilitated. There was also an increasing improvement of the small team in terms of the qualitative interview technique, such as probing and being open for emerging themes, and to avoid leading questions. This is believed being largely due to the continuous conversations between the researcher and the assistant, also subsequently after every interview; where the interview was discussed upon; how the process went on, what could be improved for next time, and information gained from it. Additionally, the researcher wrote her reflections from the interview down in her log the same day the interview was done. This also contributed to an improvement of how the interviews were conducted. The interviews were then transcribed into English; respectively by the researcher for the interviews conducted in English, and by the assistant for the Swahili interviews. The assistant was constantly reminded of the importance of verbatim translations. How quickly the transcription was done after each interview somewhat varied; as the intervals of days between the interviews varied. Initially the aim was to do only one interview per day, as the risk is greater that the analyses may become superficial when too many interviews are
performed (Dahlgren, Emmelin & Winkvist, 2007). This was largely followed, although there were cases where there were obvious reasons, such as travelling far out on the countryside with a hospital transport to conduct interviews at a cottage hospital; were conducted up to three interviews in one day. This though only belonged to one or two cases. All in all, to do the transcription as quick as possible after the interviews was always emphasized, as it is essential so that saturation can be identified in a proper way (Dahlgren et al, 2007). For most of the transcriptions, the researcher and the assistant also sat down together after they were completed and went through them word by word. In this way, uncertainties were clarified, and it often brought up and illuminated cultural aspects that the researcher otherwise might not have thought of; which was useful for the analysis. Notes were then added in linked memos in the transcripts. These continuous discussions and reflections within the small team throughout the fieldwork guided the preliminary analysis and the progression of the data collection process.

### 5.4 Analysis

Analysis of data was integrated in the fieldwork as a part of an abductive approach, where the process was oscillating between data and theory. In this way; sampling procedures, data collection and interpretation interact with each other (Dahlgren et al, 2007). In other words, the preliminary analysis were, as elaborated in the previous chapters, a continuous part of the entire data collection process, where the researcher made use of and reflected on, as well as on the collected data, on field notes, on relevant theory, on informal observations and conversations, and on conversations with the assistant, as well as with the researchers fellow student who did her own separate field work on Zanzibar the same period, and with the researchers’ cohabitant who originally is from Zanzibar and was there during the period of data collection; to guide the progress of the work. The notion that a social phenomenon cannot be understood outside its context was essential throughout the analysis. We bring context into analysis by considering how informants’ stories are shaped by their social position, economic opportunities, or religious convictions and how narratives are imbedded in the broader social, economic, and political environments in which informants live (Ulin et al, 2005). Through these continuous reflections, a growing understanding of the field was obtained; which explicitly was used to identify the emerging themes and gaps in understanding, in turn guiding the decisions revolving around for instance the recruitment of
participants, and adjustment of interview guides; as well as to facilitate reflexivity, an account of how the researcher herself, as well as the assistant, influenced the process.

The sequence of interrelated steps in data analysis is: reading, coding, displaying, reducing, and interpreting (Ulin et al, 2005). The reading, coding and initial interpretations were as described started on while being in the field. Upon returning from the fieldwork, all the transcriptions were re-read simultaneously as the corresponding recordings were listened through; for the purpose of getting as familiar with the material as possible. Including listening to the message content, both explicit and implicit, it is was also noticed quality of the data, especially with regard to methodological problems which have an impact on the credibility of the data, such as giving greater consideration to responses obtained through open-ended questions and less to those obtained through leading questions. Thus, the questions involved in an answer were always included in the coding sorts, for the purpose of keeping track of exactly the quality of the data. Again, all the notes and experiences derived from the field were made us of. Additionally, a Tanzanian first year student from the researchers’ master program agreed to do a quality assurance of the Swahili-to-English transcripts. He read through two of the transcripts while listening to the corresponding recordings, and they turned out being overall accurate and verbatim. In this way, the quality of the translated transcripts was assured. The data were after the re-reading systematically coded into themes and sub-themes, using the qualitative analysis software program Nvivo. Coding started using fairly broad labels, which mainly corresponded to the research objectives; then new, more inductive themes emerged as coding progressed. Thus, a mix of deductive and inductive codes was developed. All the transcripts were systematically examined twice; where some codes merged, some were added, and some were removed. The evolving coding scheme was kept track of in a notebook. After the coding, all the coding sorts were printed out and examined more closely manually; where the richness and variations of each theme was assessed. Finally, through the data reduction process the themes were organized and interconnected into overarching topics; which then were interpreted in form of a master thesis. In this stage of the research, there were also frequent meetings and other correspondence between the researcher and her supervisor, where the emerging results were discussed upon, and valuable input was provided. A constant review of literature was also emphasized throughout the research process.
5.5 Ethical considerations

Prior to the fieldwork, the researcher applied and received reply from REK, the Norwegian regional committees for medical and health research ethics, on a so called remit assessment; that the project did not need their ethical approval, since it “did not fall under the law about health related research” (appendix 5). Subsequently, the project was submitted for ethical clearance at the Data Protection Official for Research at the Norwegian Social Science Data Services, where it was approved (appendix 6). The project was also prior to entering the field submitted to ZAMREC, Zanzibar Medical Research and Ethics Committee. At first, the project was “approved with recommendations”, where there were small corrections that needed to be clarified before the process of data collection (appendix 7). Arriving Zanzibar, the researcher submitted the revised copy to ZAMREC, and the study was approved (appendix 8). Additionally, the researcher was after arriving Zanzibar made aware of the project also needing a research permit from Zanzibar Research Committee at the Office of Chief Government Statistician. After a few days delay due to some misunderstandings at the office, where there was given conflicting messages about what forms and documents that were required for the application; the project was finally also granted from there (appendix 9).

Ethics to research involving human subjects should be conducted in accordance with the ethical principles of autonomy, beneficence, non-malevolence, and justice (Dahlgren et al, 2007; CIOMS, 2002). To safeguard autonomy, the researcher obtained an informed consent from all the participants. An informed consent means that the study participants understand: possible risks and benefits; voluntary participation; assurances of confidentiality; the purpose of the research; how they were chosen to participate; data collection procedures; and whom to contact with questions and concerns (Ulin et al, 2005). Voluntary participation includes that the participant has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation; and that she or he has the right to withdraw at any time (CIOMS, 2002). The information letter and the consent form were prepared both in English and in Swahili. The Swahili version was prepared by the assistant. The information letters were based on the initial research objects, but the overall topic highlighted was nevertheless diabetes care- and self-care, and it was specified that it was due to possessing valuable information in relation to this topic that participants were recruited for the study (informed consents see appendix 10-11). To ensure that the participants had adequately understood the information and were willing to participate, the researcher and/or the assistant
were, in addition to obtaining a written informed consent; also talking to them and getting an impression of how satisfied they truly were. A couple of the research participants were illiterate, thus, oral information was provided and an oral consent was obtained from those. All the participants were also prior to and after the interviews explicitly asked if they had any questions or concerns regarding the research.

*Non-malevolence* is to a large extent related to confidentiality and privacy (Dahlgren et al, 2007). The data was stored on a password-protected computer where only the researcher had access. Additionally, the assistant also possessed transcriptions during the data collection process, which were stored on her private computer. The exchange of transcriptions between the researcher’s and the assistant’s computers involved that they were either transferred via a memory stick or by e-mail. The data stored on the assistant’s computer and on the two mail accounts were deleted after the field work period. Note book, tape recorder, consent forms and name list were kept inaccessible to others than the researcher, and partly the assistant, during field work. All types of field notes, data and the tape recordings were deleted at the time of completion of the master thesis. The assistant was initially taught and as an ongoing process reminded of the essential ethical principles of conducting research. It was considered whether or not the assistant should have signed a contract where she would have declared confidentiality, but finally this was instead decided to be maintained through an oral agreement after the assistant was thoroughly taught and consistently reminded of the ethical principles at play. Further, there was used the common practice of coding (Ulin et al, 2005) to protect personal identity; meaning that participants were never connected to their names in transcripts or coding sorts, but rather to a specific letter which was specified in a name list only accessible to the researcher. The name list and the consent forms were kept separate from the data. In the final report, the participants were referred to using broad descriptive codes, such as being respectively a diabetic or a health care worker; as well as an id number for each participant. Qualitative data are, as Richards & Schwartz (2002) states, full of clues to participant’s identities. This is particularly true where the study is based on a small and distinctive selection (Den nasjonale forskningsetiske komité for medisin og helsefag (NEM), 2010; Malterud, 2011), which exactly is the case here. NEM (2010) points that the risk of being recognized can be reduced by changing some data in the presentation; which is what the researcher has strived for, in terms of not including potentially personally identifiable information such as gender or age. Still, the researcher realizes that the thesis might include clues to participant’s identities, though this is believed to apply only for health care workers.
and other key persons, and not the diabetics. The solution here then is primarily the thick ethical description that Kvale & Brinkmann (2009) emphasize, namely that one approach to learning ethical research behavior is through an increased mastering of the art of thick description in relation to among others context. The art of thick ethical description is similar to what the good, in a nonmoral sense, qualitative researcher should master in order to produce new, insightful knowledge (Kvale & Brinkmann, 2009). By interpreting the data sufficiently related to context; it will counteract the risks in qualitative health services research that Richards & Schwartz (2002) and Malterud (2011) highlights, namely anxiety in and exploitation of participants, and that the publication of the findings may damage the reputation of the participants and their social group. Except from what was clarified here, the study was not believed to mean a particular risk to the participants.

Regarding *beneficence and justice*, this study did not give any direct benefits to the participants, which were also informed of in the information letter or prior to the interviews in general. CIOMS (2002) state that in general, a research project should leave low resource countries or communities better off than previously or, at least, no worse off. The aim is to give the research results back to the participants and their society after completion of the study, by distributing it to the relevant local stakeholders and authorities; with the intention that the study will contribute positively to the diabetes care development in the area.

### 5.6 Trustworthiness: the projects’ strengths and weaknesses

There are four main concepts for judging trustworthiness of qualitative data and which have been used to consider the strengths and weaknesses of this project, namely credibility, dependability, confirmability, and transferability (Ulin et al, 2005; Dahlgren et al, 2007; Malterud, 2001). Firstly, the findings from a qualitative study are not thought of as facts that are applicable to the population at large, but rather as descriptions, notions, or theories applicable within a specified setting (Malterud, 2001). Thus, this is among the obvious limitations of this study, exactly that it cannot make generalizations such as with quantitative designs. That said, this is also not the aim of qualitative studies. Rather, as Ulin et al (2005:27) similar to Malterud (2001) point; lesion learned from qualitative studies can be applied to other contexts if samples have been carefully selected to represent viewpoints and experiences that reflect key issues in the research problem, and the goal is to produce data that
are conceptually, not statistically, representative of people in a specific context. Thus, *transferability, or external validity*, of qualitative studies is the range and limitations for application of the study findings, beyond the context in which the study was done (Malterud, 2001). Through a relatively comprehensive review of contextual information about Zanzibar, as well as through descriptions of the study participants, the study setting and the way the data collection was carried out including the role of the researcher and the assistant; it is believed that the findings from this study can be applied to similar contexts. The researcher realizes that the data obtained through this study is only stories exchanged from one particular messenger, the participant, to one particular receiver, the researcher (and the assistant), in one specific moment, thereby interpreted by the receiver; thus, the *truth* belongs to precisely these limits.

*Dependability* in qualitative terms is whether the process is consistent and carried out with careful attention to the rules and conventions of qualitative research. To increase dependability of qualitative findings, you might incorporate a team approach or use multiple independent coders or analysts. This tactic will help to offset the subjective bias of the researcher (Ulin et al, 2005). Another weakness of this study is exactly the limited size of the research team, where the main investigator alone analyzed and interpreted the findings. That said; the team approach during fieldwork largely made the preliminary findings results of the ongoing conversations between the researcher and the assistant. The project was also continuously discussed and negotiated upon with among others the researcher’s supervisor, her fellow student who did her fieldwork in Zanzibar the same period, and the researcher’s cohabitant who originally is Zanzibari. All in all this is believed to have reduced the effect of the researcher’s bias to some extent. There is also a limitation in terms of the assistant doing the transcription of the Swahili interviews alone. Though, the fact that the researcher and the assistant discussed most of the transcripts in detail, as well as the “second opinion” of the researcher’s first-year fellow student on some of the transcripts; has reduced the effects of the assistant’s bias or other potential weaknesses of the work. Also the initial training of the assistant in and continuous focus on the projects’ qualitative research methods- and techniques throughout the fieldwork has increased the dependability of the findings.

*Credibility, or internal validity*, another main standard for evaluating the rigor of qualitative studies; asks whether the study investigates what it is meant to (Malterud, 2001; Ulin et al, 2005). Credible interpretations of qualitative data offer explanations that are contextually rich,
consistent with the data collected and understandable to people in the study population, and sensitive to differing perspectives in the study sample (Ulin et al, 2005). The relatively high degree of triangulation of both research participants and research sites is believed to have facilitated credibility of this study. The research process naturally developed to include a variety of participants, from a variety of sites, who offered diverse, often conflicting explanations of the same phenomenon, which precisely characterizes the findings from this study; that diabetes care and coping among diabetics in Zanzibar context is everything but a unanimous matter. This triangulation turned out to be even more diverse than planned initially, and is viewed as a result of the growing insight achieved throughout the fieldwork; where the researcher decided that a step-wise, broad approach to this phenomenon was crucial. The rival explanations from the variety of participants were largely used as exactly a basis for the interpretation of the findings. It must be taken into consideration that the limited time frame and budget also impaired the study sample, which the researcher realizes could have been even more deeply explored: An inclusion of more participants representing the diverse range of realities revolving around the phenomenon would have further increased the credibility of the findings. This could for instance have been a greater variety of traditional healers, as there is seemingly a considerable variation between these practitioners in Zanzibar. Also that the diabetics were recruited through the biomedical clinics is viewed as a limitation of this study. In addition, triangulation of methods, especially with regard to an inclusion of systematic observations, the researcher realizes would have contributed positively to the credibility. That said; considering the time frame of this project, the study sample is all in all regarded as relatively diverse and triangulated. Exactly the fact that little similar research on this topic has been conducted on the islands of Zanzibar is an obvious strength of this study. It provides an insight on diabetes care and coping among diabetics in this complex setting characterized by its decades of multicultural influence and its local interpretations of spirituality, religion, and especially the pervasive Islam; that is crucial for people's understanding and behavior directed toward health and illness. Also the fact that the project went on throughout the month of Ramadan is a considerable strength of this study, as there is found no previous studies from sub-Saharan Africa having assessed coping among diabetics in a Muslim society during Ramadan.

Confirmability in qualitative terms means neutrality of the data, though not of the researcher; that the data reflects as accurately as possible the participants perspectives and experiences. It involves opening the study process to outside inspection and verification (Ulin et al, 2005);
which is exactly endeavored through this methodology chapter. Not least, confirmability of the results involves applying reflexivity, which will be illuminated below.

5.6.1 Reflexivity

The researcher’s background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions (Malterud, 2001). During all stages the qualitative research process is systematically influenced by the researcher's preconceptions and theoretical frames of reference (Malterud, 1993). Reflexivity means that the researcher has an obligation to observe and document her role in the research process, including assumptions, biases, or reactions that might influence the collection and interpretation of data (Ulin et al, 2005). Objectivity means to recognize that knowledge is partial and situated, and to account adequately for the effect of the positioned researcher. Adequate accounts of these effects should be presented in the publication, as the frame of discussions of limitations and strengths of the study, and transferability of the findings. Bias, in the sense of undesirable or hidden skewness, is thus accounted for, though not eliminated. Subjectivity arises when the effect of the researcher is ignored (Malterud, 2001). Firstly, it is obviously essential to account for the researcher being a 30 year old white woman from a western country as Norway, conducting fieldwork in a poor, developing society as Zanzibar. She has her professional background from nursing, as well as a limited academic background from previous studies in social anthropology. This background and position in the “world order” naturally created a persistent distinction between the researcher and the locals. In Zanzibar, people are relatively used to westerners, in form of tourists, coming and going; fortunate people with money and wealth who easily make themselves convenient and leave traces that are not always popular among the locals; and there is a clear distinction between “us and them”. The researcher was naturally viewed as one of them. And she was also, to an extent, one of them. She was one of these white people, msungu, who occupies the sandy beaches; far away from the local, shanty villages, the local realities. She was one of them who comes and goes; that have the money and the passport that could take her wherever she wanted, including their little space in the world, the islands of Zanzibar. This distinction, this power imbalance or inequality; was something that could not be completely erased or ignored. The researcher would always be a white westerner, an msungu, which obviously influenced the interaction with the participants, thus the data that came out from the interviews. Though,
the researcher barely experienced that the participants for instance expected something more than only taking part in the study, except from maybe one case where a participant was hinting about the need for funding for different affairs. On the other side; the researcher’s cohabitant is Zanzibari, and she has been spending much time in Zanzibar previously and has a fairly large network of family and friends in this society. Thus, she is familiar with the local realities of Zanzibar; she is used to move in and out between the local settlements and the white sandy beaches where the tourists find themselves. She can might as well sleep in a run-down mud hut with the family in the village, as in a resort on the beach, which anyhow also normally are run by local friends, thus the connection to the locals are always there somehow. The distinction with the locals will nevertheless never disappear; exactly because she is one of those who have the choice; have the choice to come and go. The same applies to the researcher’s cohabitant: He is also one of those who have the power to decide where he wants to find himself in this world, he is someone with money. He is largely viewed as a provider of extended family in Zanzibar; someone they rely on economically. In this way, there is also a distinction between him and his former society, where he comes from. On the other side; he was born and raised in one of these poor villages of Zanzibar; he grew up as one of nine children of a mum who actually was healing people herself in form of spirit possessions, something he used to witness since he was a small boy. In other words, he is still highly an insider; someone who has introduced the researcher to the true, diverse realities of Zanzibar. Thus, the researcher’s familiarity with the context in many ways also made her an insider; in terms of knowing people and how to get around, in terms of being used to find herself in the poor conditions in which people live in this society, and in terms of partly knowing and being able to adapt to local norms and customs. This both influenced the researcher’s preconceptions ahead in the planning process of the fieldwork, and the way she approached the field during data collection. It was overall seemingly perceived positive when the participants got to know the researcher’s connections to Zanzibar; and the researcher experienced that this made them more familiar and confident with her presence. During fieldwork she also dressed culturally appropriate, which was experienced being positively perceived as a sign of respect of both participants and key persons in the society. The researcher’s Swahili skills though are limited; she has a very basic comprehension of the language, and cannot communicate it fluently. This naturally, again, created a certain distinction between the researcher and the locals that was inevitable.
The researcher traveled with her fellow student, also a female Norwegian nurse of approximately the same age as the researcher, who also did her independent fieldwork on Zanzibar the same period; as well as with her already mentioned cohabitant and her eight year old daughter. The four of them lived under the same roof largely throughout the whole data collection period. Bringing a child with for fieldwork naturally also influenced the process of data collection. Though both the researcher’s fellow student and her cohabitant helped out so that the child for instance not always had to come with during interviews; things naturally did not happen in the same speed as if the researcher had not had her child with her. That was also never an option, the child had to come with; and the data collection proceeded nevertheless. This implied though that for instance the weekends, or at least a couple of days every week, consistently were days off data collection. Though, the researcher could still spend a few hours these days writing transcriptions, writing reflections in her log, or reading theory. The times the child was taken with during data collection was experienced as being perceived positively; something bringing the researcher down on a more human level, being a mother, not just a white westerner detached from real life. A child and being a parent is something everyone can relate to, thus a communality was experienced to be created. Also that the researcher’s daughter is half African is believed to have influenced creating a common platform; that the researcher is not so unlike them after all. Another private drawback, to make a long story short, was that the researcher’s fellow student unfortunately fell and had a small fracture in her ankle in an early stage of the fieldwork. She decided to stay and finish her data collection, even though she wore a cast and used crutches throughout this period. She was obviously somewhat limited by this and needed some assistance for everything to work out. The two fellow student researchers though turned out to be a well-functioning team; helping each other out with respectively babysitting and grocery shopping and other practical issues. Especially during the month of Ramadan, it was experienced to be particularly hard being a non-Muslim in this society. In Ramadan, every local restaurant in town was closed down, at least during day time; and it was literally hard to find food to eat. Doing grocery shopping in a developing society is also something completely different than going to the supermarket back home. The marketplace in Zanzibar town, Darajani, is a large area where every single item is purchased from individual stalls. This turned out to be rather time consuming and actually something the researcher spent quite some time on. Also more restrictive attitudes in relation to typical religious norms were expressed by the locals during Ramadan; for instance in terms of women being expected to even further cover themselves.
up, and the restrictions even to drink water in public. The researcher had never before experienced Zanzibar during Ramadan, and especially to live in the middle of it, in Zanzibar town, with religious activities, men in and out of mosques, women completely covered up in niqabs, and prayers filling the air at all hours; was experienced as somewhat overwhelming from time to time, especially with an eight year old daughter to safeguard, who also periodically found it all overwhelming, being homesick in periods. There were also scary episodes of extremist activities during Ramadan; among others were two young British girls attacked with acid in Stone Town. Being a westerner with an overall atheistic humanitarian worldview, raised in the country in the world with possibly the highest degree of freedom of speech and gender equality; Ramadan in Zanzibar was overall one pervasive experience, something the researcher realizes she was not fully mentally prepared to prior to the fieldwork. In that way, the two researchers experienced it as a major plus to be two persons sharing rather identical starting points in this state they found themselves in. This relationship was highly experienced as a tool of establishing the important metapositions that Malterud (2001) highlights; strategies for creating adequate distance from a study setting that you are personally involved in. The two spent repetitious evenings discussing their experiences and reflections, laughing and crying over both success and frustrations, from their days in the field. Also the researcher’s cohabitant has in many ways distanced himself from his religious background, and shared the researcher’s experience of Ramadan as something he found hard to relate to; which also helped for creating the necessary metapositions. With him not caring so much in terms of following all the Muslim norms and rules; it was also easier for the researcher to distance herself from the intense days out in the field. In one way, it was invaluably useful to have the cohabitant’s family members around, as they were often helping out purely practically, being kind and caring. On the other side they are also products of their little bubble of a society; many of them being fairly restrictive Muslims, and would often try to impose their values on you. All in all, it was necessary with the weekend escapes to the beaches; where one could get a rest from it all, children could be children and play freely as used to; and adults could be adults, as used to. This specific period in time, Ramadan, is thus considered as having affected the interaction between the researcher and the informants somehow; it was a time of exception for both parties, but in completely different ways. Similar was that both parties also attempted to adjust, and the researcher’s attempt to adjust to the local norms is believed to have influenced the data collection process positively.
It is also necessary to account for how the researcher’s background as a nurse made her closer to the theoretical framework and the position of the biomedical health care providers than to other informants, such as the traditional healers, thus; a bias was automatically raised. The researcher was more familiar with the perceptions and interpretations of the biomedical health care providers; providing a shared platform which naturally affected the interaction. These participants were also familiar with the researcher’s background. It was experienced that most health care providers openly and confidently shared their opinions, also opinions that not necessarily placed them in a positive light. This is believed to have been, at least to an extent, due to the shared backgrounds as health care providers; where both parties knew that the other one was familiar with what he or she was talking about. The researcher background is believed to have influenced the interview with participants such as the traditional healers in a different way, in terms of seemingly representing the field of biomedicine. This might have influenced these participants’ attempts to for instance at a greater extent using a biomedical language during interviews that was not truly reflecting their realities or practices. They had most certainly met similar people as the researcher before, and they naturally had their own interpretation of who the researcher was and what she stood for. The other way around, the researcher also had her opinions about treatment of disease and illness, which in many ways differed from many participants’ perceptions. Though the researcher always attempted being neutral and professional in the field, and never shared her opinions explicitly; it was most likely times where participants knew or sensed that the researcher had a different standpoint than themselves. One example is the mentioned episode where the male traditional healer was showing the researcher his critically ill patients; which the researcher though should not have been anywhere else than in a modern hospital. In cases like this the researcher struggled remaining neutral, and although she never said it explicitly, she more likely showed it with body language or facial expressions. Also due to the researcher consistently hiding her personal opinions, must have maintained the participants’ preconceptions of the researcher as a westerner with a biomedical background. That said, the researcher was also largely influenced by theoretical framework derived from among others medical anthropology, which is experienced to have balanced her biomedical framework, thus making it easier to deal with perceptions and world-views which often differed considerably from her own, thus affecting the interaction positively.
The research assistant

