

**Health seeking and health related behaviour
for type 2 diabetes mellitus among adults in
an urban community in Tanzania**



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Abstract

Early in the 20th century, diabetes mellitus was considered to be a rare medical condition in African countries, and mostly in sub-Saharan Africa. Over the past 30 or 40 years however, the situation has changed. Diabetes is now regarded as a major public health problem throughout Africa particularly among urban communities. The disease is little understood in the general population and is often poorly detected. Previous research, for example, shows about 50 percent of people with type 2 diabetes mellitus in Tanzania are unaware of their condition and more than 80 percent diabetes cases are undiagnosed.

This thesis aims to explore factors influencing health-seeking and health related behaviour among adult patients with type 2 diabetes mellitus in an urban community in Tanzania. It seeks to answer the following key question: *What are the key factors influencing health seeking and health related behaviour and care management for type 2 diabetes mellitus?* Data collection was carried out from March to June 2007 in two diabetes clinics in Dar es Salaam, the commercial capital city of Tanzania. The main study population consisted of patients aged 35 years and above who had been diagnosed with the disease more than one year before the time of the current study. In-depth interviews were carried out with 20 frequent and 10 infrequent clinic attendees, their 14 caregivers, and seven health care workers; while key informant interviews were carried out with six key national health officials. Furthermore, eight focus group discussions were carried out with people with diabetes and selected community members.

Multiple influences on health-seeking behaviour were identified, many of which affected clinic attendance, adherence to treatment programmes, and outcomes. These influences included poor accessibility to diabetes drugs and other services at the clinics, lack of financial resources for transport to the clinic and purchasing of drugs, overcrowded and inadequate public transport, lay beliefs and models of disease causation and treatment which accentuate the role of traditional healers, and poor organisation of the clinics leading to long queues and waiting times.

The findings suggest that improving the delivery of care to people with diabetes will require action to address a range of structural, financial, cultural, and administrative

issues. These might include improving the distribution and accessibility of essential diabetes drugs, as well as the accessibility and affordability of health care services, patient and public education, involvement of traditional healers, better provision of public transport and more patient-centred organisation of care in public health clinics.

The findings have significant policy implications. First, the government needs to decentralise the current diabetes services from regional and district facilities to primary health care centres and existing dispensaries, along with procuring adequate drugs, equipment and health care providers to enhance access to services. Second, the government should develop mechanisms for working with traditional health practitioners as a strategy to enhance early referral of people with diabetes by these practitioners to biomedical care facilities to improve the rates of early diagnosis and management of this disease. Finally, the government needs to acknowledge the growing threat of NCDs such as diabetes and develop national prevention and control strategies including general public education about the disease.

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findings of this study will make a difference in health seeking and health related behaviour, care and management of diabetes in Tanzania.

Dedication

This thesis is dedicated to my mother Martha Joseph for teaching me the values of resilience; to my son James and my two daughters Cecilia and Martha for their love, encouragement, and their belief in me. Special dedication goes to my spouse Justin Nguma whose belief in me, encouragement and support has been a great source of inspiration throughout my long journey towards this goal.

Table of Contents

ABSTRACT	II
ACKNOWLEDGEMENTS	IV
DEDICATION	VI
TABLE OF CONTENTS	VII
LIST OF TABLES.....	XIII
LIST OF BOXES.....	XIV
LIST OF FIGURES.....	XV
LIST OF ABBREVIATION	XVII
CHAPTER 1— INTRODUCTION.....	1
1.0 INTRODUCTION	1
1.1 AIM AND PURPOSE OF THE THESIS.....	2
1.2 THE RESEARCHER’S MOTIVATION FOR THIS RESEARCH	4
1.3 BACKGROUND AND HEALTH CARE DELIVERY SYSTEM IN TANZANIA	6
1.3.1 Background	6
1.3.2 The health care delivery system	8
1.4 OVERVIEW OF THE STUDY DESIGN	11
1.5 KEY CONCEPTS AND WORKING DEFINITION	11
1.6 OVERVIEW OF THE THESIS	13
CHAPTER 2—LITERATURE REVIEW	15
2.0 INTRODUCTION	15
2.1 SECTION ONE: LITERATURE REVIEW APPROACHES.....	16
2.1.1 Data Sources.....	16
2.2 SECTION TWO: THE EPIDEMIOLOGY OF DIABETES	18
2.2.1 Definition of Diabetes Mellitus	18
2.2.1.1 Diagnosis of diabetes mellitus	20
2.2.1.2 Diabetes Management	21
2.2.1.3 Prevention of diabetes mellitus.....	22
2.2.1.4 Treatment and control of diabetes mellitus.....	22
2.2.1.5 WHO (2010) planned activities to prevent and control diabetes	23
2.2.2 Global Epidemiology of Diabetes	23
2.2.3 Epidemiology of Diabetes in Developing Countries	25
2.2.4 Epidemiology of Diabetes in sub-Saharan Africa	26

2.2.5 Epidemiology of Diabetes in Tanzania.....	30
2.3 COST IMPLICATIONS OF DIABETES AT THE GLOBAL LEVEL	31
2.3.1 Cost Implication of Diabetes in Developing Countries	31
2.3.2 Cost Implications of Diabetes in sub-Saharan Africa.....	32
2.4 SECTION THREE: CARE AND MANAGEMENT OF DIABETES MELLITUS	34
2.4.1 Global Management of Diabetes	34
2.4.2 Care and Management of Diabetes in sub-Saharan Africa	37
2.4.3 Challenges in Care and Management of Diabetes in sub-Saharan Africa	39
2.4.3.1 Limited Financial Resources	39
2.4.3.2 Poor Accessibility and Affordability of Diabetes Drugs	40
2.4.3.3 Access to Diabetes Care Services.....	41
2.4.3.4 Inadequately Trained Care Providers for Diabetes	43
2.4.3.5 Inadequate Health Education.....	44
2.5 THE HEALTH CARE DELIVERY SYSTEM IN TANZANIA	45
2.5.1 Challenges in Delivery of Diabetes Care Services in Tanzania.....	49
2.5.1.1 Limited Financial Resources	49
2.5.1.2 Poor Accessibility and Availability of Diabetes Drugs and Related Services	50
2.5.1.3 Inadequately Skilled Diabetes Health Care Providers	52
2.6 HEALTH-SEEKING BEHAVIOUR IN DEVELOPING COUNTRIES AND SUB-SAHARAN AFRICA.....	53
2.6.1 Awareness and Knowledge about Diabetes Mellitus.....	54
2.6.2 Social and Cultural Beliefs	57
2.6.3 Stigma and/discrimination.....	58
2.6.4 Disease Understanding and Perceptions	59
2.6.5 Nature of Health Care System and Health Providers.....	61
2.6.6 Use of Alternative Sources of Care	62
2.6.7 Summary	63
2.7 HEALTH-SEEKING BEHAVIOUR MODELS	63
2.7.1 The Health Belief Model (HBM) (Sheeran & Abraham, 1995)	64
2.7.2 Good's Model (1987) –The Pathway Model.....	66
2.7.3 Kroeger's Model, 1983.....	68
2.7.4 Young's Model (1981)–“A Choice-making Model”	70
2.7.5 Nyamongo's (2002) Health Care Switching Behaviour Model.....	72
2.7.6 McKinlay–Health-seeking Behaviour in Context	74
2.7.7 Reflections on Health-seeking behaviour Models	74
2.8 EVIDENCE OF IMPORTANCE OF MCKINLAY'S (1972) THEORETICAL FRAMEWORK	77
2.8.1 Economic Factors	78
2.8.2 Geographical factors.....	79
2.8.3 Socio-demographic factors	80
2.8.4 Social-psychological factors.....	81
2.8.5 Socio-cultural factors.....	82
2.8.6 The organisation of the health system	83
2.9 KEY FINDINGS AND GAPS	85