The research assistant was a 28 year young woman who had just graduated as a nurse from the Health Science College in Zanzibar. She was “handpicked” by an EHS tutor from the college, who was obviously assigned by his superiors to help with regard to the project, which he also forthright did. He literally designated her among the best students at the college. This was after a rather formal meeting at the Health Science College with key people, among others the Headmaster, who also turned out to be a key person at the Ministry of Health; where the researcher and her fellow student presented their separate projects and kindly asked to be connected with students as potential assistants for the data collection. Participating in these meetings was also a male family member of the researchers’ cohabitant, who was taking us there. This seemed to be appreciated from the administrations’ side; the fact that we had a foot in the door with the locals. Also that we dressed relatively culturally appropriate was pointed out by the administration as something they appreciated, something that made us different from other westerners, a sign of showing respect for the local norms. This might also have influenced their willingness to help us. The first time the researcher and her assistant met was in a small office in the Ng’ambo area of town; again arranged by the helpful EHS tutor from the Health Science College, who had found two potential female assistants for respectively the researcher and her fellow student; who were interested in being part of the projects. The EHS tutor was overall very much involved in this process of finding the research assistant. The future research assistant seemed at this first meeting quite shy and overwhelmed by the situation, clearly not used to foreigners, though still showing much humor and a clear interest in the upcoming adventure. The meeting was concluded with everyone having time to think and consider the offer. We met again at the Health Science College a few days later, where she agreed to become the research assistant. The researcher paid her monthly with a salary that exceeded local wages; which also might have influenced her motivation doing this job. This was a young woman who had grown up in a village in town area of Zanzibar, thus, her background was highly local, and was reflected in among others her world-view, her religious conviction as a devote Muslim, and her gender perspectives- and expressions. She, naturally, dressed and behaved according to the local norms; among others always wearing the black hijab costume that you typically see in Zanzibar town, and fasting faithfully throughout the whole month of Ramadan. The researcher believes that this was positive for the data collection process; as she balanced the disparities between the researcher and the field; opened doors which the researcher could not
have opened herself; asked questions in ways that were culturally appropriate. Her role was initially to function as an interpreter when the participants had lack of or limited English skills. Though, we ended up with her taking a big part of the project; as said in many ways she was a door opener to the community, also in the way that participants seemed to find it satisfactory with her as a local being around during the interviews. Especially during Ramadan, the people of Zanzibar are particularly dedicated to their cultural and religious norms and expectations; which made it valuable to have a local on your side during the data collection process. Additionally, it was interviewed more participants who did not have sufficient English skills than the researcher had anticipated in advance. Thus, it ended up with the assistant taking part of almost the entire data collection. That said, this was a highly resourceful young woman with strong integrity; one out of few women, or people in general, with higher education in this society. Her English was fairly fluent, she was academically strong, and she had that edgy sense of humor that matched the researcher well; so that little by little it became a well-functioning little team who communicated and understood each other well. Both having nursing backgrounds, thus partly a common theoretical framework of health, disease and illness; also made them closer conceptually. All in all, the researcher had a positive experiences working with her throughout the fieldwork. Though, the assistant was overall typically Zanzibari when it when it came to her laid back relation to time and timeframes; and it did not only happen once that she was delayed or not showing up without telling. Anyway, when this was talked about she improved, and it did not turn out to be an overriding problem. She also transcribed a big part of the interviews, as most of them were conducted, at least partly, in Swahili. There could be periods when the transcription process was fairly time consuming, which is believed to be largely due to her duties at home, living, unmarried, with a sick mother and being responsible for much of the household tasks. Especially during Ramadan, the progression of transcription went on rather slowly periodically. The assistant actually preferred to sit and work in the researcher’s residence, as she would not be disturbed there. Additionally, the two research assistants also knew each other from before; and all four, researchers and assistants, turned out to spend much time together in the researchers’ flat in Zanzibar town, working on and discussing the two projects.
6 Venues diabetics use for counseling and care in Zanzibar

This chapter responds to the first specific objective of the study; to describe the different venues diabetics in Zanzibar use for counseling and care. It is found that diabetes care in Zanzibar largely was a neglected field, but there were also signs of a positive shift. Zanzibar among others largely had this health facility that functioned as the “Diabetes Centre of Excellence” which the Diabetes Declaration and Strategy for Africa (IDF Africa Region, 2010) called for; namely the diabetes clinic at the referral hospital on the isles. That said, the diabetes services were also largely overloaded and understaffed, as well as unequally distributed on the isles. There were all together eight diabetes clinics in Zanzibar, but the rural clinics were basically run by nurses or clinical officers with limited training and experience in diabetes care, so that they were largely dependent on support from the first-mentioned diabetes clinic. A decentralization of the diabetes services were on the agenda of the newly established NCD unit at the Ministry of Health, but were still in the planning phase at the time of data collection. There was also an emphasis on education in the diabetes care in Zanzibar, and the diabetes educators were found to have their special role. Also community interventions were highly emphasized; where among others the media and the religious venues were utilized to increase awareness of diabetes and other NCDs in the population. The diabetes services were at a large extent dependent on funding from international NGOs. There was a lack of subsidized medicines and equipment, and especially the fact that the diabetics did not have their own glucometers at home resulted in needing to seek a clinic for blood glucose testing, which was typically done at one of the many primary care units, that were largely unempowered in terms of diabetes care. Also the traditional healers were sought exactly for these regular checkups, as they appeared to possess biomedical tools, such as exactly glucometers. And as this study has indicated; the traditional healers were largely used as a venue of counselling and care by the diabetics in Zanzibar. Though there were given attempts of increasing surveillance of the traditional healers in Zanzibar, the healers were still highly unempowered; there was an obvious lack of policies, training and regulations of this sector of health care. The increasing surveillance and the questioning of competence of the traditional healers; was also found largely resulting in the healers’ strive for legitimacy.
6.1 Stakeholder engagement in diabetes care in Zanzibar: a neglected field slowly on the rise

Firstly, the researcher finds it necessary to say a few words about the political attention diabetes care were given around the time of data collection. Participants were generally frustrated by the fact that there was an insufficient implementation of measures on diabetes care in Zanzibar; that it largely was a neglected field. They highlighted the continued high degree of undiagnosed diabetics in the society, as well as the lack of financial support to subsidize the diabetes medicines and equipment. The high number of undiagnosed diabetics was something many highlighted was being uncovered by the NCD survey that was carried out in 2011. Some related these shortcomings mainly to Zanzibar’s poor economic situation; that there were constraints the government largely could not control over. One nurse was among those who related the suppressed status of the diabetes care to the poverty of the country, and how this left the diabetics in Zanzibar pretty much on their own:

Our government has no policy to look after these diabetes patients, as other countries. We know that other countries provide many things, glucometers and all… But our country is not like that. […] We are poor here, so it’s very difficult to make a policy to look after the patients, so many patients. […] So I think it remains that the patient is most responsible for himself. (Informant 1)

Other health care workers and key persons were more directly critical to the government, and were frustrated how it consequently was given less priority to diabetes and other non-communicable diseases; that it was an obvious and deliberate absence of support. Many felt that the government was not on their side; that it was a continuous struggle and very much on the health cares’ shoulders trying their best to provide the high number of poor diabetics in Zanzibar adequate care and support. The lack of governmental support was often described as related to the remaining focus on communicable diseases in the health care in Zanzibar. This is supported by ILO (2010), who points that the main vertical priorities in Zanzibar are communicable diseases. One health care worker stated:

The government they do other things to emphasize and prioritize, because non-communicable diseases are not seen much, because it didn’t spread from one to another person, its outcome is not rapid. So if someone is diagnosed it’s already at the late stage. So there is an important effort for the government to emphasize like they emphasize in other fields like HIV. (Informant 13)
Many though also highlighted that the government had started to realize the extent of the problem of diabetes and other non-communicable diseases in Zanzibar. And on the other side, there were also ongoing changes in terms of increasing attention on diabetes care in this society. Many emphasized the signs of this shift; especially in terms of the increasing number of diabetics now attending the diabetes clinics, which was explained as related to a higher awareness of diabetes in the community. This awareness was described as a result of a variety of community interventions (which will be elaborated on in chapter 6.4), as well as of the increased access to diabetes care, which showed effects on the rest of the community. The literature shows that in 2004, eight diabetes clinics were set up in Zanzibar and Pemba, organized by Tanzania Diabetes Association (TDA) and supported financially by among others the WDF and Novo Nordisk (Ramaiya, 2006). Some health care workers pointed out that the clinics were already there in 2004, but that the TDA helped empowering the clinics that year; it was provided more equipment, and training of the staffs. Financial support from various NGOs was something that was frequently highlighted, and international NGOs proved to be exactly key providers of the diabetes care in Zanzibar. According to the Zanzibar Health Sector Reform Strategic Plan II, the government contribution accounted only for 29% of spending in the health sector, while development partners accounted for the balance of 71%, where analysis of the government budget indicated that the vast majority of resources are absorbed by health sector wages, salaries and the other allowances; while spending on drugs and supplies is covered by funding from development partners (MOHSW, 2006:49). It turned out that the diabetes care in Zanzibar had much collaboration with and support from exactly TDA, a member association of International Diabetes Federation (IDF). Also Zanzibar had its own branch, the Diabetes Association of Zanzibar (DAZ), which according to some informants had existed since the beginning of the 1980s, similar to the diabetes clinic at Mnasi Mmoja; and then reregistered in 2006. DAZ allegedly now had chairpersons in each district of the isles. All in all it is clear that there had been an emerging shift in diabetes care in Zanzibar, especially the last ten year period, and that this must be seen in relation to the implementation of various Africa diabetes programs- and initiatives; following the increased global attention on diabetes being a major public health problem, especially for developing countries. Many of the staff at the Mnasi Mmoja clinic had participated in diabetes-related courses, sponsored primarily by IDF. Some had attended courses in mainland Tanzania, some also in other African countries or in Europe. One of the nurses had in 2009 been in South Africa for training in Conversation Map, sponsored among others by IDF. According to the
IDF (2012b) websites; the Sub Saharan Africa Diabetes Conversation project, which is directed towards promoting diabetes education, started in 2011, and was also introduced in Tanzania. The Conversation Map thus was implemented in the diabetes care in Zanzibar, particularly at the clinic at Mnasi Mmoja, where the mentioned nurse carried out weekly group lessons for the diabetics, based on this technique. She had additionally trained a few of her colleagues and other key persons; among others one diabetes educator, who also stated to partly use Conversation Map when he carried out the weekly diabetes group lessons at one of the cottage hospitals in rural Unguja.

The politically correct increased attention on diabetes and other NCDs was also partly governmental; and one prominent measure was the NCD unit at the Ministry of Health, which was said being just recently established in 2011, as confirmed by the MoH (2011:8). Informants commonly elaborated on the high level of collaboration between both the diabetes care and DAZ, and the newly founded NCD unit. The unit was allegedly receiving financial support from World Diabetes Foundation (WDF) and consisted mainly of two employees in full time positions. Various diabetes initiatives, such as the *IDF Africa Region Action Plan*, in the aftermath of the *UN Resolution 61/225 on World Diabetes Day in 2006*; have emphasized exactly the need for development of national diabetes policies, and for a multi-sectorial national action group to be formed in each country; for the development of a diabetes program that fit local needs (IDF Africa Region, 2008). It was highlighted that one of their greatest achievements so far was completing the risk factor survey on NCDs in 2011, which was done in close collaboration with the health care workers at the diabetes clinic at Mnasi Mmoja. The informant at the NCD unit stated that this was the first of its kind in Zanzibar context, that “before, we didn’t even have a baseline, to say that the magnitude of the problem is this and this”. The need for data on NCDs and the risk factors were exactly stressed in the *Zanzibar Health Sector Reform Strategic Plan II* from 2006, which pointed that despite the awareness that the prevalence of diabetes is growing in Zanzibar, there was no population-based data on the magnitude of the problem (MoHSW, 2006: 36). Initiatives such as the *African Diabetes Strategy* from 2006 also called precisely for countries which did not have adequate epidemiological baseline on diabetes and related chronic diseases to undertake a risk factor surveillance survey (IDF Africa, WHO Afro, the African Union, 2006).

Among the *Zanzibar Health Sector Reform Strategic Plan IIs’* mentioned targets for NCDs were to integrate prevention and management of the most common NCDs in all PHCCs and
hospitals, and in selected second line PHCU, and to develop an integrated NCD policy, program and guidelines (MoHSW, 2006: 36). Currently, the only services had been provided at referral facilities through eight special clinics throughout the Isles (MoHSW, 2006: 36). Among others the *IDF Africa Region Action Plan* also stressed that responsibility for diabetes should be placed at a primary care level, to help increase access to diabetes care and improve outcomes. This included a minimum package of care at the primary care level (IDF Africa Region, 2008). The ongoing program at the NCD unit during data collection focused exactly on coordinating and scaling up the services for NCDs, especially with regard to decentralize the care into primary care level, and greater involvement of the district health management teams in all the districts. The informant at the NCD unit explained:

> The overall task is to coordinate all NCD related activities in Zanzibar. Because you know, the services were only available in very few points, service delivery points. So the project, we try to see that we scale up the services, to the primary health care unit. And that’s why we have identified about 34 primary health care units, which will be providing NCD services. (Informant 18)

Basic equipment, procured through TDA, was planned to be distributed at the chosen primary care units; a new treatment guideline was being developed during the time of data collection; and the staffs at the primary care units were to undergo relevant training. Some of the health care workers at the diabetes clinic at Mnasi Mmoja were largely involved in the development of the program, among others in the formulation of the new treatment guideline. The plan was an implementation as soon as possible and within 2 ½ years, which allegedly was the remaining time of funding from World Diabetes Foundation. Additionally, a main focus of the NCD unit was prevention, so that one of its main areas of intervention was also community awareness, where a number of measures were already implemented. This will as mentioned be elaborated on in chapter 6.4.

### 6.2 The diabetes care in Zanzibar: a matter of availability and accessibility

#### 6.2.1 Overloaded and understaffed diabetes services unequally distributed on the isles

The public diabetes services in Zanzibar have its center at the referral hospital on the island, Mnasi Mmoja, which is located in Zanzibar town. This diabetes clinic has allegedly existed
since the early 1980s. Mnazi Mmoja hospital caters for specialist tertiary services for the whole country and renders primary and secondary health care for Stone Town population (Zanzibar Ministry of Health and Social Services, 2006: 22). It receives complicated cases from Primary Health Care Units (PHCU), Primary Health Care Centers (PHCC), district hospitals and private health facilities of Unguja and Pemba. Due to inadequate coverage by PHCCs (cottage hospitals) and lack of district hospitals in Unguja, Mnasi Mmoja hospital also provides majority of the first level referral services for the following districts: North B, Urban, West and Central District (Zanzibar Ministry of Health and Social Services, 2006:22).

The diabetes clinic at Mnasi Mmoja thus was in the situation of having to cover a big load of the diabetes patients on the isles, and participants frequently elaborated on this issue; that they basically were doing three jobs; primary, secondary and tertiary care, all together. The staffs at this clinic had the highest level of education and most work experience in diabetes care in Zanzibar. Otherwise there was an obvious lack of sufficient qualified manpower in the diabetes care in Zanzibar, medical doctors in particular; resulting in even nurses being found to have major responsibilities. This particularly appeared to be the case in care units with less access to medical doctors, such as at the diabetes clinics at the cottage hospitals visited in this study. The four primary health care centers (PHCC), or cottage hospitals, on the islands are intended to provide basic inpatient care in areas distant from other hospital facilities (MoH, 2006). At the two outpatient diabetes clinics at the cottage hospitals in the rural areas of Unguja island, there were respectively a clinical officer and a nurse running the clinics, both with limited experience in diabetes care; basically ministering all the diabetes patients in the districts north and south. These situations were in other words quite similar, characterized by, again, heavy workloads and major responsibilities, but additionally with an inconsistent deficiency in relevant experience, training and guidelines in diabetes care. A nurse at one of the rural clinics explained:

Maybe it’s like we didn’t get any training, so we just do by our own. We depend on the government; I think we didn’t get from them; hence, we go as we think is right. (Informant 15)

That said, it also happened to be a high level of collaboration between Mnasi Mmoja and the rural diabetes clinics; there was consistent phone contact between the units, and difficult cases were normally transferred to Mnasi Mmoja. Not to mention the regular visits from the Mnasi Mmoja staffs, where they assisted in the follow-up of patients at the rural parts. This also used to count for the diabetes clinics on the island of Pemba, where there also allegedly were no
doctors, only nurses. Many of the health care workers highlighted and stressed the importance of these regular visits, which used to be once a month in Unguja, and every third month for the clinics in Pemba. Especially the health care workers at the rural clinics expressed that they largely depended on the competence of the diabetes clinic in town. During the time of data collection though; this service of visits to the rural clinics suddenly stopped, due to what was said to be stoppage of financial means from the Ministry. The health care workers expressed frustration about this; and one was explaining:

Unfortunately now it stopped. Because of the funds. There was a time we got fund, but now, unfortunately for two months now, after Ramadan, it stopped. They say no funds. [...] And Pemba is dead. Visits to Pemba. Since last year, we didn’t go. Since February I think, last year, we didn’t visit Pemba. (Informant 3)

Overall, it was expressed frustration that the diabetes clinics were overloaded; that they were understaffed, and that the diabetes services were not sufficient compared to the large and ever increasing amount of diabetes patients on the isles. An assistant medical officer at a private dispensary in town was among those who stressed that the diabetes services were insufficient:

It’s overloaded, that’s why they are given three months, because there alone can’t handle. So if they chose three-four clinics in town that did the same activity, it would be better. (Informant 14)

**Practices and procedures**

The diabetes clinic at Mnasi Mmoja hospital was open Monday and Wednesday for respectively women and men on separate days. On Tuesday and Thursday it functioned as a hypertension clinic, and on Friday it treated children with type 1 diabetes. It was closed during weekend. The diabetes clinics at the rural cottage hospitals were open only on Thursdays. Outside of the clinics’ opening hours, the patients would have to attend either the general outpatient department at the respective hospitals, or a primary care unit, such as a private dispensary. The patients got scheduled appointments according to their individual conditions. These appointments varied in frequency, but between three to six months appeared as the most regular if the patients’ condition was relatively stable. In severe cases, more frequent follow-up was endeavored. These routines appeared consistent between the different diabetes clinics. The regular procedures at the diabetes clinics were general follow-up in terms of vital values and blood glucose, medication, and counselling and education in diabetes and self-care. The type 2 diabetics were normally checked by fasting capillary blood
glucose. An HbA1c machine was available at Mnasi Mmoja, but it was normally only used for the children, or the type 1 diabetics. In general the more rare type 1 diabetics, who normally were children, were attending Mnasi Mmoja; so that the rural clinics only treated type 2 diabetics. Mnasi Mmoja overall provided a higher degree of specialist services or emergency care units, and severe cases such as diabetic ketoacidosis was difficult to treat at the peripheral clinics. The basic equipment and medical supply available at the respective diabetes clinics were otherwise relatively consistent.

The emphasis on diabetes group education for the patients and their family members, and the role of the diabetes educators

Group education sessions were found being actively used at all the diabetes clinics. Diabetes education was often emphasized as one of the key measures in diabetes care; which reflects the international priority in the field, with among others the *Diabetes Declaration and Strategy for Africa* saying that patient education as the basis for optimal self-management is an essential component of effective diabetes care (IDF Africa, WHO Afro & the African Union, 2006). Additionally, it was found that members of the diabetes patients’ families often were included, which was considered crucial and obvious in this community where individual matters largely were family matters. A health care worker at one of the rural diabetes clinics explained:

Most of the time when the patient come here, we need to include other family members. So some of them come with their family members, and when you give the education for the patient, the family members can also get this information. (Informant 13)

The Conversation Map technique was as mentioned implemented at the diabetes clinic at Mnasi Mmoja, and they carried out group education based on this technique two days a week; respectively women and men on separate days. The technique was largely based on descriptive charts, and although people mostly had positive associations with it, some also criticized the materials, which were provided by IDF, for not being adapted into Swahili.
A Conversation Map Poster used for group education sessions at Mnasi Mmoja

It was as already mentioned arranged by the nurse who had attended courses in Conversation Map in South-Africa. She had also trained some her of colleagues and other key persons in this technique, among others a diabetes educator; who was a diabetic himself, and carried out the group education sessions at one of the cottage hospitals in Unguja. Among others the *IDF Africa Action Plan* highlighted the involvement of diabetes educators in capacity building at primary care level (IDF Africa Region, 2008). The diabetes educators exactly had their special role in the diabetes care in Zanzibar, and this one in particular; who in addition to having this voluntary job of running these group education sessions, also was largely involved in diabetes related measures throughout the Zanzibari community. He had attended different courses in diabetes, and had a strong cooperation with the diabetes clinics, with DAZ, as well as with the NCD unit; and was highly accepted for his role in the diabetes care. At the other rural diabetes clinic though, it was one of the health care workers who were responsible of carrying out the group education sessions, and this one on the other hand had not received training in Conversation Map. So overall, one can conclude that the Conversation Map was
partly implemented in the diabetes care on the isles, but that the emphasis on diabetes education was a recurring finding.

6.2.2 The lack of subsidized medicines and equipment

Medical supply was an obvious issue, which corresponds to the situation of diabetes care in the rest of sub-Saharan Africa. In Zanzibar the insulin was primarily subsidized and available, though it emerged that insulin had been out of stock for two shorter periods the past few years; last time was just during the time of data collection. It was available to purchase at some pharmacies, but this was a costly experience for the patients depending on insulin, as one vial was around 20 000 Tanzanian Shilling (TZS) (about 17 USD). This shortage of insulin though was only a matter of a few days. It was a different case with the oral medication, which formally was subsidized, but in reality it was often out of stock. Meaning, if medicines were not accessible for free at the hospital, the patients had to bring their prescription and buy at a private pharmacy or dispensary. Oral medication was said to cost up to 60 000 TZS (about 40 USD) a month, and a normal income in Zanzibar did not reach more than 120 000 TZS (about 80 USD) a month; meaning that half of a diabetic and his or her family’s budget could go to pay for medicines. The health care workers experienced helplessness in relation to not having medicine to provide the patients. There was a hope for the upcoming NCD program also to improve the drug supply. Though for now, all the health care workers had power to do was to advise and teach; to advise the patients to try and find means to buy the medicines, and to teach them the importance of medication compliance. In this strongly Islamic society; expressions like Insha’Allah, if God wish, was an everyday maxim, and diabetes was often described as a test from Allah. Also the health care workers often explained diabetes to the patients, as exactly a test from Allah, and a common advice was literally “Allah will help you”. In this impoverished society; this often appeared to be all you could wish for; for Allah to endorse you. One health care worker at Mnasi Mmoja was asked what they did if the patients could not afford medicines:

Nothing. We just tell him it’s important. “I don’t have money”. And we say “Allah will help you”. Just encourage them. Actually we cannot do anything. (Informant 3)

Diabetes patients also paid 1200 TZS in user-fees for each appointment at Mnasi Mmoja clinic, which is equal to about 1 USD. At the rural diabetes clinics they paid a little less, 1000 TZS. These fees were intended to cover the costs of among others the blood glucose testing.
Equipment such as glucometer and sticks were not provided free of charge for the patients in Zanzibar, and most of them could not afford to buy this. A glucometer cost about 55,000 TZS, and a small container of 25 sticks about 15-20,000 TZS. Some diabetics could happen to have a glucometer at home, but had difficulties covering the expenses for strips. This represented a big burden for the diabetics, and resulted in needing to seek a clinic for blood glucose testing, which naturally did not happen on a daily basis. Participants often elaborated on that it was hard for the patients to cope with these regular visits to the clinic for blood glucose testing, which they were advised to repeat at least twice a month. Even to get to the clinic was to some difficult, as it demanded money for transport and was also time-consuming. One nurse revealed that she sometimes even checked the patients for free, since they simply did not have money to spend:

To tell the truth, I am the one who deal with them, because when they come here to check, they pay 1000. So I don’t ask him to pay, I check him for free. (Informant 15)

6.2.3 A consequent burden on the unempowered primary care

The NCD unit was at the time of data collection planning on exactly reducing the user-fees at the clinics to 500 TZS, which was considered to reduce the burden on the patients, as well as the planning on further decentralization of the diabetes services, so that it was going to be accessible at more service delivery point, where people lived. This though, was still in the planning phase, thus diabetics at the time of data collection often needed to travel relatively far to get to one of the diabetes clinics, just as the informant at the NCD Unit stated:

Some are travelling so far, to Mnasi Mmoja, so then it will be a bit of relief for them. Instead of taking the dala dala [local bus] to Mnasi Mmoja, they will just be walking to the nearby clinic. So it will be a relief for the patients. (Informant 18)

Thus, the diabetics normally did not seek the diabetes clinics for these regular checkups of especially blood glucose, but rather one of the primary care units, such as the private dispensaries, as they were more accessible in peoples’ local areas. In Zanzibar, there are 100 public primary health care units, PHCUs, and also 69 private so-called dispensaries (Zanzibar Office of the Chief Government Statistician, 2013). These clinics were scattered across the island, particularly in town area; and served as small outpatient health facilities, and you would commonly find the clinical officers, assistant medical officers or nurses as the highest
level of expertise. There was obviously a lack of competence and resources related to diabetes care in the primary care units. A male assistant medical officer at one dispensary in town was dissatisfied with the lack of policies and training in diabetes care at his workplace, and he wished for a closer cooperation with the specialist diabetes services:

Ah… me, the training itself… You know, with other diseases we get training, but in diabetes I don’t think so. […] What I see is maybe we should plan a seminar or course for all clinics to select their representative to attend, and we go to Mnasi Mmoja and stay together. First, they have to educate us how to diagnose these patients, and if you find a patient, what do we have to do here, in the primary care, before you refer the case there. So you need to know why you send him or her, because it’s not all cases which are necessary to refer to Mnasi Mmoja. (Informant 14)

These clinics were also normally overloaded, as they treated patients with all types of diagnoses, in exactly their own neighborhood. This also made them less appropriate for proper follow-up and counseling. They only provided basic care, such as exactly blood glucose testing. The dispensaries also did not prescribe medication for diabetics; they only sold medicines from prescriptions brought to them. In any need for further treatment they referred the patients to the hospital clinics. They had overall minimal correspondence with Mnasi Mmoja, in terms of only referring patients there, when necessary. It could happen that they diagnosed diabetes patients or received illness cases, but the routine was then primarily to give transfer to the hospital clinics. This means that the main responsibility for the diabetes patients was still left on the diabetes clinics, and the services provided for the diabetics at the primary care units were limited. A female diabetic in town confirmed this:

Sometimes I went to check my sugar at the dispensary, or if I get ill they send me to the hospital. But I only use the Mnasi Mmoja clinic. (Informant 9)

6.3 Alongside the biomedical diabetes care: Traditional healers highly existing and struggling adapting to modernity

Just as the literature has pointed; the majority of the population in Zanzibar still uses traditional medicine for the treatment of various diseases (Ministry of Health and Social Welfare (MOHSW), 2008; Larsen, 2008; Meier zu Biesen et al, 2012); and this study
supports that the traditional healers were a highly existing sector of care also among the diabetics in Zanzibar.

### 6.3.1 The increasing surveillance

Let’s start saying a few words about the increasing surveillance of the traditional healers in Zanzibar, which also has been shown among others by Meier zu Biesen et al (2012). Both the traditional healers, health workers and other key persons in this study were aware of and often highlighted the Traditional Medicine Unit at the Ministry of Health, which exactly was among the key measures of the *Zanzibar Traditional and Alternative Medicine Policy* (MOHSW, 2008). A female traditional healer was among those who elaborated on exactly this, and emphasized the importance that the healers had a *license to work*:

> We have our union, so the government decides to give us a building, because there is a council of local treatment. They also gave us license to work. (Informant 20)

Her emphasis on legitimacy of her occupational group, the researcher believes must be seen exactly in relation to this attempt of systematizing the traditional healers, which largely reflects the increasing global focus on this issue, where among others the recent *WHO Traditional Medicine Strategy* update exactly aimed to support member states in developing proactive policies and implementing action plans that will strengthen the role traditional medicine plays in keeping populations healthy (WHO, 2013a). Also initiatives such as the *IDF Africa Action Plan* stressed that partners in community actions to educate and inform populations of diabetes were suggested to be among others traditional healers (IDF Africa Region, 2008). These governmental attempts of increasingly putting the healers into the system, was an interesting aspect; which the researcher believes had duplex, complex effects on the diabetes care in Zanzibar. The health care and other key persons generally demanded a stronger evidence base and governmental control of traditional medicine, while the healers at the same time obviously strived to adopt accordingly. Firstly, this must be viewed in relation to the consistent finding that the competence among the healers in relation to treating diabetes was largely questioned, both among the diabetics, the health care workers and other key persons. It was often highlighted that the traditional healers were just after stealing money from the patients, and health care workers stressed that they overall were “on completely different levels”. The health care workers and other key persons believed that the healers somehow had picked up some information from the media and similar, but that they overall
were untrained in diabetes care. It had allegedly even occurred distinct quarrels between representatives of the diabetes care and some traditional healers at meetings they had had; where exactly cooperation had been on schedule. One informant at the NCD unit elaborated on their attempts to cooperate with traditional healers, but emphasized several difficulties in relation to this:

In fact, in one of the meetings we had, we tried to call some of the traditional healers as well. Who are also trying to deal with diabetes. And we had some discussion with them, they told us how they treat diabetes patients. So we are trying to see how we can manage to work together with them. Because we know exactly what they want from the patients. They want to take money from the patients. It’s known that once you are diabetic, you cannot be cured. But some of them say that they can cure diabetes, which is not true. So we are trying to see; maybe once they get the patient, they can do whatever they want to do, but they need to notify us, to tell us; I have this type of patient.[…] So we are trying to see what kind of approach we can use to work with them. (Informant 18)

The healers were aware of this distrust from the biomedical health sector and from the government, and they requested greater recognition and cooperation with the authorities and with the modern health care. At the same time as there were governmental attempts to systematize and integrating the healers into the modern health care system; the healers were still highly unempowered. There was still obviously a lack of policies, training and regulations; and this was something the healers were largely knew of. A male traditional healer was distraught of the situation:

I tell you that until now there are crossed fingers from the government. […] We talked with the Ministry that in order to work together, or in order for people to believe or to trust this knowledge; it means we need the government to acknowledge us! To give some feedback! To give some training! […] You know… to work under the Ministry of Health! But nothing! It’s just talking! He just blame us, the Minister! I cry. So if we have done wrong, do you give us the training? (Informant 8)

**The adoption of biomedical tools making them a substitute to modern health care**

It also appeared to be a questioning of competence between the healers themselves, which was expressed through a marked distinction between “us and them”, between the traditional healers *with* competence, and those *without* competence, generally those who were just after stealing money from the patients. Just as the male traditional healer stated, that “we don’t
have a profession, everybody can do it. It means that some people just steal money from the patients” (Informant 8). The healers largely associated this competence with the extent of being able to gain new, evidence based knowledge, from internet and books, and for having adopted and implemented modern, biomedical tools and equipment in their practice, such as glucometers. Just as the female traditional healer stated:

There are different. People like us who have knowledge we can do that, but those who doesn’t have that knowledge, they fail. Others don’t have equipment for taking tests, but they have their own clinics. The traditional clinics are many nowadays. (Informant 20)

It emerged exactly that diabetics attended the traditional healers both for regular checkups, such as blood glucose monitoring, as well as for treatment and counseling. The traditional healer clinics were easily accessible as they were scattered around, especially in town; and they offered exactly modern bio-medical check-ups such as blood glucose and blood pressure monitoring. This has also been highlighted by among others Meier zu Biesen et al (2012). The traditional healers described that they often also diagnosed diabetics. When the researcher visited these clinics there were a number of people there attending for treatment. For instance was the male traditional healer treating two stroke survivors the day the researcher visited, both being placed in a bed in separate rooms, where the healer and his assistants handled among others indwelling catheters and other advanced equipment. The traditional clinics that were visited in this study appeared in many ways as any biomedical clinic; they had for instance waiting rooms with professionally looking biomedical posters on the walls, and as mentioned a variety of biomedical equipment, such as blood pressure monitors, blood glucose meters and scales. They even had stationary bicycles, so that it was facilitated for the patients to do exercise there. They also worked in teams; the female traditional healer had four colleagues in her clinic, and the male traditional healer had several assistants who helped in various procedures. All in all this created an impression of something professional, something modern; something equal to biomedical care. This implied an accessibility to actual clinical health checks which made the healers an obvious complementary substitute for the overcrowded biomedical clinics, which not even always had treatment and medicines to offer.
The pursuit of evidence base

Another finding in relation to the increasing political pressure on traditional healers was the aspect of what was referred to as **research**. The traditional healers highlighted how they were carrying out research on the herbs they used for treatment, which the researcher again believes largely can be related to increasing signals in the society; demands for a more evidence based approach, including the fairly new policy aiming at ensuring traditional medicine treatment being done “scientifically, rationally and with safety to the Zanzibaris’ community”, with an emphasis on exactly scientific research (MOHSW, 2008). The male traditional healer elaborated how he took research serious:

> When I opened my clinic, it took me eight years, just to make this research; if this formula is working or not! (Informant 8)

This practice of conducting research was something the healers linked to the support or training they had received from abroad, as they somehow were connected to and had attended courses in herbal/alternative medicine, either in different parts of mainland east Africa, or even in Europe. In this way, they were a part of a larger, international alternative medicine community; thus, their practices were not solely local, but also influenced and legitimized through a bigger international network. Also health care workers were speaking in positive terms of what was going on in mainland in relation to traditional medicine; especially that they were ahead of Zanzibar in researching and systematizing it. The female healer explained about her connection to this larger community and to what she called a traditional medicine university in Nairobi, Kenya; at the same time as she described something about the way she experienced that their traditional medicines were looked upon in Zanzibar:

> There was a meeting for all traditional healers of east Africa, and now we have east African union for all traditional healers, so we plan ourselves how to do our work. And Dr. [name] was here to get cooperation, that’s why I joined with him and we cooperate with each other. […] And this university is where our research, meetings and even our herbs we take there for research in details. It’s different from here, they just tell you it’s harmful for human being, that’s all. At the university, they tell that it’s treating this and this. (Informant 20)

Here, she again touches upon her feeling of lack of legitimacy in this society. This strive for legitimacy which has been described in these subchapters is considered being a key issue when describing the traditional healers’ existence in Zanzibar; it was a struggle going on; a
struggle to adapt to the modern society including the biomedical discourses, to being a part of the system, and to maintaining legitimacy. This will be elaborated on throughout the next chapters.

6.3.2 Their traditional role as care providers

Participants often highlighted the healers’ traditions of treating every disease: that this was a part of their heritage, and although there was some uncertainty of how the healers achieved their knowledge; participants in this study generally believed that healers somehow had gotten their position through family, as heritage from generation to generation. Just as one male assistant medical officer from a dispensary in town stated; that “most of them have just inherited from their father” (Informant 14). This traditional legacy was normally highlighted as the reason why patients continued consulting the healers. The researcher believes this was one of the healers’ strengths in their struggle for existence in this society; exactly their deep, traditional, cultural identity and role of treating illness in the population.