2.9.1 Findings	85
2.9.2 Observed gaps in the reviewed studies	88
2.10 SUMMARY.....	89
CHAPTER 3–METHODOLOGY AND METHODS	91
3.0 INTRODUCTION	91
3.1 HEALTH SERVICES RESEARCH.....	91
3.2 RATIONALE FOR QUALITATIVE RESEARCH.....	93
3.3 THEORETICAL FRAMEWORK	94
3.4 THE RESEARCH PROCESS.....	97
3.4.1 Ethics approval and local consultation	97
3.4.2 The study setting and justification	98
3.5 PILOT STUDY	99
3.5.1 Data analysis.....	100
3.5.2 Lessons learnt from the pilot study.....	101
3.5.2.1 Study instrument	101
3.5.2.2 Data collection.....	101
3.5.2.3 Data management.....	101
3.5.2.4 Methodological responses to the experience from the pilot study	101
3.6 THE SAMPLING STRATEGY FOR THE MAIN STUDY	102
3.6.1 The Diabetes Patients and their Caregivers	102
3.6.2 The Health Care Workers	105
3.6.3 The Diabetes Clinics.....	105
3.6.4 The Community Members.....	107
3.6.5 The Key National Health Officials	108
3.7 THE SAMPLE SIZE.....	110
3.8 STUDY METHODS	113
3.8.1 Respondent validation	116
3.8.2 The triangulation strategy.....	116
3.9 DATA MANAGEMENT AND ANALYSIS.....	117
3.9.1 Data management	117
3.9.2 Data analysis.....	118
3.9.3 Data reduction and/or coding	119
3.9.4 Data display and/or data organisation.....	121
3.9.5 Conclusion and Verification	127
3.10 SELECTION OF ILLUSTRATIVE QUOTES	131
3.11 ETHICAL ISSUES	133
3.12 REPORTING OF STUDY FINDINGS	133
3.12.1 Background Characteristics.....	133
3.12.2 Presentation of Results	136

CHAPTER 4–KNOWLEDGE AND PERCEPTIONS ABOUT TYPE 2	
DIABETES.....	139
4.0 INTRODUCTION	139
4.1 KNOWLEDGE AND PERCEPTION ABOUT TYPE 2 DIABETES MELLITUS.....	139
4.1.1 Awareness about Diabetes.....	139
4.1.2 Sources of Information about Diabetes	140
4.1.3 Signs and Symptoms of Type 2 Diabetes Mellitus.....	141
4.1.4 Perceptions of Signs and Symptoms of Type 2 Diabetes Mellitus	143
4.1.5 Causes of Type 2 Diabetes Mellitus	144
4.1.6 Prevention and Treatment of Type 2 Diabetes	147
4.1.7 Perceived Magnitude of Type 2 Diabetes.....	150
4.1.8 Factors Thought to Cause the Growing Magnitude of Type 2 Diabetes.....	151
4.1.9 Views about Spread of Type 2 Diabetes Mellitus	152
4.1.10 Risk Perceptions for Contracting Diabetes.....	153
4.1.11 Perceived Type 2 Diabetes Complications	154
4.2 SUMMARY.....	155
CHAPTER 5–HEALTH-SEEKING BEHAVIOUR FOR TYPE 2 DIABETES..	156
5.0 INTRODUCTION	156
5.1 INFLUENCES ON DECISIONS TO SEEK CARE	156
5.1.1 Nature of presenting signs and symptoms	156
5.1.2 Financial Resources.....	160
5.1.3 The ‘Wait and See’ Culture.....	161
5.1.4 The Use of Traditional Healers and Herbalists.....	163
5.1.5 Role of Family Members and/or Social Networks	163
5.2 INITIAL REACTIONS AFTER DIAGNOSIS WITH DIABETES	165
5.2.1 Shock and Disbelief.....	165
5.2.2 Coping with Diabetes	167
5.2.3 Self-disclosure about Living with Diabetes.....	168
5.2.4 Stigma and Discrimination	169
5.3 SUMMARY.....	173
CHAPTER 6–CARE AND MANAGEMENT FOR TYPE 2 DIABETES	
MELLITUS	174
6.0 INTRODUCTION	174
6.1 CHALLENGES IN CARE AND MANAGEMENT OF TYPE 2 DIABETES MELLITUS	174
6.1.1 Personal and/or Individual Challenges	174
6.1.1.1 Insufficient Financial Resources	175
6.1.1.2 Poor Health Infrastructure and Public Transport.....	176
6.1.2 Health Care System Challenges	179

6.1.2.1 Long Waiting Time at the Clinic.....	180
6.1.2.2 Lack of ‘Client Friendly’ Care Services.....	184
6.1.2.3 Lack of Quality Care Services.....	187
6.1.2.4 Poor Diagnostic Skills and Equipment.....	188
6.1.2.5 Poor Availability of Affordable Drugs.....	192
6.2 IMPLICATIONS OF CARE AND MANAGEMENT COSTS	195
6.2.1 Implications for the Patients’ Treatment	195
6.2.2 Implications for Family Welfare	197
6.3 USE OF ALTERNATIVE CARE SERVICES.....	198
6.3.1 Impact of Alternative Care Services Utilisation.....	207
6.4 ROLE OF FAMILY MEMBERS AND/OR SOCIAL NETWORKS	209
6.5 CHALLENGES IN LIVING WITH TYPE 2 DIABETES MELLITUS	212
6.7 SUMMARY.....	215
CHAPTER 7–DISCUSSION AND CONCLUSIONS	217
7.0 INTRODUCTION	217
7.1 SECTION ONE: A SUMMARY OF THE STUDY FINDINGS	218
7.2 SECTION TWO: DISCUSSION OF THE PRINCIPAL FINDINGS.....	220
7.2.1 Knowledge and Perceptions about Type 2 Diabetes Mellitus	220
7.2.2 Health-seeking Behaviour for Type 2 Diabetes.....	223
7.2.2.1 Stigma and Discrimination.....	230
7.2.3 Care and Management of Type 2 Diabetes Mellitus	233
7.3 STRENGTHS AND LIMITATIONS	243
7.3.1 Strengths.....	243
7.3.2 Limitations.....	245
7.4 QUALITY OF THE RESEARCH.....	248
7.5 STUDY IMPLICATIONS.....	250
7.5.1 Policy Implications and Service Delivery	250
7.5.2 Primary Health Care Implications	252
7.5.3 Implications for Advocacy and Community Mobilisation	255
7.6 REFLECTIONS ON THE USE OF MCKINLAY’S (1972) THEORETICAL MODEL	258
7.7 PRIORITY AREAS FOR FUTURE RESEARCH.....	263
7.8 CONCLUSIONS AND RECOMMENDATIONS	266
REFERENCES	270
APPENDICES.....	294
APPENDIX 1: TYPE 2 DIABETES CLINICAL PRACTICE GUIDELINE FOR SUB-SAHARAN AFRICA.....	294
APPENDIX 2: KEY DIABETES QUALITATIVE AND QUANTITATIVE STUDIES ON SUB-SAHARAN AFRICA AND TANZANIA.....	296