Though health care workers and other key persons agreed that the traditional healers had a long history in Zanzibar context, they did not believe this counted for treating diabetes, due to diabetes being a relatively new disease in the public health agenda. Diabetes had until recently been viewed in Zanzibar society as a disease of the rich, which was highlighted by different participants. The male traditional healer recalled that “before, in Zanzibar, only rich persons had diabetes. Because I remember in 1956-57-58, when I was with my father, and it came one rich person with diabetes.” The traditional healers in this study insisted their knowledge, also of diabetes, largely being connected to heritage through family; that also their parents had dealt with diabetes, and that they had learned how to treat diabetes from their parents. The female traditional healer explained:

This education first I inherited […] My parents they were… I was seeing people coming with wounds, but I didn’t know what was wrong with them. […] But later I found out that they were patients with diabetes. (Informant 20)

This can indicate that healers somehow also had a history back in time of dealing with this disease, or at least the symptoms and the complications related to it.
6.4 The emphasis on community interventions

Many participants highlighted that it was an increasing awareness of diabetes in the society, which was described as being related to the increasing focus on community actions. The importance of community actions has been emphasized in all the recent Africa diabetes programs and initiatives, and also among the Zanzibar Health Sector Reform Strategic Plan II’s’ targets was to increase community awareness on NCDs (MOHSW, 2006). In relation to this, it was mentioned several initiatives or arenas in the community where this enlightenment took place:

6.4.1 The Obama exercise groups

We can start saying a few words about the exercise groups of Zanzibar, the so-called Obama groups; which the informant at the NCD unit pointed out as one of their greatest achievements at point of data collection. Other informants also often spoke of the Obama groups in positive terms. The Obama groups were allegedly a result of the collaboration between the NCD Unit, DAZ, and the diabetes clinic at Mnasi Mmoja. Additionally, they had turned to the local village leaders, the shehes, for approval; which is both required and culturally appropriate before approaching the specific villages. These exercise groups were planned to be preventative measures, and they were established in every district of Zanzibar, including Pemba. The Obama groups were used as arenas of educating the community about diabetes and other NCDs and their risk factors. The health care workers from Mnasi Mmoja were the ones who were in charge of teaching the community, in addition to the diabetes educator. Especially in Zanzibar town area the Obama groups had become fairly prominent, and it was specified that there were more than 200 members in town. In town the groups were said to be mixed of women and men, while in the countryside they were normally separated, due to cultural conditions. Though most people spoke positively about the effects of the Obama groups, some were also more restrictive. One nurse was among those, as she elaborated on the lack of funding for this purpose:

We work together with the NCD unit, because they use us to educate the community. […] That program is that we plan to go to educate, we already started, we went to the shehe; but because we don’t have money and support the program is stopped. […] So the reason why the program is slow is because of the capital and funds. (Informant 2)
6.4.2 The commemoration of the World Diabetes Day

Informants also commonly highlighted the *World Diabetes Day* on the 14th of November, which was also funded by IDF in form of supplies and equipment. It turned out that there was put much emphasis on this day in Zanzibar; a day of seeking out and educating the community about the disease, in addition to given attempts of screening the general population for diabetes. Activities around World Diabetes Day were also among the essential community actions that among others the *IDF Africa Region Action Plan* (IDF, 2006) emphasized. The key person of DAZ explained about the World Diabetes Day in Zanzibar:

When it reaches 14th of November each year it’s World Diabetes Day; so we test people, those who feel they are not well and are not patients; we went to the villages, we communicate with people and provide education on diabetes. So that is what we are doing every year. (Informant 17)

6.4.3 The usage of local media

It also proved that diabetes education somehow was provided through the media. Exactly diabetes education via mass media has also been emphasized by initiatives such as the IDF Africa Region Action Plan (IDF, 2006) as one among essential community actions. Both local radio and TV were used, and the NCD Unit had also distributed information leaflets about the NCDs, as well as a documentary about the NCDs that had been broadcasted through the media. Especially one health education program on the local Zanzibar TV, called the TV Doctor, was often highlighted. A male diabetic elaborated on this:

We are so many at the clinic. […] That’s why they did it in media, to provide education; we are many patients. […] They teach; they educate the effect on someone who uses the sugar, and prevention that you can take; in a special program. (Informant 6)

It was largely highlighted how education through mass media managed to reach the whole population, including the less affluent ones. To have a TV at home was fairly common, or people gathered together at a neighbors’ place watching TV jointly. The researcher frequently observed relatively large groups of people sitting in front of a TV in the neighborhood. Also in the countryside, it appeared that there were made attempts of broadcasting diabetes education through local radio stations; and this nurse elaborated on how she had been involved in diabetes education through the local radio:
We have a radio station here in [southern district]. So on Thursdays, like today, we have our airtime program concerning health issues. So we stay together and prepare the topic, so it’s on air between 10.30 am and 12. (Participant 15)

A few on the other side were not that enthusiastic of what had been what had been achieved in terms of diabetes education through mass media. An assistant medical officer at a dispensary in town expressed exactly an opposite opinion, that there was a lack of use of media to educate the society:

The government should make slogans, announcements or strategies that make people know what diabetes is. I think if there is much advertisement in television, everyone at home when he or she feels ill they will go to the hospital for checking and they will follow the instructions. […] But no, they just keep in the clinic and the people go. […] So you see, the government itself does not contribute much. (Informant 14)

All in all though, one can conclude that educating the people through media was something that was on the agenda; and media appeared being increasingly used in the Zanzibar society as a channel to educate its people on health related issues, including diabetes and other NCDs.

Also the traditional healers were utilizing the media

This trend of making use of mass media, interestingly, did not only apply to the biomedical health care. It also appeared that the traditional healers somehow were advertising and approaching the society through media. This included the traditional healers who participated in this study, as they elaborated on their appearance in the media, regarding health related issues. The researcher discussed this topic with one of the health care workers, who, similar to her colleagues and other key actors in diabetes care, were highly frustrated how the traditional healers made use of the media to spread their conflicting messages, opposing the biomedical standpoint. She stated:

And they start to announce, to advertise; I can heal your diabetes, your hypertension… There are a lot of announcements, I really hate those announcements, in the radio; I can heal diabetes, I can heal hypertension, I can heal cancer… And still the government allows them to do their announcements in the radio. It’s very bad. (Informant 5)

What this tells us; is exactly that the conflicting messages of health and illness were being highly an uncontrolled and pervasive phenomenon. The fact that this dualism between the two
sectors of health care were playing out even on the TV and the radio, subsequently made it even further pervasive and made people even more exposed to it on an everyday basis.

### 6.4.4 The cooperation with the religious venues

The religious venues, the mosques and madrasas, were accessible in big numbers; and especially during Ramadan, it was apparent how people rigorously carried out their religious duties and sought these venues. Participants highlighted the power these institutions and its religious leaders had on Zanzibari people, and it appeared that the religious venues also had a sort of function as an area of counseling for diabetics, as they often brought up health related topics. This turned out to be especially prominent during Ramadan, when a natural issue coming up was the fasting. The health care workers consequently had started to negotiate with and teach some of the imams about diabetes and the risks related to fasting; basically what they should emphasize to their followers. Additionally, they had also participated together on TV during Ramadan; elaborating on this topic. An imam from Zanzibar town explained:

I am among the ones who participate to educate the society. […]. Most of the time the diabetes patients do not believe their doctors, they believe in their sheikh much. We are not experts in treatment, so we ask him; what did the doctor say? That’s where we cooperate with the doctor. […] And there is a program called TV Doctors. […] Sometimes they invite us imams. They explain health issues according to their profession, and they ask us what it says in Islam; we explain in religious way what it says. So there is a time in this program explaining about this disease [diabetes] only. (Informant 19)

Though, it was not only the imams and the modern health care that showed greater efforts during Ramadan; also the male traditional healer elaborated on how he both approached the mosques as well as the media to spread his message during this holy month:

In Ramadan, we go around Zanzibar… more than 50 mosques, to explain how to eat. […] You know, I have a program in the radio more than five times during Ramadan, or… more than ten times! […] To explain the people how to eat during Ramadan. (Informant 8)
7 Care providers’ perceptions of diabetes and diabetes care

This chapter is aimed to answer the second specific objective of the study; namely to explore local health care providers’ perceptions of diabetes and diabetes care. The purpose is to provide a description of how diabetes and diabetes care was understood and interpreted by the different actors at stake, which is believed to be crucial for getting a comprehensive picture of diabetes care in Zanzibar; thus what the diabetics had to deal with in their everyday coping with illness. At some extent also the diabetics’ and other informants’ perceptions and descriptions are included in this chapter; for the purpose of, again, seeing the overall picture. The study has found that there were certain similarities in how diabetes and diabetes care were interpreted across the various venues of care. Firstly, diabetes was being explained as a lifestyle disease both by the modern health care and by the traditional healers; which was largely associated with to the modern way of life; the sedentary lifestyle, the new eating habits. Additionally, there was found an extensive use of biomedical terminology, also beyond the modern hospital- and clinic walls. The traditional healers’ utilization of a biomedical framework clearly did not match their level of competence; where in-depth knowledge of the clinical picture of diabetes with its symptoms and complications was absent. Another major issue revolving around diabetes care in Zanzibar; was the distinct dualism between the biomedical care and the traditional healers’ treatment goals; where the biomedical care provided lifelong treatment for chronically ill patients, in contrast to the traditional healers who stated that there is no disease without its treatment and cure. The belief in a cure appeared to somehow being embedded in the Islamic discourse; it was a religiously based perception in the society; revolving around that every disease has its cure, and that Allah is the one who treats illness and cures. It was also found that the traditional healers were directly linked to Islam through the utilization of Sunnah medicine. Lastly, it was found that the biomedical health care usually discouraged the diabetics to carry out the Ramadan fast; as they emphasized that the majority of the diabetics in Zanzibar were in such poor condition that it indicated to refrain from fasting. This was often justified by referring to the Quran; which says ill persons do not need to fast, though there were conflicting messages in this regard.
7.1 Common features of approaches

7.1.1 Diabetes explained as a lifestyle disease

Firstly, it is necessary to show the certain similarities in how the *cause* of diabetes was understood and described across the various venues of care in Zanzibar. There was among others an agreement that the occurrence of diabetes was related to the recent and ongoing change into a more sedentary lifestyle and new eating habits in the population. The various health care providers all emphasized that typical modern food, “chicken and chips”, was inappropriately readily available in the society today, thus referring to the numerous fast food kiosks scattered around, especially in town area; serving grilled meat, chapattis, French fries and soft drinks. Additionally, especially town life was increasingly associated with a sedentary lifestyle. The male traditional healer was furious about this negative development:

> You see someone buy chips, eggs, coke… I say “Ah! Do you think this is nutritious food?!”

(Informant 8)

Also a diabetes educator was emphasizing change away from these modern lifestyle habits when educating the diabetics:

> We teach them to change the lifestyle, because you see now there are things that aren’t our way of life. Therefore I advise them to return to the former way of life, as our parents used to live. (Informant 16)

The traditional healers, similar to the modern health care; thus emphasized diet and exercise as essential in the treatment of diabetes. These commonalities between the traditional and the modern health care have also been demonstrated by Meier zu Biesen et al (2012:26), who revealed that healers largely associated diabetes with lack of physical activity and unbalanced diet, and the patients who suffered from diabetes were among others told to rest and modify their lifestyle. Great emphasis was put on the type, characteristics, and nutrition value of different foods and beverages. Consequently, healthy dietary practices emerged as a distinct field of medical knowledge among the healers. Also Young & Ali (2005:6) point that a diet of nutritious food is the most clearly delineated commonality between traditional and biomedical cures of, in their case, anemia. This finding indicates that there is a common platform between the otherwise two opposing sectors of health care, which largely can mean two things: One is that this made it more logical for diabetics to juggle between the two, as they somehow
represented some common features. The other is that this may represent the starting line for a future cooperation between the two sectors, which could be a positive thing.

### 7.1.2 The utilization of biomedical terminology

It was not only biomedical equipment, as previously mentioned, which was utilized beyond the modern hospital- and clinic walls. The various venues of care had in certain ways similar terminology and explanations of diabetes; also stretching beyond the mentioned commonalities in relation to lifestyle explained as the cause of the disease, which, again, also has also been found by Meier zu Biesen et al (2012).

![A biomedical food pie chart, used at a diabetes clinic](image1)

![A traditional healers' pie chart, with among others “water” and “air” as constituents.](image2)

The bio-medical health care emphasized evidence based education for the patients in diabetes and associated self-care in terms of diet, exercise and medication; and the importance of glucose control to prevent late complications. The traditional healers also emphasized diet and exercise when advising the diabetics. Interestingly, they to some extent utilized a biomedical terminology. However, there were large variations in how the biomedical terms were interpreted and used. The way the traditional healers approached it was in many ways deviating from the evidence based biomedical care, and a lack of knowledge was quite obvious. It was essentially a borrowing of both equipment and concepts, which did not match their level of competence and educational background. In-depth knowledge of the clinical
picture of diabetes with its symptoms and complications was clearly absent. This was, ironically, as described previously also something the traditional healers actually requested; better follow-up and training from and cooperation with the government. The male traditional healer was elaborating on the connection between diet and exercise and diabetes; and showed an indicative example of how certain discourses were adopted from the biomedical framework, but how it turned out so wrong due to the clear lack of knowledge, as here, where he was claiming how the pancreas “extracts insulin from plants”:

When the standard is going up, it means you get diabetes. Why is the standard going up? Because you don’t want to eat some plants, from which the pancreas can extract insulin. […] There are people who don’t know, that there are plants that have insulin inside; like vegetables, morringa, curry leaves… If you eat them, it means the pancreas can extract the insulin from the food you eat, and the insulin can explode. But people are eating a lot of sweets, no vegetables, no exercise… And that is why the insulin goes down, and diabetes is there. (Informant 8)

Particularly precarious appeared to be the diverging competence in treating acute illness episodes and complications. The biomedical health care emphasized teaching the patients of symptoms and late complications of diabetes, and the importance of adequate glucose control to exactly prevent late complications. Particularly precarious were the symptoms of hypo- and hyperglycemia; due to the fact that most people simply did not have access to a glucometer at home thus were not able to regularly monitor themselves, or even often being out of blood glucose-lowering medication. An attempt of empowering the patients by this thorough education was a natural substitute of the insufficient supply of equipment and medicines. One of the health care workers stated:

It’s a bad thing, that they don’t have a glucometer at home. But at least we educate them the signs and symptoms of hyperglycemia and hypoglycemia. So at least they will know. (Informant 5)

The traditional healers showed missing knowledge regarding treating acute illness episodes and complications. Meyer zu Biesen et al (2012) found that the chronically ill tended to make use of the hospital if their condition became critical, as the biomedical sector seemed to be chosen for its professionalism in case of emergencies. The female traditional healer actually admitted her shortcomings in this matter, as she revealed that she usually sent complicated diabetes cases to the hospital, if she failed with her treatment. This the researcher believes is
quite obviously saying something about how she acknowledged the biomedical health care for their competence in treating severe cases, compared to themselves:

If we fail here we will have to send there. (Informant 20)

What has been attempted to show here, is how these two different actors of care for diabetics in Zanzibar in certain ways showed a fairly common approach to diabetes and diabetes care. The traditional healers had largely made use of a biomedical terminology, but showed major deficiencies in knowledge. When you in your daily struggle to cope with a chronic disease experience different actors with both similar concepts and devices; it must be difficult to distinguish between blurred differences. Then it is natural that you some time during the course of illness seek the option which offers most promising prospects for the future. Exactly this was the key issue in dualism between the two actors at play; the future prospects offered at respectively the modern health care and the traditional healers; a cure versus lifelong treatment.

7.2 Diverging explanatory models: to cure versus lifelong treatment

One major issue revolving around the diabetes care in Zanzibar; was the distinct dualism between the biomedical care and the traditional healers’ treatment goals; where the biomedical care provided lifelong treatment for chronically ill patients, in contrast to the traditional healers who stated that there is no disease without its treatment and cure. This implies diverging explanatory models according to Kleinman (1980: 105), and it corresponds to the evidence base from elsewhere in sub-Saharan Africa. In Zanzibar, this was found to create major conflicts between the two treatment arenas. The biomedical diabetes care was emphasizing exactly the lifelong prospects of diabetes. They were teaching the diabetics the importance of maintaining adequate glycemic control, so as to reduce or prolong late complications and premature death related to diabetes. Improving the diabetics’ coping and their quality of life was aimed for. They put much emphasis on educating their patients that diabetes is a chronic disease, and that it requires lifelong treatment and self-management. First and foremost, the health care workers highlighted their struggle against the remaining fairly common notion in the society; that diabetes is a curable disease. Some also highlighted
the belief in the *bewitched diabetes* in the society. One health care worker at Mnasi Mmoja was asked what the diabetics need to have knowledge about:

First, I have to have them to accept their illness. Because there are still a few people who go around, thinking that they could get rid of diabetes. So first I have to convince them that they have this disease for their lives. (Informant 5)

Diabetes being curable was exactly a contradictory explanation offered by the traditional healers. They emphasized that all treatment, regardless the nature of the illness, has a limited timeframe, and that there is no treatment without a cure. The female traditional healer was asked why she thinks the modern healthcare stresses lifelong treatment for diabetics:

I don’t know. But to us they don’t use lifelong, because there is no disease without its cure. (Informant 20)

The male healer did not even regard diabetes as a disease, in comparison to transferable diseases; but only as a matter of wrong diet, caused by lack of knowledge:

And diabetes is not a disease! This is what I hate! I get a headache! Because if it was a transferable disease, like malaria from mosquitos. […] But diabetes is not a disease! It just wrong feeding! […] So diabetes is very simple! It’s just to give people knowledge! (Informant 8)

The health care workers and other key persons in the diabetes care at some extent agreed that the traditional medicine *did* have an effect; that the herbs and other substances *were* powerful, they *were* blood sugar lowering, but that this also was among the reasons why diabetics still kept on using traditional medicine, because it had a rather immediate effect, giving the diabetics the hope of having been cured. They still highly denounced the use of traditional medicine, due to the way this treatment was utilized; that there was a lack of research, evidence base, and proper dosage; which made it highly risky and dangerous to the diabetics. The health care workers were frustrated by the typical pattern of diabetes patients coming back to the hospital after longer or shorter periods trying out traditional medicine, often ending up with severe outcomes. It was emphasized that traditional medicine eventually led to poorly controlled blood glucose, which often resulted in hospitalization or fatal diabetes complications, such as kidney failure, stroke, amputation and blindness. It was also emphasized how this made it particularly important with diabetes education; so as to undermine the wrong information the diabetics were fed from the outside; ideas which were
very difficult to get through. They strongly advised the diabetics to abstain from traditional
treatment. A male diabetic from town underpinned this, when elaborating on the group
education they had received at the diabetes clinic:

They explained in a good way of using food or to avoid using sugar or to stop use traditional medicine.

(Informant 7)

On the other side, the traditional healers also had their own opinion about the biomedical
treatment of diabetes. They particularly did not agree in the concept of lifelong treatment; that
there exist diseases that require lifelong treatment in terms of tablets or injections. They also
emphasized how they gave proper education and follow-up, compared to the congested
biomedical care that only provided, in their eyes, unnecessary medication. The male
traditional healer described a discussion he had had with a representative from the health care:

If you think injection and tablets are the best way, ok continue! But my method is just to give the
knowledge to people, which is missing! And then to eat, in order to produce insulin.[…] The herbal
medicine; eat this, eat this, eat this… is more active than tablets. Always with tablets, there are side
effects. […] How long the doses take? One year? Two years? Three years? For your life? That means
it’s not a medication! Medication is a special dose! One, two, six, five, and it’s finished! But if you
take the medication for the whole year or rest of your life, is that a medication? No! (Informant 8)

A variety of participants highlighted that traditional healers usually encouraged the diabetics
to leave hospital treatment. The male traditional healer for instance was explicit about how he
advised the patients to stop using insulin; as a scaled down process, simultaneously as
stepping up with the traditional treatment. A male diabetic from town explained about his
experience in this matter:

I stopped using insulin, because they advised me to use their medicine and stop hospital medicine.

(Informant 7)

It differed though, how the traditional healers appeared to guide the patients in use of bio-
medical treatment. The female healer on the other side claimed that she did not advise the
patients to stop using hospital medication, due to, as previously elaborated on, then ruling out
the option of sending the diabetics back to the hospital in case of problems or complications.
This failure in treatment though she explained as a result of the diabetics’ unsuccessful diet
control, not of the treatment she provided itself. Anyway, she somehow in this way aspired
cooperation with the modern healthcare. These diverging practices between the various
healers the researcher believes only shows their large latitude; that they could very much define their own role and responsibility, a clear sign of the continued lack of supervision and regulations from the authorities.