APPENDIX 3: ETHICAL APPROVALS	301
APPENDIX 3.1 UNIVERSITY OF OTAGO ETHICS APPROVAL	301
APPENDIX 3.2 MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCE.....	302
APPENDIX 3.3: THE DISTRICT MEDICAL OFFICER LETTER OF APPROVAL TO CARRY OUT THE PRE-TEST STUDY IN TEMEKE DISTRICT.....	303
APPENDIX 3.4: THE DISTRICT MEDICAL OFFICER LETTER OF APPROVAL TO CARRY OUT THE MAIN STUDY IN ILALA DISTRICT	304
APPENDIX 3.5: THE DISTRICT MEDICAL OFFICER LETTER OF APPROVAL TO CARRY OUT THE MAIN STUDY IN KINONDONI DISTRICT	305
APPENDIX 3.6: THE MEDICAL OFFICER IN CHARGE LETTER OF APPROVAL TO CARRY OUT THE STUDY IN AMANA DIABETES CLINIC	306
APPENDIX 3.7: THE MEDICAL OFFICER IN CHARGE LETTER OF APPROVAL TO CARRY OUT THE STUDY IN MWANAYAMALA DIABETES CLINIC.....	307
APPENDIX 4: STUDY INTERVIEW GUIDES	308
APPENDIX 4.1: IN-DEPTH INTERVIEW GUIDE FOR PEOPLE WITH TYPE 2 DIABETES MELLITUS.....	308
APPENDIX 4.2: IN-DEPTH INTERVIEW GUIDE FOR CAREGIVERS OF PEOPLE WITH DIABETES	312
APPENDIX 4.3: IN-DEPTH INTERVIEW GUIDE FOR HEALTH CARE WORKERS.....	315
APPENDIX 4.4: FGD INTERVIEW GUIDE FOR PEOPLE WITH TYPE 2 DIABETES MELLITUS	318
APPENDIX 4.5: FOCUS GROUP (FGD) INTERVIEW GUIDE FOR COMMUNITY MEMBERS	321
APPENDIX 4.6: KEY INFORMANT INTERVIEW GUIDE FOR KEY NATIONAL HEALTH OFFICIALS	324
APPENDIX 5: CONTACT FORM.....	326
APPENDIX 6: INFORMATION SHEET	327
APPENDIX 7: KEY INFORMANTS/IN-DEPTH INTERVIEW CONSENT FORM.....	329
APPENDIX 8: FOCUS GROUP CONSENT FORM.....	330
APPENDIX 9: MAP 1: LOCATION OF DAR ES SALAAM REGION SHOWING THE THREE DISTRICTS UNDER THE CURRENT RESEARCH.	331

List of Tables

TABLE 3.1: KEY NATIONAL HEALTH OFFICIALS INTERVIEWED	109
TABLE 3.2A: BREAKDOWN FOR IN-DEPTH AND KEY INFORMANT INTERVIEWS IN THE CURRENT STUDY.....	111
TABLE 3.2B: BREAKDOWN FOR FOCUS GROUP DISCUSSION (FGDS).....	112
TABLE 3.3: EXAMPLE OF DATA DISPLAY MATRIX.....	122
TABLE 3.4: EXAMPLE OF DEVELOPED MAJOR THEMES, SUB-THEMES, AND CONCEPTS	123
TABLE 3.6: SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PEOPLE WITH DIABETES....	134
TABLE 3.7: ILLNESS STATUS OF THE PEOPLE WITH DIABETES.....	135
TABLE 3.8: TREATMENT STATUS OF PEOPLE WITH DIABETES	135

List of Boxes

BOX 2.1: KEY WORDS USED IN THE LITERATURE SEARCH	16
BOX 2.2: KEY DATABASES USED DURING THE LITERATURE SEARCH.....	17
BOX 2.3: MAIN SOURCE OF PAPERS FOR LITERATURE REVIEW.	18

List of Figures

FIGURE 1.1 MAP OF TANZANIA WITH PROVINCIAL BOUNDARIES	7
FIGURE 1.2: MWNANYAMALA DIABETES CLINIC (REFURBISHED CONTAINER BY TANZANIA DIABETES ASSOCIATION), KINONDONI DISTRICT, DAR ES SALAAM 2007..	10
FIGURE 2.1TANZANIA HEALTH REFERRAL SYSTEM	47
FIGURE 2.2: THE HEALTH BELIEF MODEL (SHEERAN & ABRAHAM, 1995)	65
FIGURE 2.3: GOOD’S MODEL, 1987.....	67
FIGURE 2.4: KROEGER’S MODEL, 1983	69
FIGURE 2.5: A CHOICE-MAKING MODEL (YOUNG, 1981)	71
FIGURE 2.6: NYAMONGO’S (2002) HEALTH CARE SWITCHING BEHAVIOUR MODEL	73
FIGURE 3.1: MAP OF THE STUDY SITE.....	99
FIGURE 3.2: RESEARCHER CONDUCTING IN-DEPTH INTERVIEW AT PATIENT’S RESIDENCE 2007.....	104
FIGURE 3.3: VIEW OF SOME STREETS AND HOUSES WITHOUT NAMES AND NUMBERS IN DAR ES SALAAM 2007	104
FIGURE 3.4: RESEARCHER TRYING TO LOCATE PATIENT’S RESIDENCE IN ILALA DISTRICT, DAR ES SALAAM 2007	105
FIGURE 3.5: MWANANYAMALA DIABETES CLINIC IN KINONDONI DISTRICT, DAR ES SALAAM 2007.....	106
FIGURE 3.6: ILALA DIABETES CLINIC IN ILALA DISTRICT, DAR ES SALAAM 2007	106
FIGURE 3.7: FOCUS GROUP DISCUSSIONS (FGDS) WITH COMMUNITY WOMEN IN ILALA DISTRICT IN DAR ES SALAAM 2007	108
FIGURE 3.8: COMPONENTS OF DATA ANALYSIS: INTERACTIVE MODEL	119
FIGURE 3.9: THE PROCESS OF DATA ANALYSIS.....	128
FIGURE 3.10: TRIANGULATION OF INFORMATION FROM VARIOUS SOURCES.....	137
FIGURE 6.1: ‘SURVIVAL OF THE FITTEST’-COMMUTERS BOARD A BUS THROUGH THE WINDOWS DURING RUSH HOUR IN DAR-ES-SALAAM 2007.....	177
FIGURE 6.2 PASSENGERS TRYING TO FORCE THEIR WAY ONTO A BUS THAT IS ALREADY FULL WITH PASSENGERS IN DAR-ES-SALAAM 2007.....	178
FIGURE 6.3: FEMALE PATIENTS WAITING TO SEE THE DOCTOR AT DIABETES CLINIC-ILALA DISTRICT, DAR ES SALAAM TANZANIA 2007	180