### 7.2.1 The belief in a cure embedded in Islamic discourse

The belief that every treatment has its cure, appeared to somehow being embedded in the society’s profound cultural background of Islamic influence. It was a religiously based perception in the society; revolving around that every disease has its cure, and that Allah is the one who treats illness and cures. This is also supported by other studies from Zanzibar, where among others Beckmann (2012) highlights that in Zanzibar there is a belief that the Quran is the ultimate medicine and source of scientific knowledge, and that God can cure any disease. Despite of the growing impact of the modern world, such as exactly biomedicine; Zanzibar remained in many ways a traditional, conservative Muslim society. Thus, interpretations of health and illness rooted in Islam were still highly applicable, and fought for the strongest position with modern biomedical explanations. The traditional healers were exactly representing these pre-modern theories of health and illness. Their impact revolved around this position; as representatives of the traditional Zanzibari culture, with the religion of Islam at its core. An imam in town was elaborating on the Muslim interpretation of illness and cure:

Prophet Ibrahim say; when I’m sick Allah is the one who cure me. So we Muslim believe that Allah is the one who cure us when we are sick. […] And prophet of Allah prophet Muhammad says; treat yourselves servants of Allah. Surely Allah has not sent disease unless to bring its treatment. So everything has its treatment. That’s what we Muslim believe. (Informant 19)

Informants often highlighted the direct link between tradition healers and Islam; the *dawa [medicine] Sunnah*; which is also described by among others Meyer zu Biesen et al (2012). The Sunnah was a product of the Islamic influence, was somehow deeply embedded in the Zanzibari culture; and was a part of the treatment traditional healers offered. The male assistant medical officer at a dispensary in town explained:

The word Sunnah is religion word, and most people who are believers, they believe in this treatment more than anything. So they depend more on that than hospital medicine. […] So the names are Arabic; so they are similar with the herbs. Many drugs have been brought here by Arabians; hence
they are the ones who discovered. So they are the ones who gave the names, and its relation is big.

(Informant 14)

The traditional treatment for diabetes was often described as something bitter; basically that bitter products were used to balance the sucari [sugar or blood sugar], as it was often phrased; and this theory appeared to be originating from the Sunnah medicine. Beckerleg (1994:2) describes exactly that Islamic medicine is humorally constituted; where notions of hot and cold, balance, movement, and blockage forms the basis of many Swahili notions of the body and of illness. This can largely be reflected in the use of bitter treatment for the sucari found in this study. A male diabetic from town was elaborating on the importance of this bitterness associated with traditional medicine:

There is a traditional herb, known as shubiri; it’s a crystal, the Arabic one. It’s bitter. So I just put it in the glass in the morning and drink before eating. When you drink it’s very bitter, the body senses the bitterness. So I used it till I felt it was sweeter. Then it was the tree roots which are bitter, and they said that it was diabetes drugs. There must be things that are bitter that can lower the blood sugar.

(Informant 6)

The healers in this study exactly explained how they utilized both local herbs and the Arabic drugs that they bought from the local shops in the treatment they provided the diabetics. Young & Ali (2005:6) found in their study from Pemba that among traditional treatment, it was reported using both local herbs and crystal-like substances that dissolves in water, obtained in Oman. Beckerleg (1994:11) described in her study that Swahili practitioners make up their own medicines, based on recipes given in Arab language textbooks or compounds they have developed themselves. The raw materials are sold in medicine shops found in all Swahili towns. All around Zanzibar town, you could exactly find special shops selling this type of Arabic originated drugs; small jars with this typically powdered drugs. The female traditional healer described the treatment she offered:

First there is a tree called “Muango ”, it’s not boiled, it’s put in water for sugar, this tree treat both together. Also there is drug called “Kaumwa ” for abdominal pain, which is blended. So this is taken raw, blended to powder, boiled, and then filtrate in a clean cloth. If you give this to a diabetic patient it’s going to work in pancreas. There is also a drug in which we buy from local traditional shop like Al Kisusi, Sua and Kamnal Abia, that are Arabic by origin. (Informant 20)
One health care worker at Mnasi Mmoja though was of the opinion that the Sunnah medicine actually was a growing phenomenon in the society, and complained how the traditional healers increasingly utilized these elements from religion as a part of their treatment:

Nowadays they have this new thing coming up; dawa Sunnah. It’s traditional medicine, but they put it in a religion way. So they introduced this one to confuse people. […] Before they used to use the herbs, those that are in roots type or leaves. But now they are in powder form, in bottles. (Informant 15)

The healers’ link to dawa Sunnah, medicine of Islam, the researcher believes is among the factors that reinforced the healers’ position in the Zanzibari society.

7.3 Precautions for Ramadan fasting

As already elaborated on in the previous chapter; one cannot avoid considering the impact of religion when assessing perceptions of diabetes and diabetes care in Zanzibar. In many ways the religion of Islam permeated the culture, and subsequently also the different venues of diabetes care. Islamic influence was particularly evident in relation to Ramadan; the holy month of fasting. This issue was a prominent part of the workday for the health care workers, as Ramadan was the peak season for admissions of acutely ill diabetics. In general, the biomedical health care advised the diabetics not to fast. They emphasized that the majority of the diabetics in Zanzibar had poor blood glucose control and/or complications, which indicated to refrain from fasting. One nurse explained:

During the holy month of Ramadan we told them not to fast.[…] Patients with chronic diseases are not supposed to fast during Ramadan. (Informant 15)

Nevertheless; the health care also endeavored assessing each patient individually, and the minority of diabetics that had good glycemic control, were approved to try fasting. It was highlighted a particular guideline for diabetes in Ramadan, which they adhered to. This was developed by Muslim diabetologists in Casablanca, and was allegedly broadly speaking dividing the patients into four groups; “very high risk, high risk, moderate risk, and low risk on complications during Ramadan”. This classification corresponds to relevant literature (Al-Arouj et al, 2010). For the relatively healthy diabetics, the health care emphasized that it was acceptable to fast. This though implied adequately controlled blood glucose continuously for the past three months ahead of Ramadan; which was stressed as being rare, that very few
diabetics actually reached this level. These diabetics were also advised to break the fast if the condition deteriorated during Ramadan. For the diabetics that attempted to try fasting; the health care recommended checking the blood glucose frequently throughout Ramadan; preferably by having their own glucometer at home, or otherwise by attending a clinic. The diabetics’ thorough knowledge of their condition was also considered a criterion, and the signs of hypo- and hyperglycemia in particular; so that they could be able to monitor themselves adequately.

As described previously, there was an attempt of cooperation between the health care and the influential religious leaders during Ramadan, and there had allegedly been meetings between these two venues with the topic of diabetes and fasting on the agenda. There appeared to be an agreement between the two venues that an ill person do not have to go through with fasting. Informants normally highlighted that according to Islamic teachings, according to the Quran; patients with chronic diseases in general do not need to fast during Ramadan. One nurse explained:

We taught them: Don’t fast, don’t fast. […] And it is in the holy book, in the Quran. It was written there. So every Muslim knows about that. […] The Quran teaches everything; the way of life.[…] Every religion emphasizes on the wellbeing of its people, also Islam. So that’s why in this holy month of Ramadan, it’s forbidden for the diabetic patient to fast. (Informant 4)

An imam from town described correspondingly:

The Quran explains that a patient is allowed to eat and not to fast. (Informant 19)

Though, he continued:

But he is also told that if he can fast during sickness he is not prohibited, because Allah says; if you fast it is better for you. And Prophet Muhammad says; fast and you will get healthy. So diabetes patients are not forced to fast; if he fast it’s because of his own will, if he thinks he can fast he will fast, and if he can’t fast he will not fast. (Informant 19)

This indicates that although it was an agreement that the diabetics were not obliged to fast according to Islam; there was still a religious expectation or norm that said the best is to fast, as promoted by Prophet Muhammad. This was something that was frequently highlighted; the fact that fasting is one of the five pillars of Islam; the mandatory foundation of Muslim life. Thus, the religious norm of fasting was still highly an overriding rule in the Zanzibari society.
The traditional healers were also naturally also dealt with diabetics around the time of Ramadan. Though the male traditional healer pointed that fasting is not for all diabetic, it is not for the weak ones; he emphasized that the best for the diabetic is to fast:

Fasting is the best medicine for the diabetic! Because you eat only one time, and you already control the diet. It means it’s very easy! […] But it depends. Sometimes if too weak; no fasting. Yes. Because he’s too weak. But maybe if he has 100 kilos, and he’s supposed to be 58; better to fast. […] Because in Ramadan we have salt dishes, we have sweet dishes… All this includes carbohydrates! It means that you are gaining weight! But the meaning of Ramadan is to fast, in order to be healthy! […] So I check the standard of sugar; no sugar, you must fast. (Informant 8)

Lastly; it additionally appeared that if you did not fulfill the fast in Ramadan, you were expected to provide something to compensate. This was a religious norm, an implicit rule of conduct; which also counted for the ill persons including the diabetics: If you did not go through with the fast, you were supposed to replace it with this compensation. This was said to allegedly be equal to the ibadah of fasting. The researcher also observed this phenomenon in her own residential area; as some neighbors every afternoon during Ramadan handed out juice for all the neighborhood children, who always came in big numbers. The imam explained about the compensation:

The patients that we expect not to get well, like diabetics, can provide something to compensate and he will not fast. But diabetics differ from each other; there are some patients who can fast two-three days, and there are some diabetics whose sugar is always high, so he cannot fast. He will give out 1 kilogram [rice] and that will be his fast. So he will be like he has fast. To compensate is a part of his fasting. (Informant 19)

Although the health care workers realized how practically difficult this compensation could be for the patients, as most of them after all lived below the poverty line; it was anyhow nothing they particularly discouraged. It was rather utilized as an obvious advice to give diabetics who were not recommended to fast. The compensation was, ironically enough, intended to go to the poorest of the society, for instance by giving away food, such as a bag of rice. Just as one nurse explained when she was asked what they recommended if the patients had difficulties accepting to refrain from the fast:

He can provide something, and we explain to them. (Informant 15)
8 Coping mechanisms among diabetics and associating factors

This last chapter of findings will return to the diabetics and answer the last specific objective, which intended to investigate coping mechanisms among diabetics and associating factors; though this to some extent also has been touch upon throughout the two previous chapters. A web of factors were found being at stake in terms of coping strategies among diabetics in Zanzibar; where the researcher identified three main overarching categories of factors being frequently described. The researcher must point that all the factors naturally overlapped and were interconnected. However, this systemization seems as an appropriate way of organizing and elaborating on the topic. The first subchapter is describing cultural and religious factors that were found negatively influencing coping among diabetics. Firstly, it is found that the diverging explanatory models on diabetes in this society largely determined the diabetics’ illness actions, and the healer shopping was evident, which largely had the hope for a cure as the driving force. The healer shopping implied an aspect of secret use; the diabetics often did not reveal to the biomedical health care that they were using traditional treatment. Also the social network was found to be crucial for the diabetics’ illness actions; for instance did people around the diabetics directly influence their choice of using traditional treatment. It was also described how cultural or religious norms and expectations in the Zanzibari community negatively influenced their coping, and particularly in relation to the holy month of Ramadan diabetics experienced difficulties in coping with their illness; as to refrain from fasting implied a social stigma. The second subchapter elaborates on how poverty and limited accessibility to modern healthcare constituted a large impact on the diabetics and their families’ lives and coping, and consequently also reinforced the healer shopping. The diabetics struggled with the diabetes diet; as the main constituents, such as vegetables, were fairly expensive; which was largely being associated with the increasing tourism on the isles. Normally living within a large nuclear family with many mouths to feed also implied a starchy diet. All this had impact on coping among the diabetics. Lastly; it is given an attempt to also showing positive factors influencing the diabetics in Zanzibar. This was usually associated with increasing knowledge and awareness of the disease. It was also described as related to wealth, though a contradicting view was that the basic way of life in the rural parts of Zanzibar promoted coping. In this matter it was highlighted a more active life of farming and fishing, and a healthier diet. Coping well was, again, related to the diabetics’ social
environment, and especially to their families’ capability of safeguarding their diabetic family member.

8.1 The “stubborn” diabetics: cultural and religious factors as constraints for coping

The “stubborn”, “ignorant” or “difficult” diabetics were frequently touched upon by a variety of informants. These diabetics were described as those who had no intention of changing behavior; they were eating whatever pleased them, they were fasting during Ramadan, or they kept on using traditional treatment. This “stubbornness” was described as relating to lack of acceptance; these diabetics did what they were used to do, or what the culture indicated. These diabetics were described as often being highly aware of their own condition, they had been in contacts with the health care and had received education; but still they did not change their inadequate behavior. They would typically return or come to the clinic when they got ill, or after complications occurred. Only after fatal complications occurred, they would often attempt to change. One nurse was explaining why some patients did not follow the advices they had been given:

I’m going to say what: Attitude. Some people have a negative attitude. Whatever you teach them, their attitude is not good. Until maybe they come with kidney problems or eye problems; he realizes that he’s doing a mistake. […] They change attitude when they got complications. (Informant 4)

8.1.1 Healer shopping: hoping for a cure

Let’s start repeating the concept presented by De-Graft Aikins (2005); healer shopping, which is defined as “the use of a second healer without referral from the first for a single episode of illness”. The “stubborn” diabetics in Zanzibar were often described as those who were attending traditional healers or using traditional medicine. According to Kleinman (1980:105); explanatory models offer explanations of sickness and treatment to guide choices among available therapies and therapists and to cast personal and social meaning on the experience of sickness. Beliefs outside of the biomedical framework were exactly found to be crucial regarding Zanzibari diabetics’ illness actions; traditional beliefs, which largely involved the heritage from Islam. Particularly precarious was the common hope that diabetes might be cured. Despite the increasing access to modern health services and biomedical
explanations of diabetes in Zanzibar, people still availed themselves of the traditional
treatment, partly due to these contradictory beliefs. Stress was something that was frequently
touched upon; living with a chronic disease like diabetes involved coping with stress, and
many described how this was affecting their illness experiences. Having diabetes was
described as constantly having to deal with your illness; to deal with symptoms, to deal with
everyday struggle, to deal with fear and uncertainty, and to constantly seek accessible
treatment or possibly a cure. This was largely associated with the fluctuating switching the
diabetics made, the healer shopping, between the various health sectors in Zanzibar. A male
diabetic from town explained:

You know when you are sick you’re restless… You go here and there looking for treatment, because
they told us they cure diabetes, so I was excited and used their medicine, but they lie. (Informant 7)

It varied how informants described the process of health care seeking behavior among the
diabetics. The diabetics in the study, who revealed that they had tried traditional treatment,
emphasized that this was something that happened initially, just after being diagnosed. After
experiencing illness episodes related to using it, they claimed that they had stopped. Others
highlighted that diabetics continuously made use of traditional treatment; either by
combining , which normally resulted in hypoglycemia; by completely ignoring biomedical
treatment until experiencing severe illness; or by seeking traditional healers after years and
years of ill health sticking to modern treatment. Some informants highlighted that it was a
greater use of traditional treatment in the countryside, that here; you could often find persons
who had never been to a modern hospital, but only sought traditional healers. The traditional
healers described how they frequently diagnosed persons who turned out having diabetes, by
utilizing modern diagnostic tools; and then continued to follow up the diabetic from there.
One can conclude that the diabetics in Zanzibar in one way or another combined the
traditional treatment with the modern one. In other words, the occurrence of healer shopping
among the diabetics was persistent; and this revolved at a large extent around exactly the
multiple realities and truths of diabetes and treatment of diabetes in this society, where the
hoping for a cure was particularly prominent. A male diabetic from town revealed his belief
in the difference between respectively the “bewitched diabetes” and “pancreas diabetes”, and
his strive for a cure; when he elaborated on the background of him unsuccessfully trying out
traditional medicine:
There is a friend who told me that there was someone who had been cured by traditional healers, but I think she had been bewitched; the bewitched diabetes. […] Not the pancreas diabetes, no. They said that they had treated her and she got cured, so I told him to give me the medication so I can try.

(Informant 7)

This has previously been highlighted by among others Meyer zu Biesen et al (2012), the fact that there is a clear distinction in disease causation between “illness brought by God”, “illness brought by man” and “illnesses caused by spirits” in the Zanzibari society. Illnesses of man are those brought by sorcery or different sorts of dawa, such as an evil eye, used by others in order to inflict harm (Meyer zu Biesen et al, 2012). The diabetics in Zanzibar were somehow juggling between these diverging explanatory models, searching for accessible treatment and hopefully a cure.

Secret use

It also appeared that the diabetics often did not tell the biomedical health care the fact that they were using traditional treatment. Health care workers explained that it was often difficult to assess why the patients’ blood sugar was poor; due to the patients normally keeping the use of traditional treatment as a secret while it was ongoing, and that it was a pattern that complications or illness episodes occurred as a result of the patient using traditional treatment.

A female diabetic confirmed this:

I went to the clinic, and the clinic told me that you mix the drugs, the traditional and hospital. I denied, but it was true! (Informant 9)

8.1.2 The impact of the social network: negotiating illness actions

Also the social network was found to be crucial for the diabetics’ coping. Illness actions among diabetics in Zanzibar involved constant negotiations with people around you and with the nuclear family in particular. Illness matters were in other words family matters. One health care provider at Mnasi Mmoja stated:

I our society we live with our family. We don’t live like you in Europe, alone. So everything is done by family. Any decision we make is family decision. (Informant 3)
This also meant that if you had people around you giving inappropriate advice, you were most likely to make inappropriate choices. This reflects Kleinman’s *popular sector*; which is made up of a series of informal and unpaid healing relationships of variable duration, occurring within the sufferer’s own social network, particularly the family (Helman, 2007). All the diabetics in the study described how people around them for instance directly influenced their choice of using traditional treatment. Men in Zanzibar for instance tended to spend many hours every day at specific meeting places in the neighborhood, talking and discussing their lives with other men in their social network. All in all this means that the beliefs, the knowledge, the perceptions of truth and the social norms among those surrounding the diabetic; were crucial to his or her coping strategies. Thus, inadequate illness actions could be direct results of negotiation with people in your social network. A female diabetic from town was asked who gave her the information about the herbs she used for treating diabetes:

We are just talking to each other; that the herbs reduce it. (Informant 9)

On the other side, it was also diabetics who emphasized resisting the social norms or inputs from their environment. A male diabetic from town also elaborated on how his family and other people in his social network advised him regarding his illness actions, though he stressed that despite all the people advising him to use traditional treatment, had had accepted his condition and remained on biomedical treatment:

My parents gave me the traditional medicines to use. I used traditional medicine, but after seeing that they were not effective, I left them. […] And also the way we live… For example there are people who know me; they come and tell me that there is a witch doctor who is treating diabetes. […] There are so many people who follow me and tell there is a traditional healer who can cure you, but I tell them ah! I have already accepted this condition, so leave me as I am. (Informant 6)

### 8.1.3 Being diabetic during Ramadan: coping with the social stigma

Many diabetics described the aspect of stress in conjunction with cultural or religious norms and expectations in the Zanzibari society, and particularly in relation to the holy month of Ramadan, diabetics experienced difficulties in coping with their illness. As previously described; Ramadan in Zanzibar was encompassing and rigorous. The researcher observed a society that during this period changed drastically: People generally changed their behavior patterns; where women who nevertheless used to cover themselves, switched to the even more
restrictive full-face burqas; and five times a day at all hours men flocked to the mosques, and prayers filled the air. Further, there were generally strict norms of not being supposed to eat and drink in public. All the little fast-food kiosks around were all by the sudden closed down, some only in the daytime, some continuously throughout the whole period. There was literally no access to food when you were outdoors, except from maybe the overpriced, typical tourist restaurants in Stone Town where no locals went. The diabetics experienced difficulties due to these cultural constraints; they did not want to show in public that they were eating, and many had work or errands to do outside during the day. So that even though “every Muslim knows that an ill person is not supposed to fast”, as many also highlighted, it was still experienced as difficult to adhere to. Even though some intended to refrain from fast, it was practically difficult to carry out. From early childhood you were taught that fasting is one of the five pillars of Islam, it is one of Allah’s commands; and then after maybe forty years you were suddenly told that you needed to stop it, and consequently needing to deal with the reactions from the community that this necessarily entailed. This was described as being highly difficult to relate to; to refrain from fast felt like sinning, or having the feeling of showing the society that you were sinning. To eat in front of people, even your own family, simply felt odd. A social stigma related to breaking the fast was evident. A male diabetic from town was providing a picture of his great efforts trying to hide the fact that he was not fasting:

What I am doing is not to show off yourself, even if you are ill then eating front of the people so everyone can see you. You know how our things are? [looks at the research assistant] It is not good, even myself I don’t feel good. So I eat on my own during morning, see? Then I make sure that this food is enough for me, and sometimes it happens I feel hungry, so I just go find the corner and hide that I eat so that no one will find out that I am not fasting. If they saw me they believe I am fasting, but the truth is I don’t fast. To tell the truth it is difficult. I thought about it today because during Ramadan we are not supposed to eat at the streets, so for example when I face the hypoglycemia, so I asked myself what shall I do? I need to eat something so as to stabilize the condition. So sometimes I think, then I said God help us! But it is very risky, very risky. God forbid, but if it happens, what will I do? Sometimes there are no foods. Sometimes there are no foods, so I just tell myself that I have to take something in my pocket to go with. That’s what I think, but you know our pocket, all the time you are with people. So if they saw it, it is a problem. To tell the truth the Ramadan gives us a hard time little bit. Because of our customs. (Informant 6)