FIGURE 6.4: A HEALTH EDUCATION SESSION AT THE DIABETES CLINIC IN DAR ES SALAAM 2007.....	185
FIGURE 6.5: A DEMONSTRATION COOLING CLAY POT ON TOP OF A TIN WITH SAND USED TO STORE DRUGS IN THE ABSENCE OF A REFRIGERATOR 2007.....	191
FIGURE 6.6: A PRIVATE PHARMACY OUTSIDE A PUBLIC HOSPITAL–KINONDONI DISTRICT IN DAR ES SALAAM, TANZANIA 2007	192
FIGURE 6.7: A PLANT OF ‘STAR OF JERUSALEM’ FLOWERS USED FOR DIABETES TREATMENT	200
FIGURE 6.8: ALOE VERA PLANT USED BY PEOPLE WITH DIABETES FOR DIABETES TREATMENT	202
FIGURE 7.1: FACTORS ASSOCIATED WITH TYPE 2 DIABETES MELLITUS IN THE CURRENT STUDY.....	221
FIGURE 7.2: FACTORS ASSOCIATED WITH TYPE 2 DIABETES MELLITUS.....	222
FIGURE 7.3: PATHWAYS TO HEALTH-SEEKING BEHAVIOUR.....	225
FIGURE 7.4: DETERMINANTS OF HEALTH-SEEKING BEHAVIOUR	229
FIGURE 7.5: CHALLENGES TO PATIENTS’ ADHERENCE TO DIABETES CARE AND MANAGEMENT PROGRAMMES	234

List of Abbreviation

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
CHF	Community Health Fund
CAMBoD	Cameroon Burden of Diabetes study
FGD	Focus Group Discussions
HbA1C	Glycosylated Haemoglobin
HIV	Human Immunodeficiency Virus
IGT	Impaired Glucose Tolerance
IDF	International Diabetes Federation
IDFARR	International Diabetes Federation Africa Region Report
IWGDF	International Working Group Diabetes Foot
L.E	Egyptian Pound
LGAs	Local Government Authorities
MDAs	Ministries, Department and Agencies
MoHSW	Ministry of Health and Social Welfare
MRALG	Ministry of Regional and Local Government
MSD	Medical Store Department
MUHAS	Muhimbili University of Allied Health Sciences
NDCs	Non-Communicable Disease
NGOs	nongovernmental organizations
NIDDM	Non-Insulin Dependent Diabetes Mellitus
OAU	Organisation of African Union
TB	Tuberculosis
TDA	Tanzania Diabetes Association

TFDA	Tanzania Food and Drug Authority
TZ	Tanzania
WDD	World Diabetes Day
WDF	World Diabetes Federation
WDR	World Diabetes Report
WHO	World Health Organization
UNFPA	United Nations Fund for Population Assistance
UNAIDS	Joint United Nations Program on HIV/AIDS
Tshs	Tanzania Shillings

Chapter 1— Introduction

1.0 Introduction

Diabetes affects people worldwide and is becoming a major public health problem posing significant socioeconomic challenges (Mbaya et al., 2010). The International Diabetes Federation (IDF) estimated in 2009 that the global number of adults with diabetes will increase by 54%, from 284.6 million in 2010 to 438.4 million in 2030. The disease is reported to be growing at an alarming rate in most developing countries (Dagogo-Jack, 2006). For example, it is estimated that by the year 2025 about 80% of all new cases of diabetes will occur in developing countries (International Diabetes Federation, Diabetes Atlas, 2006).

In developing countries, and sub-Saharan Africa in particular, type 2 diabetes mellitus appears to be fuelled by rapid cultural changes, aging populations, dietary changes, decreased physical activity and other unhealthy lifestyles, all of which are associated with westernization and urbanization (Levitt et al., 1999; Mennen & Mbanya, 2000). Type 2 diabetes is now regarded as a major public health problem and an illness of high impact in the developing world including African countries (World Diabetes Foundation, 2009). Yet many sub-Saharan African countries, including Tanzania, have over the years paid limited attention to establishing public health preventive measures against diabetes. Part of this problem emanates from under-reporting coupled with limited epidemiological data on the prevalence of diabetes (Wild, Roglic, Green, Sicree, & King, 2004). However, the situation has been changing over the past thirty or forty years with increasing availability of data on this disease.

Studies show that as soon as new lifestyles are established in urban African areas, the number of people with diabetes tends to increase (McLarty, Pollitt, Swai, & Alberti, 1997). The prevalence of diabetes in urban and rural areas in sub-Saharan Africa varies. For example, surveys carried out in Tanzania (Aspray, Mugusi, & Rashid, 2000; McLarty, Swai, & Kitange, 1989) show a rural-to-urban prevalence ratio of 1.3: 4, and from Cameroon (Mbanya, Ngogang, Salah, Minkoulou, & Balkau, 1997) a ratio of 1:2. These data highlight the need for further studies to document changing lifestyles among urban African communities, and to explore the care and management of diabetes (McLarty et al., 1997).

The problem of diabetes management in sub-Saharan Africa is characterised by late and poor clinic attendance, delayed diagnosis and poor quality care (Mbanya et al., 1997). Evidence from across sub-Saharan Africa suggests that diabetes is under-diagnosed. For example, in a Cameroon study (Mbanya et al., 1997) 60 per cent of diabetes cases were undiagnosed. The equivalent figure was 70 per cent in Ghana (Amoah, Owusu, & Adjei, 2002), and over 80 per cent in Tanzania (Aspray et al., 2000). The prognosis of diabetes in Tanzania is reported to be poor (McLarty, Athaide, & Swai, 1990c) and so is the quality of care (Neuhann, Water-Neuhann, Lyaruu, & Msuya, 2002). The observed reasons for these trends are poor clinic accessibility and drug availability, high costs of treatment and care, inadequate supplies of trained staff and equipment, as well as the use of alternative health care providers, for example traditional healers and/or herbalists (Beran, 2006; Paschal, Unwin, & Phillimore, 2008). Further, poor patient education on the management of diabetes including self-monitoring and control of glycaemia, together with unhelpful health-related beliefs on the management of this disease have been reported to contribute to poor diabetes care and treatment outcomes (Dagogo-Jack, 2006; Kiawi et al., 2006; Neuhann et al., 2002; Ramaiya, 2005; Simpson, 2003; Smide, 2002). This thesis investigates the key factors influencing health seeking and health related behaviour for type 2 diabetes mellitus among adult men and women in an urban community in Tanzania.