Thus, diabetics in Zanzibar usually attempted to go through with the fast, despite being advised not to by the health care. Fasting subsequently often led to poorly controlled blood
sugar and illness episodes with hypo- or hyperglycemia, and admissions during Ramadan was a common phenomenon. A nurse explained:

They like to fast. Many patients even today they came here with high blood sugar because they are fasting. […] The patients are being so stubborn because they think if they don’t fast they are going to get sin. That’s why they want to fast. (Informant 2)

Ramadan also involved a change of diet, in terms of heavy, unhealthy meals in the evening, and the diabetics were often eating what the rest of the family was eating. And yes, the researcher herself experienced these overwhelming evening meals with family during Ramadan; with tablecloths on the floor filled with delicious, but fatty and carbohydrate rich dishes, accompanied with sweet chai. This tendency was often described as being a diversion from the actual meaning of ibadah and fasting; which is to promote health. Thus, wrong diet in the evenings was often, also by the health care workers, described as the leading cause of the frequently appearing disease exacerbation among diabetics during Ramadan, manifested by the high numbers with hyperglycemia and hospitalization during this period. An older diabetic stated that she was fasting, and she further explained difficulties of having a healthy diet during Ramadan, as she had no other option than to eat the family’s meals in the evenings:

I was told not to eat sweet jams, but during this Ramadan I did not have food, then I told them to give me. I didn’t have anything, would I stay without eating, no. (Informant 11)

A few participants emphasized that diabetics who were in good control and were able to check their blood sugar regularly, handled the fasting well. A key person in DAZ, who was on oral treatment, explained that he was fasting and that this turned out well. Though, he emphasized the importance of controlling the diet in the evening, and that most diabetics in Zanzibar did not have the capability of doing so:

For myself I am fasting. […] I am taking pills, that is why I can fast. […] But you have to control your diet at the time of the evening when you are eating. […] That’s why the doctors forbid every diabetic to fast, because most of them can’t program their dish, their diet. They use everything they get. (Informant 17)
The difficulties of providing the compensation

The attempts to go through with the fast were often also associated with the diabetics not being able to provide the compensation, which you according to Islam were obliged to if you for some reason were not able to complete the fast. The diabetics were poor, and it was difficult to find the means for compensation. A diabetic from town elaborated on how her fasting resulted in hypoglycemia, due to not being able to provide compensation:

They told us not to fast, but sometimes the situation is not good for providing something. To tell the truth I fast 13 days, because I didn’t have anything to give out. I fast 13 days. 14. day I brake my fast. I couldn’t finish, the sugar reached 14.6 something. [...] I stayed three more days, I wasn’t fasting. In the evening, I felt like my body had no energy, I wasn’t even able to cook this Ramadan. So I told them to send me to hospital. I was being checked, and the sugar was 3 mmol. (Informant 9)

8.1.4 Other stigma related to being diabetic

There was also touched upon other types of stigma related to being diabetic in Zanzibar. The issue of impotence among men was particularly elaborated on; that men sometimes did not want it to come out that they were diabetic, due to what appeared as being a well-known fact in the Zanzibari community, exactly the association between diabetes and impotence. One health care worker at Mnasi Mmoja explained this as related to some men being reluctant not showing up at the clinic:

Some patients don’t like to come here. Our society is very small, so people know each other. So some of them don’t like to be seen that they are diabetic, especially men; because there is a relation between diabetes and impotence in our society. (Informant 3)

This issue has also been highlighted through other studies from sub-Saharan Africa, such as Baumann et al (2010); who pointed that considering the high value of fertility in most African cultures, this dysfunction presents a significant psychosocial issue for sexually active men. This could be transferable to Zanzibar; largely being a sex-segregated society (Larsen, 2008).

Additionally, a female diabetic from town also revealed a belief in the association between weight loss and AIDS, and an ambivalence of losing weight due to this matter:

If you lose weight people will say that she has AIDS. But also losing this weight makes me feel better than I was. (Informant 9)
This could mean that there was a stigma related to weight-loss associated with HIV/AIDS in the Zanzibari community which were giving spillover to the diabetics; as also been shown in studies from among others Ghana (De-Graft Aikins, 2005) and Cameroon (Awah et al, 2008). Beckmann’s (2012) study on HIV-positive in Zanzibar actually found a stigma related to HIV. The issue of weight loss though could somehow also be related to a matter of obesity as an esthetic ideal in African women, as among others Levitt (2008) has highlighted. The typical Zanzibari women you saw on the streets were overall overweight. Also the STEPS survey found significantly higher prevalence of obesity among women than men (MoH, 2012). The STEPS survey also found that the level of physical activity clearly differed with higher proportions among men than women (MoH, 2012). The MOHSW (2006:35) has previously pointed that attempts to control changes in local dietary patterns and obesity in Zanzibar are constrained by the popular cultural perception that obesity is associated with wealth. Levitt (2008) though also stressed that some evidence indicates that cultural perceptions of body size may be changing, and that women may be willing to reduce their body size for improved health. This might also to be the case in Zanzibar, where among others the habit of doing exercise appears to be increasing, also among women. This is also reflected in the latter informants’ emphasis on “weight loss making her feel better”.

8.2 Poverty influence on coping

This was the factor that was commonly highlighted as the most prominent issue: Poor coping and ill-health among diabetics in Zanzibar were strongly associated with limited resources and poverty. It was often emphasized that the diabetics normally accepted the information and advises they had received from the modern health care, but that it was hard to adhere to due to life conditions. One nurse explained:

Some will come and say “don’t think I didn’t understand you; I understand, but I didn’t have an option. So I can’t do until someone does it for me, or I can’t do those things”. (Informant 15)

Having a chronic disease and poverty was described as a poor match; as the sustainability was clearly missing. The diabetics pretty much did not have many options in terms of controlling life and factors in life, but had enough with coping from day to day. The vicious cycle was evident. Especially with regard to exactly diet, the diabetics were obviously constrained. They were basically eating what they had available, which was typically starchy foods, such as rice,
ugali and chapattis, cooked in saturated fats, especially coconut- and palm oil. Ingredients of a healthy diet were found being relatively expensive; compared to starchy foods, food such as vegetables and fish was evidently pricier. This was something the researcher also experienced doing grocery shopping at the market. Despite that the researcher often did shopping with her partner, who originally is Zanzibarian, and he normally was in charge of the negotiation of price; vegetables for instance were fairly expensive. Also the STEPS survey found a low intake of fruits and vegetables in the population of Zanzibar, with an average of 1.7 servings per day (MoH, 2012). This finding was supported by a mixed method study; that interpreted the low consumption being explained by exactly the low availability and high price of fruit and vegetables (Keller et al, 2012). People also highlighted the excessive use of saturated fats among Zanzibaris, especially coconut- and palm oil. Coconut was easily accessible and cheap; compared to healthy oil like sunflower oil, which was available, but fairly expensive. Palm oil was sold cheaply at the market in large yellow barrels, by the name of OKI oil. The STEPS survey found exactly that 82.9 % of the population used cooking oil rich in saturated fats; hereby palm oil or coconut (MoH, 2012). This imbalance in actual access to a proper diet naturally had a great impact on the diabetics’ coping. A female diabetic from the rural north was explaining about this hardship:

To tell the truth the life is so hard, so I don’t get it [proper diet]. But I try to follow diet, like not using coconut or sugar. (Informant 12)

The diabetics also normally did not only have themselves to care for, but a large nuclear family; and bringing enough food on the table for the whole family was a part of the diabetics’ every day struggle. They were often in the age of being caregivers, and had many children and other family members to provide for. Otherwise they were relatively old, and were totally dependent on the family. Additionally, the Islamic tradition of polygamy was still quite common in Zanzibar, where men in Zanzibar often had more than one wife, normally two or three; which meant large families with multiplied flocks of children. Some men had their wives in the same household, others in different homes so that they altered between. Also failed marriages were quite common in the Zanzibari society; it was normal to have ex-wives- or husbands out there, and the men were, at least on the paper or as a general norm; obliged to provide for their children of the failed marriages. The researcher also witnessed large matriarchal nuclear families; where for instance sisters and all their children from previous marriages lived together. These structures the researcher believes must have
influenced the family economies largely, and one can ask if the polygamy and the fluctuating marital relationships contributed to poor coping of the diabetic individual. The diabetics often had, exactly, these quite complex family structures; and they normally described that they were eating the family meals. ILOs’ (2010) Zanzibar Social Protection Expenditure and Performance Review and Social Budget showed that the larger the size of the household, the larger was the proportion of those living below the basic needs poverty line, and also analysis of dependency ratios showed that the greater the number of dependents, the more likely you were to be in poverty. Also other studies from sub-Saharan Africa, such as Kolling et al’s (2010) study from Dar es Salaam; found that the family circumstances, where poverty was the fundamental life condition; make continual prioritizations crucial for the patients’ illness actions, and make the dynamics of illness action discontinuous. A male diabetic from town had two wives, and was explaining of his difficulties having a proper diet, due to the family condition:

The family takes me as a normal person; I am the one they depend on. [...] I have two wives and four children. I used to have three wives, but I divorced one. [...] The first wife who I divorced I got one child, and the other who I live with, one has two children and the other has one. [...] So sometimes because of the lifestyle you cannot afford to use them [proper diet], maybe because of money or our condition or family. So you cannot separate your food from the family because of your condition.

Hence, if we decide to cook rice, the whole family will eat rice. (Informant 6)

A few contradictory claimed that healthy food was easily accessible in Zanzibar, and especially in the rural areas where people were peasants and did not even have to pay for the vegetables. The STEPS survey found only slightly higher prevalence of fruit and vegetable consumption in rural areas (MoH, 2012). One health care worker from a rural area claimed that most people there had good access to vegetables:

Some can afford, others not. The food like rice they said that they are eating, as well as vegetables that they can get. He is eating four times a day, but it’s not like he can have a huge fish. But in case of vegetables they do afford. (Informant 15)

Others stated that the peasants often needed to sell their crops, and in this way still ended up with a starchy diet. Some people related this to the steadily increasing tourism, and described the tourism as a negative factor for diabetics’ capability of coping. Firstly, this was associated with the price increase on especially fruits, vegetables and seafood. The demand for such food from the tourist hotels made it both less accessible, but also more expensive. Some
highlighted that even in the countryside, this food got progressively less accessible, as people exactly often sold the crops or the catch to the markets in town or for the hotels. Keller et al (2012) found oppositely to the STEPS survey, that people from urban areas had a more diverse diet and ate more fruits and vegetables, than people from rural areas. One health care worker at Mnasi Mmoja was explaining about this negative trend:

It’s very very expensive. Because of the tourism now. […] So people cultivate vegetables but end up selling it, because they need other things to survive. (Informant 5)

8.2.1 The limited accessibility to modern health care, essential medicines and equipment

Being a diabetic in Zanzibar was not free of charge; as we know that medicines and equipment were only partly subsidized. Lack of medicines and equipment and limited accessibility to health services was the reality the diabetics’ were facing. This corresponded poorly to the fact that most people in Zanzibar, also diabetics, were living on less than 1 USD a day, as many emphasized. Diabetics often described that they were simply empty of medicines or equipment, such as glucometer or sticks; and they could go on for longer periods literally unmedicated or with an unchecked blood sugar. A male diabetic from town area explained:

For me I only use the experience; I know if the sugar is high or low. But that machine is not like I don’t want, but they didn’t give us. But it’s important. (Informant 6)

This particularly applied for the ones on oral medication, as the oral medication was only partly covered for, compared to insulin, which was largely available free of charge. The diabetes services normally only had enough oral medication to give the diabetics for a limited number of days. The rest of the period until their next appointment, they needed to take their prescription and find means to buy the medication, which most people could not afford. Thus, the diabetics often ended up staying without anything. The health care workers described it as if they were running in a vicious circle, which there was no breach in. A fatal, but sadly a commonly seen, consequence was often early complications, as well as premature deaths. A female diabetic from town was explaining about the limited access to her oral medication:
I get drugs, Alhamdulillah! But sometimes it appears, maybe because now they arrange every six months’ appointment day at the clinic; so in between I have to find means to find them, and if I don’t have then I stay still. But if I stop using medication my sugar raises. (Informant 9)

Though the insulin only had been out of stock two shorter periods of time the past five years, this was particularly fatal, as the insulin was extremely expensive, about 20 000 Tanzanian Shilling (17 USD) for one vial; and for a diabetic to be able to buy this was simply unrealistic. Diabetics on insulin who had experienced it being out of stock, was telling about the stress and disease exacerbation related to this; just as this female diabetic from the north:

It’s difficult, because I don’t use any other drug. And that time my sugar is increasing, because they told me that I have to use only insulin; I have to find means to go to town, to buy at the pharmacy, at the dispensary. Ah, I feel miserable, I feel that the sugar is raised; if I didn’t get this drug I will not feel well. (Informant 12)

Also the limited accessibility to diabetes services was an obvious obstacle of coping. It was a concrete barrier of even reaching the diabetes clinics, in particular; as they were often far away from where the diabetics lived. This meant that you would need to pay for the transport, which imposed yet another cost for the diabetics to handle. One health care worker at a rural diabetes clinic explained:

Sometimes one can say “I have no money. Even to pay for daladala [local bus] to come to the hospital is difficult. No one can help me with money to get transport to the hospital”. (Informant 13)

Again, the social network turned out being crucial. Poverty was something that concerned the whole family, and many highlighted how this directly influenced the diabetics’ capability of getting to the health services, and getting sufficient medicine and equipment. Many of the diabetics were old and not having any form of income, thus solely depending on the rest of the household and their capability of safeguarding them. One informant explained:

Some of the patients are old, they can’t work. They depend on the family and the family is poor, so sometimes they can’t attend there at the clinic; they remain at home, since they depend on help from other people. (Informant 16)
Reinforcing the healer shopping

With the modern health care services being limited, this naturally reinforced the diabetics’ healer shopping. It was often emphasized that going to the hospital seemed useless to a patient if there were simply no drugs available. Also travelling distances was as mentioned an important barrier; as well as the costs related to blood glucose monitoring, which were not subsidized. This consequently made the diabetics turning to traditional medicine. A nurse was asked what the patients do if they did not get or were able to buy medication:

They try to eat herbs, some of them eat herbal medicine. (Informant 2)

8.3 Positive factors for coping

Adequate coping was something that was largely described as associated with knowledge, awareness and acceptance of the biomedical explanation of the disease. Many highlighted that the increasing accessibility to counseling and diabetes education through the diabetes services largely had contributed to this the past few years. Also community campaigns such as through the media, as well as the use of internet; were highlighted. There was overall an increasing awareness of diabetes and its signs and symptoms in the community. It was often highlighted how increased knowledge or awareness made the diabetic to refrain from the traditional treatment, and instead consulting the biomedical health care; and that this was increasingly evident. Thus, this awareness was also associated with why the number of diabetics on Zanzibar was steadily increasing; that people increasingly accepted and sought biomedical treatment when experiencing illness. Some health care workers highlighted the clear decline in diabetes complications the past few years, and particularly the number of amputations. One nurse was explaining about the increased awareness and acceptance of the biomedical explanation of the disease:

They used to say that this isn’t diabetes, that they have been bewitched by someone. So we try our best to educate, and now they understand and accept us.[…] Most of them come here. (Informant 15)

Also wealth was highlighted in this matter; those who were financially better off were often described as more likely to cope well. Wealth and a certain level of education was associated with living in town area; they more often had a certain income, compared to the more hand-to-mouth existence in the countryside, where people were surviving on fishing and basic farming. Illiteracy for instance was often associated with living in the countryside. ILO
(2010) show that two-thirds of poor people live in rural areas, which equates to one-third of the total population of Zanzibar. A quick look showed how life in town differed from rural life; in terms of among others housing and dress codes. In the countryside; people lived in simple mud huts, the women wore the traditional clothing, kanga, and the children were running around playing in the villages in dirty, ragged clothes. In town; the housing was, although still very basic, more modern. Women often wore black, Muslim outfits and were dressed up with jewelries and henna painting, and even little girls were often dressed in ornate Muslim style outfits. Being wealthier was naturally also associated with the diabetics being able to follow up their treatment financially; being able to pay for medication, glucometers, and regular checkups. Participants sometimes highlighted that those who were more affluent often attended the private hospital or clinics in town; where they got more frequent appointments, thus had closer follow-up. A health care worker at one of the rural clinics was stressing how the higher standard of living in town influenced the diabetics’ level of coping positively, compared to the situation on the countryside:

Life in town is always different, also for the patients in town. Even the education for him- or herself and his family is different. So he will have a greater desire, or because he will be pushed to do this; let’s go to hospital, don’t do this… So it’s different, because here the patients missing appointments are many. (Informant 13)

A contradicting view though; was that the modern, sedentary lifestyle in town was a negative factor for coping, compared to the basic way of life in the countryside. In this matter it was highlighted a more active life of farming and fishing, and a healthier diet. Some related this to the higher rates of diabetes in town, compared to the countryside. In this way, some meant that diabetics in the countryside were better off. Also the STEPS survey found a high prevalence of 82.4 % having moderate or high levels of exercise; though that this clearly differed between urban and rural areas, with a clearly lowest proportion in Zanzibar town. This was explained due to work in Zanzibar still being very labor intensive, such as fishing, farming and construction; as well as active transportation such as walking or cycling. Also the prevalence of obesity was found being significantly lower in rural than in urban areas (MoH, 2012). The key person in DAZ highlighted the negative impact of an urban lifestyle, compared to the rural life:

In town the rate of diabetes is very high, than in countryside. Because most of the town people have no activity at all; they are just eating, sleeping… And that is the main problem for diabetic. But people
living in the countryside there are farming, walking, doing activities most of them. So that is how they got prevention. (Informant 17)

On the other side, it was also highlighted that exercise in modern sense not had been part of Zanzibari culture; and some people meant that it was a greater receptivity to the idea of doing exercise in town than in the countryside, and especially among the rural women. They meant that the newly founded Obama exercise groups had had greater success in town than in countryside. The researcher frequently observed people jogging in groups on the beach or playing soccer on the field, and this was especially evident in town area. Mostly you saw men, but it also happened that you could see women, especially in town area. The STEPS survey found higher proportions among men than women doing exercise (MoH, 2012). It varied how participants explained the importance of gender in terms of exercise. Though, the women in this study explained that they were doing exercise, such as one female diabetic from the north:

I cultivate. And I’m running to reduce the weight, during morning. (Informant 12)

This could mean that there were tendencies in the society towards a greater susceptibility on doing exercise, also among women; as also mentioned previously.

Coping well was, again, related to the diabetics’ social environment. It often appeared that the quality of support not solely was related to the economic situation of the household; relatively poor families also tried to safeguard their diabetic as best they could. Health care workers highlighted those supportive families where one family member normally came along for the diabetics’ appointment days, as well as for the group education sessions. The families often also had big influence on the diabetics’ diet. This corresponds to other studies from sub-Saharan Africa, such as Mosha & Rashidis’ (2009) survey; that social support was associated with higher level of self-care. The daughter of an older diabetic explained how the family tried to help their mother the best they could:

The health care workers have educated us on how to live with a diabetic patient. […] The advice we are given we follow every day. […] (She eats special diet. Like beans, pears, banana punch, and rice mixed with beans, legumes. We cook millet ugali millet rice and millet porridge, and bread, but not every day.) The small amount of money we have, we go and buy food for her. (Informant 10)
A matter of oppression and power struggles: an analysis of the findings

This study has largely been viewed in the light of medical anthropology, with the emphasis that a society’s health-care system cannot be studied in isolation from other aspects of that society, especially its social, religious, political and economic organization; and has exactly found that there is a web of factors at play, revolving around local diabetes care and coping mechanisms among diabetics on the isles of Zanzibar. Though the study has found that diabetes care is on the rise in this society, there are still a number of limiting factors present. These revolve around the multiple explanatory models of health and illness which still circulates on the isles, and are being put into action by the different actors at play. The diabetics move in between; driven by the distinct poverty and the hope for cure. It is all reinforced by the still limited access to modern health care, as well as the continued poor regulation and unempowerment of the traditional sector; leaving the latter very much to define their own role. This reality, the researcher believes, can largely be viewed as a matter of power struggles, using Foucault’s terms; both on global and local levels; both historically and contemporary. The structural violence is obvious; this social machinery of oppression against the poorest of the world, which Dr. Paul Farmer describes. Below is an analysis of the findings from this study, in light of relevant theoretical perspectives.