This chapter presents the goal and purpose of this thesis followed by the researcher's motivation for the study, and an overview of the health care service delivery system in Tanzania. Highlights of the current study's design are presented coupled with brief key terms and working definitions used in the thesis. The chapter concludes with an overview of the remaining thesis chapters.

1.1 Aim and purpose of the thesis

The aim of this thesis is to explore health seeking and health related behaviour among adult patients with type 2 diabetes mellitus in an urban community in Tanzania. The ultimate purpose of the study is to generate information on the key factors influencing health seeking and health related behaviours for type 2 diabetes mellitus that may inform policy frameworks to guide public health prevention initiatives against diabetes, as well as diabetes care and management in Tanzania.

The study intends to answer a series of related questions with regards to type 2 diabetes mellitus including the following:

- i) What are the prevailing socio-cultural and economic factors, lay perceptions, beliefs, attitudes, and knowledge among patients, family caregivers, and community members that may be influencing health seeking and health related behaviour for care and management of type 2 diabetes mellitus?
- ii) What are the health system related factors that may contribute to delayed health care seeking behaviour, detection and treatment of people with type 2 diabetes mellitus?
- iii) What are the existing challenges, opportunities and solutions for early detection, and provision of quality care management for type 2 diabetes mellitus?

Chapter Two present a literature review which highlights a wide diversity of beliefs, cultures, religions, traditions, educational backgrounds and economic structures that have made and continue to make care seeking and management of diabetes in Africa challenging and unique (Tshabalala & Gill, 1997). Care and management of type 2 diabetes mellitus in sub-Saharan Africa has faced a number of obstacles including poor infrastructure, low accessibility of services, the high cost of diabetes drugs, and lack of trained health care workers and public health educators at the district and primary health care level where most of the population is likely to seek health care (Gill, 1997). However, an adequate number of health care workers and public health educators may not make a difference. Effective management of diabetes will still be a difficult task without adequate understanding of the existing attitudes, beliefs and knowledge related to type 2 diabetes mellitus as influenced by socio-cultural and economic forces at the community level. How much influence, for example, do these factors have on the patient's decision to seek care for diabetes treatment? How much influence do they have on the nature of the patient's self-care once diagnosed with diabetes? How do they influence the nature of services that patients get from their caregivers as well as their social networks? What type of information do the general public, people with diabetes, family caregivers and health care providers need to enhance prevention of this disease, care seeking and diabetes management in Tanzania?

1.2 The researcher's motivation for this research

This study was influenced by a number of factors: personal family experience, professional training, and work experience. When I was in secondary school, the issue of pregnancy came up in the middle of a conversation with my aunt. Our conversation led us onto the problems that women face during pregnancy. My aunt told me that when a woman is pregnant her body becomes vulnerable to all sorts of health problems. She said, “you have got to be careful and well prepared for it”. She paused for a while and then explained what happened when she was pregnant with her last child.

“...when I was pregnant with my last child ten years ago I had this health condition which I have not been able to figure out to date. My throat and lips used to be dry and I was always thirsty. I used to drink a lot of water but my thirst was persistent. As expected with all this water that I was drinking I was always using the toilet. The smell of my breath was similar to sweets or nail polish that you girls use. Everybody in the family was worried about me because at that time there was this belief that a pregnant woman should not take any medication particularly the biomedical medications. Interestingly, no similar restriction was put on traditional medications. Pregnant women were allowed to take all sorts of traditional medicines most of which were known to come from herbalists and traditional healers in our community. My mother-in-law knew about some of these herbs and used to prepare some for me before we consulted other herbalists or traditional healers. One time she took me to this herbalist who made some incisions on my chest (I still have the scars) to let the bad spirit blood flow out after which she applied ground-up black charcoal mixed with some powder made from herbs. My condition did not improve much ...but after delivery every thing went back to normal and the baby was also fine”.

My aunt died years later but her story has always been at the back of my mind. For some time I kept asking myself: “What could she have been suffering from? Would I also suffer from this very problem when I get pregnant?”

It was only when I attended a lecture on diabetes and pregnancy years later at the School of Nursing where I was a student that the bits and pieces of my aunt's story started to come together. Some of the signs and symptoms of diabetes that were presented during this lecture were similar to those which my aunt described to me years ago. Sadly, neither she nor any of her family members could have thought about or even related these signs and symptoms to diabetes. The disease was hardly known back then and is still not familiar now to many Tanzanians.

During my fifteen years of professional health practice as a health practitioner I have seen patients who have lost their eyesight or limbs through amputation because of

diabetes. I have seen patients dying in the emergency room due to hypoglycaemia and many diabetes related health complications. Throughout these experiences I have never stopped asking myself: “Could my aunt have died from diabetes? Would she be alive today had she sought care at the hospital instead of the traditional healers?” My aunt’s death coupled with the premature deaths and disabilities caused by diabetes that I have observed over the years in my career have left me with many unanswered questions: What holds people back from seeking health care at a health facility when they fall sick? Is it ignorance? Is it lack of motivation? Is it lack of awareness and knowledge about available biomedical health care services? Is it socioeconomic problems? What role do the family members and/or social networks play in influencing decisions to seek care? What role do traditional health care beliefs and practices play in influencing decisions to seek care?

After being exposed to public health literature when I was doing my Masters degree in Public Health at the University of New South Wales in Australia, my curiosity about the above questions led to my earlier study exploring health-seeking behaviour among patients with TB in Tanzania. In this study family members and/or their social networks appear to have a significant influence on a patient’s decisions to seek care, and where and when, such care is sought. Although I did not interview family members and/or other members of their social networks at that time due to logistical reasons. While the findings partly explained why my aunt went to the traditional healers for treatment as opposed to the biomedical care facilities, the information motivated me to delve deeper into health-seeking behaviour by examining wider parameters that can influence care seeking behaviour including family caregivers and/or social networks. This time I focused on a different disease – diabetes. Influenced by McKinlay’s (1972) theoretical frameworks, I decided to explore the factors influencing health seeking and health related behaviour among patients with type 2 diabetes mellitus in Tanzania which is a currently evolving public health problem. It is envisioned that the findings of the current study will not only inform policy on the overall care and management of non-communicable disease (NCDs) but specifically strengthen the health care infrastructure for the prevention and control of diabetes. The study findings will also provide relevant information for development of public health interventions in Tanzania. It is my strong belief that public health interventions on diabetes will significantly reduce the number

of patients with diabetes and the number dying from complications associated with diabetes and related morbidity.

1.3 Background and Health Care Delivery System in Tanzania

1.3.1 Background

Tanzania is a tropical country in the sub-Saharan region of Africa. It is a medium-sized country with total area of 945,087 square kilometres. The country is located on the eastern part of the African continent. Neighbouring Uganda and Kenya are to the north, and in Northern Tanzania the famed Olduvai George has provided rich evidence of the area's prehistory, including fossils of some of humanity's earliest ancestors (Bureau of Africa Affairs, 2008). The Democratic Republic of the Congo, Zambia, Rwanda and Burundi are neighbours to the west, while Malawi and Mozambique lie to the south, and the Indian Ocean is on the eastern side (Figure 1.1). Tanzania includes the islands of Zanzibar and Pemba in the east which were annexed in 1964 following the establishment of the union between Tanganyika and Zanzibar. Tanzania is home to Mount Kilimanjaro, one of the tallest mountains in the world. Further, the country has a number of great lakes including Lake Victoria (the source of the River Nile), Lake Tanganyika (one of the deepest volcanic lakes in the world), and Lake Nyasa in the southern part. Alongside these large fresh water bodies are more than six large wildlife conservation areas including the famous Serengeti and Ngorongoro. Mount Kilimanjaro, the great lakes, the wildlife conservation areas and the spice islands of Zanzibar with their ancient Arab architecture make Tanzania one of the world's most attractive tourist destinations.

Figure1.1 Map of Tanzania with provincial boundaries



Source: Bureau of Africa Affair (2008)

The country is culturally diverse, with about 125 ethnic groups. Each ethnic group has its own language, but the national language for official government communication is Kiswahili, a Bantu-based tongue with strong Arabic influences. The English language is used in education as a medium of instruction and in business as the language of administration (Bureau of Africa Affairs, 2008). Tanzania has enjoyed general political stability and national unity for more than forty years. The population is estimated at 42 million people with an average annual population growth rate of 3.1 per cent (National Bureau of Statistics Tanzania, 2002). Dar es Salaam is the commercial capital city of Tanzania with the largest urban population estimated at close to 4 million people. With a population growth rate of 4.39 per cent annually it has become the third fastest growing city in Africa after Bamako in Mali and Lagos in Nigeria, and the ninth fastest in the world. Dar es Salaam's population is expected to reach 5.12 million by 2020. The rapid growth of the city is attributed to the high rural urban migration associated with job incentives brought about by the ongoing large and small trading investments in the city (Wikipedia, 2009).

In Ilala and Kinondoni districts where this study was conducted the main economic activities include large-and small scale trading, formal employment in the government or private sectors and fishing. As highlighted in earlier studies rapid urbanisation in sub-

Saharan Africa appears to be associated with a high rate of diabetes (Aspray et al., 2000) Dar es Salaam is no exception. According to personal communications from key informants during the study, Dar es Salaam is now estimated to have more than 10,000 people with type 2 diabetes mellitus and the number is increasing.

The country's Gross Domestic Product is very low with an annual per capita level of USD 432 (Economic Research Department Rabobank, 2009). More than a third of its 42 million people live below the national poverty line (World Diabetes Foundation Report, 2009). The economy of the country is heavily dependent on agriculture which produces 41 per cent of the Gross Domestic Product mainly from the export of unprocessed agricultural produce. According to the National Encyclopaedia (2009) Tanzania continues to experience slow economic growth which results from a combination of factors including extremely poor infrastructure – such as transport, energy and telecommunications—and under-developed manufacturing industries. Although the country has attracted extensive foreign investment in the mining and tourism industries as well as in the financial institutions over the past ten years, these investments have not yet improved the economic growth of the country, let alone the lifestyles of its population.

1.3.2 The health care delivery system

Since the colonial period and for almost over forty years after independence in 1961, health care service delivery in Tanzania has largely been a prerogative of the government through the Ministry of Health and Social Welfare (MoHSW). Although the private sector was involved in the provision of health care services before independence, its role was minimal. For example, only a limited number of private health services existed before independence, most of which were based in cities and townships. The majority of free services were provided through non-governmental organisations, particularly religious institutions. After independence, however, health care facilities were re-directed towards rural areas and free health care services were introduced except for patients wishing to be treated in Grade I and II health facilities (the Grade I and II health facilities were similar to the private care facilities used to treat top government officials). In 1977 private health services were banned under the Private Hospitals Regulation Act and the practice of medicine and dentistry on a commercial

basis was prohibited. This Act had some negative effects for the overall health services across the country (Tanzania Ministry of Health and Social Welfare Report, 2007). However in 1976, after a series of major social and economic changes, the government renewed its interest in working with the private sector in the delivery of health care services. New policies were developed that looked favourably on the role of the private sector in health care service delivery. The amendment of the 1977 Private Hospitals (Regulatory) Act led to the establishment of the Private Hospitals Regulatory (Amendment) Act (1991) which allowed individual qualified medical practitioners and dentists to own and operate private hospitals, with the approval of the Ministry of Health and Social Welfare. Unlike conventional health practitioners, traditional health practitioners, including traditional healers and herbalists as well as traditional midwives, have over this time been providing alternative health care services to the great majority of the country's population (Minister of Health's Speech, 2002)

Later, the Ministry of Health appraised the performance of the health sector with the intention of developing strategies aimed at improving the quality of health services at the same time as increasing equity in health accessibility and utilisation. The appraisal led to the 1994 Ministry of Health report "Proposals for Health Sector Reforms" (Tanzania Ministry of Health Report, 1994) consisting of a number of suggestions including:

- managerial reforms or decentralisation of health care services;
- financial reforms introducing user charges in government hospitals;
- introduction of health insurance and community health funds; and
- public/private mix reforms aimed at promoting public/private sector partnerships in the provision of public health care services.

The report also called for the integration of vertical health programmes into general health care services; providing funding for research and propagation of demand-oriented research in the health sector.

Further, the report emphasised the need to adhere to the health care referral system in the provision of public health care services as a strategy to streamline service provision and reduce patient congestion in the national referral hospitals. The health care system referral process follows a pyramidal pattern of service delivery starting from the

dispensary to national referral hospitals. The referral structure of the health care system is divided into seven levels of service provision (Tanzania Ministry of Health and Social Welfare Report, 2007) as described in Chapter Two and summarised in Figure 2.1. However, provision of diabetes care services has been almost non-existent at the village and the dispensary, as well as at the health centre and at the district level in Tanzania. It was not until 2004 when the Tanzania Diabetes Association through a project funded by the World Diabetes Foundation (WDF), the World Partnership Project (WPP) of Novo Nordisk A/S and Dr. M. Zolli of Italy established diabetes clinics in nineteen regional hospitals and four referral hospitals in the country to provide initial care services to the people with diabetes (Ramaiya, 2006). In the city of Dar es Salaam these facilities were established in each of the three districts (Figure 1.2), two of which were involved in the current study.