9.1 Being objects of oppression

Farmer (2004) stresses that any thorough understanding of modern epidemics requires the recognition of the large-scale social and economic structures in which affliction is embedded. Structural violence is often embedded in longstanding ubiquitous social structures, normalized by stable institutions and regular experience. It is linked very closely to social injustice and the social machinery of oppression (Farmer et al, 2006). For Zanzibar, and for its escalating major public health problem with diabetes and other NCDs; oppression was manifesting in different shapes. Firstly; one must view Zanzibar in relation to its position in the world order; starting with its profound history of centuries with oppression under a variety of mighty rulers, from Arab sultans to the British Empire; where among others an extensive slave trade left its marks (Larsen, 2008; Bennett, 1978). Still, Zanzibar is only a semi-autonomous region within the United Republic of Tanzania (MoH, 2012), a case that is highly
debated in the Zanzibari society today (Parkin, 2006). Contemporary Zanzibar still finds itself in the bottom of the world order, a developing country; with among others 44 percent of the population having an income below the poverty line (Zanzibar Office of the Chief Government Statistician, 2013); around a third of the whole population having no education, less than 5 % having achieved post-school level qualifications; and only about 15 % of all employed persons being in paid employment (ILO, 2010). And these realities were what surrounded the Zanzibari diabetics and their families. Coping with chronic illness in Zanzibar also entailed coping with these tough living conditions. The literature describes that effective diabetes-related coping involves identifying factors contributing to current and near-future glycemic status, such as life stress or physical stress; having the knowledge and skills to evaluate the circumstances and respond appropriately; implementing a new treatment strategy or behavior; and having access and willingness to use a health care professional or support person who can help solve problems and collaborate in a treatment decision (ADA, 2012). Diabetes self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (IDF, 2012a). This all appears blurred when contextualized to a society where people normally cannot make all these deliberate choices for improving life and health; the prerequisites for these lifestyle changes were in many ways simply missing. Being a diabetic in Zanzibar meant struggling from day to day; to find means so that, not only you, but you and your often large, complex nuclear family could keep your head above water. Following a diabetic diet was necessarily given a lower priority than providing your family enough food every day. When a healthy diet such as vegetables was simply unavailable due to the relatively high cost; a starchy, fatty diet was a natural consequence. To change these so-called lifestyle patterns had its natural limitations in the poverty which encompassed the lives of the Zanzibari diabetics. The oppression and poverty was profound and a part of the consciousness of the Zanzibari people; which were reflected in among others the hoping for a cure: Having a chronic disease such as diabetes in Zanzibar simply did not pose many positive future prospects. The stress and despair related to living with a chronic disease under these conditions reinforced the cultural belief that every disease has a cure; this was sometimes the only future prospects they had; a dream, a belief, a hope. And also that, until very recently, having a severe disease in Zanzibar was synonymous with either die, or, if lucky, being cured. This again might be reflected in among others the stigma related to the association between weight-loss and AIDS; that until very recently, people in Zanzibar died
prematurely of especially transferable diseases; thus their consciousness was still on that path. The new trend, this message from the global society that one can be healthy and live a long life with a chronic disease must have seemed blurred, especially when the life conditions were so limiting that being diabetic in Zanzibar was still highly synonymous with eventually developing severe complications and often premature deaths.

Another obvious manifestation of oppression was the insufficient measures allocated on diabetes care in Zanzibar. Although the situation was improving, as a consequence of the increasing global attention on “the burden of diabetes and other NCDs being one of the major challenges to development in the 21st century, especially for developing countries” (IDF, 2007; United Nations, 2011; United Nations, 2012), and various measures were being endeavored, with the newly established NCD Unit at the Ministry of Health at the core; the diabetics in Zanzibar still lacked basic health services that are taken for granted in the western world. People complained that the main focus of the health care in Zanzibar was still on communicable diseases, so that diabetes care remained suppressed. The diabetes care was also largely dependent on international aid, and a variety of NGOs were found to be involved. The international support was obviously not sufficient, as especially the lack of essential medicines and equipment presented major difficulties in the diabetics’ lives. As the medicines, particularly the oral medication, were only partly subsidized; the diabetics were imposed major expenses that they normally simply could not manage. This resulted in other strategies of action. Helman (2007) points that ill people, in any society, move freely between the popular, folk or professional sector and back again, often using all three sectors at once, especially when treatment in one sector fails to relieve physical discomfort and emotional distress. People make choices, not only between different types of healers, but also between diagnoses and advise that makes sense to them and those that do not (Helman, 2007). It obviously does not make sense with health services who tells you the importance of medication compliance, when the medicines and the essential equipment are simply not available. This reinforced the continued use of the popular- and the folk sector amongst Zanzibari diabetics; as the biomedical health care was not able to provide some of the elementary constituents of its regime, namely the medication and the monitoring equipment. Health care workers described it as working in a vicious cycle; where the diabetics repeatedly came back to the hospital with deteriorated conditions after not having been able to buy medicines or after using traditional treatment. Also the fact that the glucometers were not subsidized contributed to disease exacerbation, as the diabetics were not able to monitor their
blood glucose values at home. When the diabetes services additionally were relatively inaccessible; as a combination of the large amount of diabetics in need of the services, together with the limited number of service delivery points that were often far away from where the diabetics lived; this contributed to the diabetics seeking health care elsewhere. In the need of regular health checks, and then especially the blood glucose monitoring; they often consulted either one of the larger number of primary care units, or dispensaries; or a traditional healer, who also happened to possess among others glucometers so that the glucose monitoring could be maintained from there. The use of traditional drugs; either by mixing it with the hospital medication, or by completely abandon the latter; largely caused disease exacerbation. The vicious cycle was clearly evident; rooted in the continuous structural violence that was the sad reality among the Zanzibari diabetics; this strong association of poverty and social inequalities being embodied as differential risk for disease and for adverse outcomes including death, that Farmer (2004) describes.

9.2 The truth embedded in the biomedical discourse: a breeding ground for ongoing power struggles

There were ongoing changes in terms of increased attention on diabetes care in Zanzibar: People emphasized that the government during the past few years had started addressing the growing major public health problem of diabetes and other NCDs, with among others the NCD Unit at the Ministry of Health being established in 2011. The international community was largely involved, where various NGOs, such as the International Diabetes Federation and the World Diabetes Foundation, were responsible for a large part of the funding of the diabetes care in Zanzibar. Increasing knowledge and increasing awareness were keywords highlighted; the diabetics and the Zanzibari society in general were steadily enlightened about this disease; about causes, symptoms and proper treatment; and increasingly sought modern diabetes care. This corresponds to signals from the international policymakers, who have stressed that education of individuals, families and communities is an essential component of effective diabetes care (IDF Africa, WHO Afro & the African Union, 2006). According to Kleinman (1980), the professional sector comprises the organized, legally sanctioned healing professions, such as modern Western medicine or bio-medicine. Bio-medicine can be regarded as the ethno medicine of the Western, industrialized world, and is unique in the
increasingly important role, both practical and symbolic, played by technology in both its
diagnosis and treatment (Helman, 2007). This biomedical framework of diabetes and diabetes
care, the ethno medicine of the Western world, was increasingly being imposed and
permeated the Zanzibari society; and this was happening through a variety of channels,
starting with ruling policies from the international community, to legislative measures from
the government, through the modern health care, and through various community
interventions, such as the common use of the media for health promotion. Even the religious
arenas, spearheaded by the influential imams; were attempted to cooperate with in terms of
diabetes health information. Foucault (1980:133) suggests that truth is linked in a circular
relation with systems of power which produce and sustain it, and to effects of power which it
induces and which extend it; a regime of truth. The biomedicine and its discourse being
increasingly prominent in Zanzibar, thus is a reflection of the power relationship between the
western world and this small society. The few resources available to deal with this ever
increasing public health problem of diabetes were coming exactly from the West and from the
biomedicine, which naturally set the standard and defined the balance of power. Thus, the
biomedical care was highly legitimized in the Zanzibari society; and people increasingly
accepted and sought biomedical treatment when experiencing illness symptoms compatible of
diabetes.

The strong position of the biomedicine was also reflected by the way the traditional healers
tended to utilize exactly a biomedical framework as well as equipment as a part of their
practice. As Helman (2007) points out; in many non-industrialized societies, even the simple
syringe is seen as being the very embodiment of modern Western medical science, and also
highlights a rising group of healers in non-industrialized countries, namely the untrained
injectionists. Foucault (1980:97) states that one should try to locate power at the extreme
points of its exercise, where it is always less legal in character. The researcher believes that
the power of the western biomedicine was reflected exactly in the way the biomedical
discourse and equipment were utilized by the traditional healers. The traditional healers were
subjects of the monitoring gaze; which according to Foucauldian theory is the surveillance
associated with disciplinary forces that have become pervasive throughout the social body of
modern western cultures, and especially in the field of health. The process of distinguishing
people is what Foucault calls dividing practices; which work to qualify or disqualify people or
practices as fit and proper members of the social order. Modern western societies, and the
disciplinary institutions that compromise them, organize their practices through actively
producing scandalous identities or subject roles who serve as the other against which normality can be measured. So institutions, and the subject roles they make available, are constantly being judged in terms of their relative normality or abnormality (Danaher et al, 2000). The increasing surveillance of the traditional healing practices in Zanzibar were reflected among others in measures such as the Zanzibar Traditional and Alternative Medicine Policy and the strengthening of the Traditional Medicine Unit at the Ministry of Health; which was carried out in close collaboration with among others WHO (MOHSW, 2008). Included were keywords such as exactly coordination, regulation and supervision, and a focus was on scientifically and rationally conducted practices (MOHSW, 2008). The healers were clearly objects of this surveillance; there was a struggle of attempting to adapt to the pressure from the top, with among others this pursuit of evidence base, the research, that the healers emphasized carrying out, as well as their despair for organized training and other support from the authorities. They obviously still lacked adequate training, supervision and other resources needed to have this role in keeping populations healthy, as WHO (2013a) endeavors. They were systematized, but only in the suppressive way; where their legitimacy was largely at stake. The attempt of utilizing a biomedical discourse and modern machines was a consequence of increasing surveillance, but at the same time a tool in the strive of maintaining legitimacy. The healers were highly aware of the stigmatization and criticism from the government and the modern health care; they felt that they were nothing but blamed and imposed a number of demands, simultaneously as being highly neglected. In Foucauldian terms; discipline and knowledge make us certain kinds of people, and disciplinary power accords a person a space within an institution and a rank within a system (Danaher et al, 2000). This rank within an increasingly westernized system was exactly what the traditional healers of Zanzibar were striving for, and their utilization of various constituents of the biomedicine was also partly what gave them the persistent power to treat illness among Zanzibaris, including the relatively new disease on the agenda, namely diabetes. This is believed to largely have contributed to the ongoing power struggles that were witnessed in the diabetes care in Zanzibar. There were also other actors largely involved in the diabetes care in Zanzibar which were not health care workers by profession; the diabetes educators. What distinguished them from the traditional healers, apart from not offering herbs and cures; were their well-integrated role within the biomedical health care system; where they exercised just the right amount of power and did not enter beyond their level of competence. They had also had sufficient training in diabetes care. Meier zu Biesen et al (2012:8) consider the
appropriation of biomedical language and the diagnosis of disorders using biomedical terminology to leave traditional healers in Zanzibar vulnerable to scrutiny by biomedical practitioners. The researcher believes that it is nothing but justified for health care workers to ask questions about a practice that clearly contributed to disease exacerbation and often fatal outcomes for their patients; as well as worsening their already poor working conditions, where a lack of basic medical material and drugs, things health care workers take for granted in the western world, was a reality they faced every day. The health care workers in Zanzibar were on one side representatives of the western medicine, they possessed this disciplinary power that Foucault talks about; but on the other side they were nothing but subjects of the same oppression, the structural violence, as the rest of their society. The biomedical diabetes services being largely unavailable contributed to the persistent presence of traditional healers in this community. The traditional healers too, naturally were also products of the structural violence; their strong role in this society was exactly a result of lack of development and resources. All in all, the vicious cycle was evident. In turn, these conflicts, these power struggles, between the traditional and the modern health care contributed to the parts of the vicious cycle involving secret use and uncontrolled, fluctuating illness actions among the Zanzibari diabetics; they were given conflicting, condescending messages about the other party on both sides, often with the encouragement of leaving the other form of treatment. As already touched upon, Foucault (1980) suggests that power is never owned by anybody, but must be analyzed as something which circulates, or rather as something which only functions in the form of a chain. Not only do individuals circulate between its threads, they are always in the position of simultaneously undergoing and exercising this power. Individuals are the vehicles of power, not its points of application. The way in which this flow moves around depends on how different groups, institutions and discourses negotiate, relate to and compete with one another (Danaher et al, 2000). Thus, the diabetics themselves were also exercising power, being the vehicles of the power; moving between its various points of exercise, healer shopping; striving for disease management in the deprived society of Zanzibar, where the opportunities for improved health were so limited. The healer shopping again, caused the diabetics disease exacerbation and often premature deaths; clearly showing an example of how structural violence affects the weakest.
9.3 The resistance produced by the traditional Zanzibari world-view

According to Foucauldian theory, knowledge and truth are not essential and ahistorical, but are produced by epistemes and, at the same time, hold that episteme together. Foucault’s concept of epistemes; periods of history organized around, and explicable in terms of, specific world-views and discourses; shows that the way in which people make sense of their world depends on an order of reason and sets of discursive formations that do not translate from one to another. They are the grounds on which we base everything, so we more or less take them for granted (Danaher et al, 2000). Crucial to understanding diabetes care and coping among diabetics in Zanzibar, the researcher sees also largely involves a consideration of its complex history of multicultural influence, and particularly the Muslim legacy, dating as far back as to the seventh century (Larsen, 2008; Bennett, 1978). The Islamic discourse was very much embedded in this society, and a large part of the findings from this study is believed to be related to this aspect. Although a western discourse, including the biomedicine, was steadily advancing in Zanzibar; this was somehow competing with the society’s traditional, largely Islamic world-view. Foucault (1980: 97) states that power is never able to completely control things; that it never achieves what it sets out, or claims, to do; because it always produces resistance (Foucault, 1980). The western world was in many ways increasingly penetrating the Zanzibari community; through the access to the internet and media; through the steadily increasing tourism; and through policymaking processes and funding, resulting in for instance exactly the sovereignty of the biomedical health care. The western, modern way of life was often considered as something negative; and particularly regarding the lifestyle which it entailed. People were particularly skeptical to the growing tourism in Zanzibar, which was considered as the cause of the higher prices and reduced access to natural food resources; exactly the main constituents of a healthy diet, such as vegetables and seafood. Also other sources have highlighted that there is a general feeling among the population that their surroundings are dominated by people who do not follow Zanzibari morality and etiquette (Larsen, 2008), and that it is people from outside Zanzibar that are benefiting from the employment opportunities generated in the tourism industry today, leaving the local community to bear the full brunt of the environmental and cultural costs of tourism (The Revolutionary Government of Zanzibar, 2010:25). There were many signs in the Zanzibari community of this resistance that Foucault talks about; exactly a resistance to the penetrating,
powerful West. For instance could the ongoing political movements towards a separation from mainland Tanzania, as the union also represented constraints to their Zanzibariness; as well as the tendencies of extreme Islamism in Zanzibar; be viewed as exactly this. Preserving their Muslim identity appeared crucial to most Zanzibaris; which entailed everything from eating habits to gender roles and family relations. All this somehow affected how the diabetics coped with life and disease. The culture of polygamy for instance appeared to largely influence the economies of the nuclear families, thus directly influencing the diabetics’ prerequisites for coping. On the other side the biomedicine imposed the diabetics a number of requirements, involving among others an extensive lifestyle change that they often were not capable of coping with. The western world was somehow both causing poor lifestyle and disease, but on the other side also imposing lifestyle change; with otherwise limited means to assist the diabetics achieving improved health. These requirements together with the limited offers from the health care somehow triggered resistance among the diabetics. This can be reflected in what was sometimes termed “stubbornness” by various informants; this tendency of the diabetics doing oppositely of what they were being told to do. The structural violence was, again, evident; where lifestyle should rather be termed life conditions, conditions that were largely caused by still ongoing oppression. The traditional healers on the other side also encouraged lifestyle change, but they promised a golden outcome; a cure. This belief in a cure for every disease was strongly rooted in the traditional, Islamic Zanzibari world-view; which the traditional healers exactly represented. Particularly prominent was the extensive use of the Islamic Sunnah medicine. Some regarded the traditional healers’ affiliation with the Sunnah as an increasing trend; which the researcher believes, again, can be related to the tendencies of extreme Islamism in this society. An increased utilization of the Sunnah was another tool in the traditional healers’ power struggles with the modern health care. In a changing society, with an increased influence from the outside, western world; the traditional healers represented the counterpart. This is believed to be part of the reason why the traditional medicine and traditional healers were still taking such a big space in the society of Zanzibar, including being an arena of care for the diabetics; they were representing exactly the traditional values. Traditional, Islamic values were also related to the major issue found in relation to Ramadan fasting; the holy month of devotion to Allah, one of the five, mandatory pillars of Islam. This highly persistent norm in the Zanzibari society implied a stigma of not carrying out the fast; which suppressed the health care providers’ and other key peoples’ recommendations in this regard; and at a large extent caused disease exacerbation and
hospitalization among diabetics during this month. Though even the religion itself, the Quran, was said to describe that an ill person does not need to fast, the stigma, together with the inability to pay for the required compensation; still represented a major stress factor and dominated the diabetics’ illness actions. The persistent significant role of the Islamic discourse and world-view, the researcher believes is also largely related to the poverty and to the limited resources of this society; the wish for Allah to endorse you, Insha’Allah; was sometimes your only future hope. To the chronically diseased, such as the diabetics; this was particularly precarious. The West, in one way, contributed to some degree of development, though Zanzibar was still degraded, still oppressed; still in the bottom of the world order. This is believed to have reinforced the resistance Foucault describes; where traditional, Islamic values continued to flourish. The vicious cycle becomes a recurring topic, describing how all these factor related to oppression and power struggles; so clearly shaped diabetes care and coping among diabetics on the isles of Zanzibar.
10 Conclusion

In Zanzibar, there were a number of truths, or explanatory models, at play, revolving around diabetes and diabetes care; truths produced out of various epistemes, at various time periods; but all somehow exercising power, struggling for power, in contemporary Zanzibar. Associated with the oppression embedded in the structural violence exerted on Zanzibar for centuries to this day; these power struggles largely shaped the diabetics’ illness actions. Oppression was manifested as the pervasive poverty in the society, giving spillover to the diabetes care on the isles, which largely was at the starting line of development and still relatively inaccessible to the diabetics; both geographically and by the partial lack of subsidized medicines and equipment. Thus, despite the growing impact of modern diabetes care and the increasing awareness and acceptance of the biomedical approach to the disease in this society; it was also impaired by its limited accessibility. This resulted in continued favorable conditions for the traditional health sector, which, despite the recent governmental attempts of systematizing them; still largely were poorly regulated and unempowered, thus very much left on their own to customize their own practices. The attempts of putting the traditional healers into the modern system was also causing their strive for legitimacy, which was reflected in among others their largely inadequate utilization of biomedical tools and terminology; which also reinforced their role as care providers for the diabetics. On the other side the healers also represented the traditional Zanzibari values; where among others the largely Islamic theological based belief in a cure for every disease was embedded. Thus, the diabetics moved in between the two conflicting sectors of health care; searching for accessible treatment and preferably a cure, which was sometimes the only future prospects they had. Instead of a cure though, this healer shopping largely resulted in fatal outcomes. The West contributed to development of this society including the diabetes care, which largely was dependent on international aid; but on the other side it continuously oppressed by providing insufficient measures, still leaving this society in the bottom of the world order. The western, modern world was in many ways viewed negatively by the locals; it permeated the society and imposed a number of demands for a way of life that were difficult to relate to in various levels; both practically and symbolic. It brought with it poor lifestyle habits, and, particularly manifested in form of the increasing tourism, also robbed the society of its natural resources, where among others increased prices on vegetables and seafood was a consequence. On the other side the West imposed lifestyle changes that were often simply unrealistic to adhere to.
The structural violence was evident; the social machinery of oppression against the poorest of the world. This oppression is believed to have created resistance and reinforced the society’s traditional, largely Islamic world-view; which, in addition to maintain the persistent existence of the traditional sector; also implied rigorous norms that the diabetics struggled to cope with, such as the Ramadan fasting. To refrain from fast still largely implied a stigma in this society, which undermined the health cares’ dissuasion and largely caused deteriorating health in the patient group. All in all, the vicious cycle kept spinning; where disease exacerbation, complications and often premature deaths still were the sad fact among the Zanzibari diabetics.