Figure 1.2: Mwnanyamala Diabetes Clinic (refurbished container by Tanzania Diabetes Association), Kinondoni District, Dar es Salaam 2007



With the health budget well below the African average, the capacity and availability of health care personnel and facilities is low in Tanzania (World Diabetes Foundation Report, 2009). The current doctor/patient ratio in Tanzania is 1:26,000 people, whereas the WHO recommended ratio is 1:7,500 (Kilimanjaro Christian Medical Centre, 2007).

Similarly, the nurse/patient ratio is 1:37 in most district hospitals in the country while the recommended ratio is 1:4 (Thompson & Langford, 2008). This indicates a severe shortage of health care workers across all levels in Tanzania, which reduces the standard of health care provision and management.

1.4 Overview of the study design

This is a qualitative study designed to explore the factors influencing health seeking and health related behaviour for type 2 diabetes mellitus. Qualitative methods consisting of in-depth and key informant interviews and focus group discussions were used to generate information and ideas from the study participants. Data were collected from people with diabetes, patients' caregivers, health care workers, key national health officials and community members in two diabetes clinics in the city of Dar es Salaam, between March and June 2007 (Chapter Three). In-depth interviews were carried out with twenty diabetes patients and their fourteen caregivers, ten frequent attendees and their seven caregivers as well as ten infrequent clinic attendees and their six caregivers, and seven health care workers; key informant interviews were carried out with six key national health officials. Similarly, focus groups were carried out with selected male and female with diabetes in each of the two clinics as well as selected groups of male and female community members without diabetes in the areas surrounding the clinics. Data analysis was carried out using Miles and Huberman's approach (1994, pp.9-10) of data reduction, data display, and conclusion drawing and verification (Chapter Three).

1.5 Key Concepts and working definition

A number of concepts and working definitions have been adopted in this thesis includes:

Traditional healers: For the purpose of this thesis the term refers to people who are thought to have acquired special healing skills to treat and cure diseases. Some traditional healers claim to use supernatural powers or magic to treat or cure diseases. Often these skills are acquired through apprenticeship from someone with such skills, or as a gift passed over from one generation to the next through visions, stories, and dreams. Normally the healing does not follow written guidelines. Healers work

differently with each person they help. Some use herbs, ceremonies and supernatural power in the process of treating their clients.

Herbalists: Unlike the traditional healers who use ceremonies and supernatural powers in diagnosing and treating their patients, herbalists mainly rely on their expert knowledge and experiences in the use of medicinal plants and animal and mineral-based products for treatment of the various disease signs and symptoms.

Alternative care services: The term refers to a variety of therapies that are provided to patients outside the “biomedical mainstream” to treat the signs and symptoms of diabetes and enhance wellness. These therapies may include use of medication from herbalists, self medication (use of non prescribed treatment), and or use of services from traditional and faith healers.

Social networks: The term refers to a range of close friends, distant relatives and neighbours who happen to be socially close to the patient. This group of people often happens to share the same socio-cultural background with the patient but having more knowledge and experience in the management of various diseases based on the presenting signs and symptoms. It is because of this wealth of knowledge and experience that social networks tend to have significant influence on a patient’s perception of the signs and symptoms of the disease as well as on his/her decisions to seek care, when and where. In other studies the term ‘significant others’ is sometimes used to refer to members of social networks.

Health -seeking behaviour: This behaviour will include all activities undertaken by the patient and his/her family and/or social networks for the purpose of finding an appropriate diagnosis and treatment for an individual’s ill health. Health-seeking behaviour has also been referred to as a process for responding to the onset of signs and symptoms and/or episodes of an illness. It is more evident when looking at the pathways that people go through in making health care and treatment choices.

Health related behaviour: This consists of activities or actions carried out by patient and his/her family and/or social networks (individuals) to prevent illness, to restore, maintain or improve health. Health related behaviour may also include those activities

that have a negative impact on individual health including smoking, alcoholism, inactivity and unhealthy food intake. It also involves poor adherence to prescribed medication following disease diagnosis.

1.6 Overview of the thesis

This thesis is organised into three main sections which include the research methodology and methods, the results, and the discussion and conclusions. It comprises seven chapters.

Chapter One presents the background and overview of the health care system in Tanzania.

Chapter Two provides an overview of the literature related to the key concepts and issues covered in the study. It sets the overall research context. The chapter presents background information on diabetes, examining the epidemiology of diabetes globally, in developing countries and in sub-Saharan Africa in particular. The chapter also discusses care and management of diabetes mellitus. Evidence about challenges related to the provision of services is examined. Lastly the chapter highlights the health-seeking behaviour models that have been used and refined through a number of studies both in developed and in developing countries as well as sub-Saharan Africa.

Chapter Three describes the methodology and methods used in data collection, analysis and interpretation. The chapter justifies the use of the McKinlay (1972) and Miles and Huberman (1994) theoretical frameworks which are used to guide data collection, analysis and interpretation of the study findings.

Chapter Four presents the major findings related to diabetes knowledge, understanding and perceptions of people with diabetes and their caregivers as well as community members.

Chapter Five outlines the specific factors that influence health seeking and health related behaviour for type 2 diabetes patients.

Chapter Six describes the key challenges encountered by patients and their caregivers in health care seeking and management of diabetes after initiation of treatment at a health care facility.

Finally, Chapter Seven discusses the principal findings of the study, bringing together the findings presented in Chapters Four to Six in the light of the literature review and the theoretical framework presented in Chapter Three. Based on this discussion some conclusions and recommendations are presented.

Chapter 2–Literature Review

2.0 Introduction

This chapter describes the literature review and topics covered in the thesis. The chapter is divided into five sections. The first section explains how the literature review was performed. This section covers the primary and secondary sources and data used to review the literature. The main aim of the review is to identify and evaluate studies on health seeking and related behaviour for type 2 diabetes mellitus, particularly from sub-Saharan Africa. The review begins with a global scope, then concentrates on developing countries, especially sub-Saharan Africa, then with a focus on Tanzania.

The second section looks at the epidemiology, definition, diagnosis and management of diabetes and state of diabetes mellitus including the risk factors for natural history of diabetes, especially in sub-Saharan Africa. The cost implications of diabetes are presented.

The third section describes the care delivery and management of diabetes mellitus globally and in sub-Saharan Africa including Tanzania. The management challenges for diabetes in sub-Saharan Africa and Tanzania are highlighted.