The local stakeholders in the diabetes care, with the newly founded NCD Unit at the core; largely emphasized decentralization of the services; where empowerment of a number of primary care units was the main future plan. The researcher was in contacts with one informant at the NCD unit not long before handing in this thesis, and was told that training of health care workers and equipment for the primary care units were just around the corner. This is believed will be having large impacts on the quality of the diabetes care in Zanzibar, as it will reduce the burden on the current, overloaded diabetes clinics; making proper diabetes services more accessible to the increasing number of diabetics on the isles. Together with continued efforts on educating the population on a community basis; this points that the diabetes care in Zanzibar is heading in the right direction. A specific recommendation coming out of this study is the need for increasing focus on the traditional sector in terms of diabetes care. Today, they are very much still running their own business, with fatal outcomes for the diabetics on the isles. If it is intended that the traditional healers should proceed being a part of the diabetes care as they in reality are today; this demands much larger efforts from the government; in form of consistent policies and legislation, but equally important; training and guidance. This should be a greater part of the governmental including the NCD Units’ priorities than it is today. It is crucial that the traditional healers clearly know their area of responsibility. They could possibly have a role as diabetes educators, if they were sufficiently trained. The common approach to diabetes as a lifestyle disease and the emphasis on nutritional treatment and exercise as essential components in the care for diabetics could be a starting point for further collaboration. Though, if the traditional healers are willing to leave their herbs aside is another question; as it is largely a part of their identity and prerequisite for existence. This demands strong efforts on governmental level.
That said, the future of the diabetes care in Zanzibar naturally also largely depends on the attention from international stakeholders; where empowerment of the Zanzibari society in general and diabetes care specifically are crucial measures for escaping the still encompassing structural violence exerted on this society. Sufficient medical supply is a must, included the coverage of equipment such as glucometers. Though obviously, medical supply itself is not sufficient. Empowerment of communities and individuals is equally important; where among others education and employment should be key measures. This is believed will narrow the extreme, encompassing religious bubble this society finds itself in, and everything that it entails. Considering the predicted significant aging problem this society is facing in the near future, with the simultaneous continued increase of diabetes and other NCDs; this is an area that should no longer be neglected.
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Appendix

Appendix 1: Interview guide for in-depth interviews with health care providers.

Examples of specific questions:

- Can you tell me your profession, and how long you have been working? How long have you worked with diabetes patients?
- Can you tell me about the training you had in relation to diabetes care?
- Do you have access to guidelines for diabetes care?
- Can you tell me some positive and negative sides about your job?
- Which patient groups are using this clinic?
- Can you tell me your responsibilities, your tasks, when it comes to diabetes patients?
- Can you tell me about a typical appointment for a diabetes patient?
- Can you estimate how many times annually the diabetes patients attend the clinic? (Are these planned appointments, or is it more due to emergency cases?)
- What does an appointment with newly a diagnosed diabetes patient contain?
- What do the diabetes patients need to have knowledge about for good self-care?
- If you think back to a diabetes patient who successfully changed behavior...: how do you think you influenced on this?
- What is the reason why some diabetes patients do not follow what you taught them?
- How are the diabetes patients’ families included in your interventions?
- How do you perceive that the diabetes patients comply with the treatment you provide?
- What is your perception of how the diabetes patients cope with their disease?
• The diabetes patients who do not cope so well… what is the reason for that?

• How is family and social network influencing the diabetes patients’ behavior?

• How does religion or beliefs influence the diabetes patients’ behavior in your opinion?

• What is your impression of where the patients seek health care; is it mainly at the clinic, or do they have other areas of seeking health care? If so; why are they seeking other types of health care?

• Is it any difference being diabetic in town than in the countryside?

• Who has responsibility for the diabetes patients’ health? (Is it first and foremost their own responsibility, or the health care/the system?)

• What can improve the diabetes patients’ self-care?
Appendix 2: Interview guide for in-depth interviews with persons diagnosed with diabetes type 2.

Examples of specific questions:

- Can you start tell me what you do during a typical day?
- Can you tell me how you found out that you have diabetes?
- What type of treatment are you on?
- Can you describe what is being done when you attend the clinic?
- What type of information have you received on how to manage your disease?
- How do you follow the health care workers’ advice?
- How do you relate to the health care workers?
- Can you tell me how you deal with your disease from day to day?
- How do other diabetics you know normally deal with their disease?
- How are you experiencing Ramadan?
- Can you tell me about someone you know that attends a traditional healer for treatment? Have you ever tried it?
- Can you tell me a little about your family, and how they relate to your disease?
Appendix 3: Interview guide for in-depth interviews with traditional healers.

Examples of specific questions:

- Can you tell me a little about your profession, and how you ended up in this profession?
- How did you achieve your knowledge?
- Can you tell me a little about your colleagues?
- Can you tell me some positive and negative sides about your job?
- What type of illnesses are you treating?
- What is diabetes (type 2)?
- Can you tell me what type of treatment you are providing the diabetics?
- Where did you get the knowledge about this form of treatment?
- What is the goal of the treatment you provide the diabetics?
- Can you tell me a little about the diabetics who seek your help? (Examples)
- Can you tell me how you cooperate with the hospitals/the clinics?
- Can you tell me how you cooperate with the government?
- What can improve the situation for the diabetics in this community?
Appendix 4: Interview guide for in-depth interviews with other key people.

Examples of specific questions:

- Can you start telling me a little about your position? (Background, education/training, responsibilities…)

- Can you tell me about your colleagues?

- Can you tell me about this organization/unit/religious arena?

- Can you tell me about your cooperation with the government?

- Can you tell me about your cooperation with the health care?

- What are your views regarding the diabetics’ situation in Zanzibar?

- How do the diabetics cope with their disease? (Where do they seek health care? How are they coping during Ramadan? What else is influencing them?)

- (What is the Quran saying about treating disease/diabetes? What is it saying about disease/diabetes, fasting and Ramadan? What is your opinion about fasting for a diabetic?)

- Can you mention any cases where you advised a diabetic?

- What can improve the situation for the diabetics in this community?
Appendix 5: Letter of exemption, REK

PhD Arnfinn Helleve
University of Oslo

Regional Committee for Medical Research Ethics
South-East Norway, Section A
Postbox 1130, Blindern
NO-0318 Oslo

Date: 14 June 2013
Your ref.: 
Our ref.: 2013/705

Dear sir


The project as it is described in the application and in the Research Protocol and has been assessed in accordance with the Norwegian Research Ethics Act of 30 June 2006 and Act on Medical and Health Research (the Health Research Act) of 20 June 2008.

The objective of the study is to explore local health care providers’ perception of diabetes self-management education on Zanzibar, Tanzania.

The patients do not receive any extraordinary treatment which would not have been part of their normal routine management. Hence the investigation does not include any risk to the patients than they otherwise would be exposed to.

After examination it is concluded that the research project to be outside the remit of the Act on Medical and Health Research and therefore can be implemented without the approval from the Regional Committee for Medical Research Ethics.

Yours sincerely

Gunnar Nicolaysen
Chairperson, Section A
Regional Committee for Medical Research Ethics, South-East Norway
(P.P.)

Jørgen Hardang
Committee Secretary
Appendix 6: Research permit, NSD

Jørgen samfunnsvitenskapelig datatjeneste AS
JORWEGIAN SOCIAL SCIENCE DATA SERVICES

Akhtar Hussain
Institutt for helse og samfunn
Universitetet i Oslo
Postboks 1130 Blindern
0318 OSLO

Vår dato: 03.06.2013
Vår ref: 34495 / 3 / LME

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 08.05.2013. Meldingen gjelder prosjektet:

34495 The concept of diabetes self-management education on the island of Zanzibar: A qualitative study

Behandlingsansvarlig Universitetet i Oslo, ved institusjonens øverste leder

Daglig ansvarlig Akhtar Hussain

Student Martine A. Olimb

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsloven. Personvernombudet tilbår at prosjektet gjennomføres.

Personvernombudets tilkledning forutsetter at prosjektet gjennomføres i trikk med opplysningene gitt i meldingsmata, korrrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helsetilsieringsloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.


Vennlig hilsen
Vigdis Namviedt Kvalheim

Kontaktperson: Linn-Merethe Rød tlf: 55 58 89 11
Vedlegg: Prosjektvurdering
Kopi: Martine A. Olimb, Feddersensgate 6a, 0473 OSLO
Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 34495

I følge prosjektmeldingen skal det innhentes skriftlig samtykke basert på muntlig og skriftlig informasjon om prosjektet og behandling av personopplysninger. Personvernombudet finner informasjonsskrivene tilfredsstillende utformet i henhold til personopplysningslovens vilkår.

Ombudet forstår at det legges opp til at helsepersonell ikke skal uttale seg om identifiserbare enkeltpasienter. Det anbefales at prosjektleder minner utvalget om dette, i forkant av hvert intervju. Videre legges det til grunn at taushetsplikten ikke er til hinder ved rekrutering av personer med diabetes til studien.

Innsamlede opplysninger registreres på privat pc. Personvernombudet legger til grunn at veileder og student setter seg inn i og etterfølger Universitetet i Oslo sine interne rutiner for datasikkerhet, spesielt med tanke på bruk av privat pc til oppbevaring av personidentifiserende data.

Prosjektet skal avsluttes 20.09.2013 og innsamlede opplysninger skal da anonymiseres og lydopptak slettes. Anonymisering innebærer at direkte personidentifiserende opplysninger som navnkoblingsnøkkel slettes, og at indirekte personidentifiserende opplysninger (sammenstilling av bakgrunnsopplysninger som f.eks. yrke, alder, kjønn) fjernes eller grovkategoriseres slik at ingen enkeltpersoner kan gjenkjennes i materialet.
Appendix 7: Ethical clearance letter, ZAMREC

ETHICAL CLEARANCE LETTER

PROTOCOL NUMBER: ZAMREC /0001/MAY/013

DATE: 10 JUNE 2013

Martine A. Olimb
Principal Investigator

PROTOCOL TITLE: The concept of diabetes self-management education on the island of Zanzibar.

RE: ETHICAL CLEARANCE FOR CONDUCTING MEDICAL RESEARCH IN ZANZIBAR.

This is to certify that the research protocol entitled "The concept of diabetes self-management education on the island of Zanzibar." was received and reviewed by the Zanzibar Medical Research and Ethics Committee on May, 2013.

We would like to inform you that the decision of the committee to this protocol was "Approved with Recommendation" Kindly address the following comments, do the necessary corrections and submitted revised copy the protocol to the committee before the process of data collection:

Comments:

1. The study sites are not clearly mentioned in this proposal. Zanzibar is constituted by two major Islands Unguja and Pemba and there are more than one hospital in these Islands. Where exactly are you going to conduct your discussions and in depth interviews.
2. The study participants in the in depth interview group is not properly elaborated. Kindly clarify while pointing out inclusion and exclusion criteria for study participants.
3. Swahili version of the informed consent form and a local contact person are needed for study participant.
4. Curriculum Vitae (CV) of the principal investigator needs to be attached together with the protocol.

Thanks in advance,

DR. JAMALA A. TAB
CHAIRPERSON
ZAMREC
ZANZIBAR.

DR. MSAFIRI MARIJANI
SECRETARY
ZAMREC
ZANZIBAR.
Appendix 8: Ethical clearance letter, ZAMREC (2)
Appendix 9: Research permit, Zanzibar Research Committee

REVOLUTIONARY GOVERNMENT OF ZANZIBAR

SECRETARY
ZANZIBAR RESEARCH COMMITTEE
P. O Box 239
Tel: 2233808
FAX: 2233788

RESEARCH/FILMING PERMIT
(This Permit is only Applicable in Zanzibar for a duration specified)

SECTION
Name: MARTINE A. OLIMB
Date and Place of Birth: 15/01/1983
Nationality: NORWEGIAN
Passport Number: 27496595
Date and Place of Issue: 03/11/2009 OSLO NORWAY
Date of arrival in Zanzibar: 26/06/2013
Duration of stay: THREE MONTHS AND TWO WEEKS
Research Titles:
"THE CONCEPT OF DIABETES SELF-MANAGEMENT EDUCATION ON THE ISLAND OF ZANZIBAR"

Full address of Sponsor:

This is to endorse that I have received and duly considered applicant’s request I am satisfied with the descriptions outlined above.

Name of the authorizing officer: HASSAN LILA MRISHO

Signature and seal: [Signature]
Institution: Office of Chief Government Statistician
Address: P. O Box 2321
Zanzibar
Date: 12/07/2013
Appendix 10: Informed consent, in-depth interviews

Request for participation in a research project

The concept of diabetes self-management education on the island of Zanzibar

A qualitative study

Background and purpose

This is a request for you to participate in a research study that intends to investigate health care providers’ and their community’s perception of diabetes self-management education (DSME), in the context of Zanzibar. This setting is interesting because of the sudden rise of diabetes cases; which corresponds to the situation in the rest of sub-Saharan Africa; where diabetes is becoming a pressing public health problem. Different diabetes intervention programs in Africa are emphasizing the concept of diabetes self-management education. Insight on the Zanzibari health care providers’ and their community’s perception on this topic, can contribute to increased understanding of current status on diabetes care in sub-Saharan Africa. You have been asked to participate because I believe you can share important information about this topic. This study is a part of a master thesis of the M.Phil. Programme in International Community Health, at University of Oslo, Norway. The researcher is a professional nurse as a background, and also has her background from social anthropology.

What does the study entail?

You are asked to participate in an interview of about 1 hour. Here, we will talk about issues related to the topic. I will ask you to do the interview in English, but if you have objections to this; we do it in Swahili, and my research assistant will help me to translate afterwards. We will sit in a suitable place, and no one else than my research assistant and me will be present. I will take notes while we talk. I ask you for permission to tape record the interview, for the purpose of better memorizing it. You are free to end the interview whenever you want. I might ask you to meet me again for a second interview, if there is a need for additional information.
Potential advantages and disadvantages

There will be no direct benefits to you; but the results are meant to increase understanding of current status of diabetes care in Zanzibar, which might benefit your society. You are entitled to receive information about the results of the study, and it will be provided electronically in form of a master thesis.

You will not get any incentives for participating in this study. Any expenses you will have in relation to this study, like travel costs, will be reimbursed.

During the interview, there might be some topics you will feel uncomfortable to talk about. You are not obliged to respond to any question, and you do not have to give any reason for not responding. This also applies for ending the interview at any time you want.

What will happen to the samples and the information about you?

If you agree to participate in the study, you are entitled to have access to what information is registered about you. You are further entitled to correct any mistakes in the information we have registered. If you withdraw from the study, you are entitled to demand that the collected samples and data are deleted, unless the data have already been incorporated in analyses or used in scientific publications.

The data that are registered about you will only be used in accordance with the purpose of the study as described above. The information you share during the interview is confidential, and will not be given to anyone outside of the research team. All the data will be processed without name, ID number or other directly recognisable type of information. A code number links you to your data through a list of names. Only the researcher and her assistant will have access to the list of names and be able to identify you. This also applies to the tape recordings. The tape recordings and the list of names will be deleted after the project is finished. It will not be possible to identify you in the results of the study when these are published.

Voluntary participation

Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. This will not have any consequences for you. If you wish to participate, sign the declaration of consent. If you agree to participate at this time, you may later on withdraw your consent without any consequences.
for you. If you later on wish to withdraw your consent or have questions concerning the study, you may contact the researcher.

**Contact information**

Martine Andersen Olimb

Institute of Health and Society

Faculty of Medicine

P.b. 1130 Blindern, 0370 Oslo, Norway

Phone: +47 xxx/ 077xxx. e-mail: xxx

**Consent for participation in the study**

I am willing to participate in the study.

--------------------------------------------------------------------------------

(Signed by the project participant, date)

I confirm that I have given information about the study.

--------------------------------------------------------------------------------

(Signed, role in the study, date)
Appendix 11: Informed consent, in-depth interviews; Swahili version

CHUO KIKUU CHA OSLO, NORWAY

FOMU YA KUOMBA RIDHAA YA KUFANYA UTAFITI

Madhumuni

Maombi ya kushiriki katika utafiti wa elimu ya kujiunga binafsi kwa wagonjwa wa kisukari Zanzibar, Tanzania.

Yaliomo na malengo

Hili ni ombi kwako la kushiriki katika somo la utafiti ambalo linakusudia katika kutizama mawazo ya watu kuhusu elimu ya kujiunga binafsi kuhusiana na ugonjwa wa kisukari katika maeneo yote ya jangwa la Sahara Africa. Unaombwa kushiriki kwa sababu mtafiti anafikiri kwamba unaweza kutoa maelezo muhimu kuhusu suala hili. Somo hili ni sehemu ya mpango wa afya ya jamii kimataifa na ni sehemu ya masomo yangu ya shahada ya pili ya afya na jamii kimataifa katika chuo kikuu cha Oslo, Norway.

Nini lengo la utafiti huu?


Uwezekano wa kuwepo faida na hasara

Hakutakuwa na faida ya moja kwa moja kwako, lakini ushiriki wako unaweza kupelekea kuengeza ufahamu wa elimu ya kujihuudumia binafsi kwa wagonjwa wa kisukari Zanzibar, na hili unaweza kufaidisha jamii. Wakati wa mahojiano unaweza kutoa baadhi ya mchango wako
binafsi. Unaweza kujisikia aibu kuzungumzia baadhi ya mambo katika mada hii. Pia hutopaswa kujibu suala lolote katika mahojiano haya ukiwa ukiwa hutaki kufanya hivyo, na yote ni sawa kwani hakunà tamu. Na hupaswi kutupa sababu yeyote kwanini umekataa kujibu maswali, ua kwa kukataa kushiriki katika mahojiano haya.

Hutotakiwa kutoa kichococho chochote katika utafiti huu, ingawaje unaweza kupata gharama yeyote katika utafiti huu zitarejeshwa.

**Nini kitatokea katika maelezo kuhusu wewe?**

Ikiwa utakubali kushiriki katika utafiti huu, utahitajika/utaruhusika kuzifikia taarifa ambazo zilizosajiliwa. Utahitajika zaidi kurekebisha makosa yeyote ndani ya taarifa tulizozisajili. Endapo utajitoa katika utafiti huu, una haki ya kudai ushiriki wako pamna taarifa zako kufutwa, isipokuwa taarifa zile ambazo zilizosajiliwa kwa uchambuzi au zishazotumika katika kuchapishwa.


**Ushiriki wa kujitolea**

Ushiriki katika utafiti huu ni wa kujitolea, unaweza kjitoea katika makubaliano ya ushiriki katika utafiti huu wakati wowote bila kuelezea sababu yoyote ile. Hii haitakuwa na kipingamizi chochote kwakho, Kama utataka kushiriki katika utafiti huu saini makubaliano ya makutoka mkataba huu katika ukurasa wa mwisho. Na kama utakubali kushiriki mwanza na baadhe ukaamua kujitoea katika makubaliano bila ya kikwazo inaweze kwa ajili yako. Endapo utaamua kujitoea au utakua na maswali kuhusiana na utafika huu unaweza kuwasiliana na mtafiti kwa anuani ifuatayo.
Taarifa za anuani

Martine Andersen Olimb.

Simu: 077xxx /+47xxx. Tovuti: xxx

Mtafiti msaidizi: Maryam Ahmed Ahmad.

Simu  077xxx

Ridhaa ya ushiriki katika utafiti.

Mimi nimekubali kushiriki kwa hiiyari yangu katika utafiti huu.

…………………………………….  ……………………………

Saini ya mshiriki                     Tarehe

Ninathibitisha kwamba nimetoa taarifa zote kuhusiana na utafiti huu.

Saini  ……………………….  Cheo ulionayo …………………