The fourth section examines previous studies exploring the influences behind health seeking and health related behaviour among patients with type 2 diabetes mellitus. This includes a critical examination of the beliefs and socio-cultural context under which diabetes is perceived and acted upon. Similarly, influences of patients' awareness, understanding and knowledge and their cultural perceptions in the interpretation of the signs and symptoms of the disease and consequent course of action are assessed. The role of the health care system and its providers in the process of health-seeking behaviour is examined.

The chapter ends with a review of health-seeking behaviour models that have been used and refined through a number of studies both in developed and in developing countries. A synthesis of how these models interact in explaining the observed health-seeking behaviour for various communicable and non-communicable diseases (NCDs) is presented.

2.1 Section One: Literature Review Approaches

The review focused on various publications on health seeking and related behaviour for type 2 diabetes mellitus from different disciplines including public health, sociology, psychology, anthropology, medicine, epidemiology, economics, social policy and population studies. These disciplines offered a broad array of views both on the complexity of health seeking and health related behaviour for type 2 diabetes and care and management challenges.

2.1.1 Data Sources

An extensive literature review of books, computer databases and related scientific journals was carried out in the initial stages and throughout the study. The purpose of this review was to assess and evaluate the studies on health seeking and related behaviour for type 2 diabetes mellitus. The reviews began with a global scope, then concentrated on developing countries, specifically sub-Saharan Africa, then ended with a focus on Tanzania. Looking at the conclusions of these studies, and the gaps in their findings, the areas needing further study were discovered.

Different strategies were used in the literature search and review. To start with I used key words (Box 2.1) to search for available literature from multiple bibliographic databases.

Box 2.1: Key words used in the literature search

- “diabetes mellitus”
- “type 2 diabetes mellitus”
- “health seeking”
- “help seeking”
- “care seeking”
- “health care utilisation”
- “medical care utilisation”
- “acceptance of health care”
- “attitude to health”
- “health behaviour”
- “health related behaviour”
- Traditional medicines

- Role of traditional medicines
- Role of traditional medicines AND diabetes
- “health seeking AND “attitude to health”
- “health seeking AND related behaviour”
- “health behaviour OR attitude to health” OR “patient acceptance of health care”
- “diabetes mellitus AND “health behaviour” OR “attitude to health” OR “patient acceptance of health care”
- “patient education”
- “diabetes mellitus/type 2” AND “health behaviour” OR “attitude to health” OR “patient acceptance of health care” OR “patient education”
- “diabetes mellitus /type 2” AND “health behaviour” OR “attitude to health” OR “patient acceptance of health care” AND “patient education”.

Using the key words in Box 2.1. I gathered extensive literature on the subject from the different databases presented in Box 2.2

Box 2.2: Key databases used during the literature search

- Medline, PubMed
- ProQuest, CINAHL
- MeSH, Web of Science
- EMBASE
- PsycINFO
- Google Scholar
- Africa on Line

Still using the key words in Box 2.1, websites were searched through Google scholar. Through this approach a range of literature was generated mainly from the sources of papers presented in Box 2.3.

Box 2.3: Main source of papers for literature review.

- *International Journal of Diabetes in Developing Countries*
- *Social Science and Medicine*
- *British Medical Journal*
- *Lancet*
- *Diabetic Educator*
- *Diabetic Medicine*
- *Diabetes Care*
- *Diabetes Research clinical Practice*
- *Diabetes Spectrum and Healthcare Demand and Disease Management*

African online journals:

- *African Health Science*
- *Eastern Africa Social Science Research*
- *African Journal of Traditional Complementary and Alternative Medicines*

The journal articles cited repeatedly in this section of the literature review are summarised in Appendix 2.

The literature review involved in this thesis covers a period of twenty year between 1989 and 2009 although in some instances some essential earlier international studies are included where relevant. This is more so in areas where there is dearth of recent studies on the topic in question (i.e. studies related to McKinlay's (1972) model).

2.2 Section Two: The Epidemiology of Diabetes**2.2.1 Definition of Diabetes Mellitus**

According to WHO, the term diabetes mellitus describes a metabolic disorder of multiple etiology characterized by chronic hyperglycemia with disturbances of carbohydrate, fat and protein metabolism in the body resulting from defects in insulin

secretion, insulin action, or both. The effects of diabetes mellitus include long-term damage, dysfunction and failure of various body organs. Diabetes mellitus may present with characteristic symptoms such as thirst, polyuria, blurring of vision, and weight loss. In its most severe forms, ketoacidosis or a non-ketotic hyperosmolar state may develop and lead to stupor, coma, and, without effective treatment, death. The symptoms of this disease are often not severe and/or may be absent hence levels of hyperglycaemia sufficient to cause pathological and functional changes may be present for a long time before the diagnosis is made. The long-term effects of diabetes mellitus include progressive development of the specific complications of retinopathy with potential blindness, nephropathy that may lead to renal failure, and/or neuropathy with risks of foot ulcers, amputation, Charcot joints, and features of autonomic dysfunction including sexual dysfunction. People with diabetes are also at increased risk of cardiovascular, peripheral vascular and cerebrovascular disease (WHO, 1999).

Several pathogenetic processes are involved in the development of diabetes. These include processes which destroy the beta cells of the pancreas with consequent insulin deficiency, and others that result in resistance to insulin action. The abnormalities of carbohydrate, fat and protein metabolism are due to deficient action of insulin on target tissues resulting from insensitivity or lack of insulin (WHO, 1999).

Since there are several reasons for diabetes mellitus, the disease according to WHO (1999) can be classified into four principal types. These include: i) type 1 (IDDM) diabetes mellitus (associated with destruction of insulin-producing beta-cells, usually leading to absolute insulin deficiency) – autoimmune and/or idiopathic; and ii) type 2 non-insulin dependent (NIDDM) diabetes mellitus (may range from predominantly insulin resistance with relative insulin deficiency to a predominantly secretory defect with or without insulin resistance). Other specific types of diabetes include gestational diabetes mellitus (GDM), which develops only during pregnancy when there is a high degree of glucose intolerance, and malnutrition-related diabetes mellitus (MRDM). The most common types of diabetes seen in sub-Saharan Africa are types 1 and 2. Types 1 and 2 diabetes are referred to throughout this thesis, although type 2 diabetes mellitus is the main focus of the current study.

Type 1 diabetes mellitus is commonly found among children and young people with about 25-50% of cases occurring before the age of 15 years. However, type 1 diabetes

mellitus is also known to occur in middle age and later. These are mostly lean individuals who present with symptoms of metabolic de-compensation over a short period of time. The individuals mainly present with classic symptoms of hyperglycaemia that may include excessive thirst (polydipsia), frequent urination (polyuria), increased hunger (polyphagia), general fatigue and weight loss (Cooke & Plotnick, 2008). The disease is nearly always acute and needs regular doses of insulin to sustain life at the same time avoiding acute and more long-term complications (Vaughan et al., 1989). The major complications of type 1 diabetes are long-term complications affecting the eyes, nerves and kidneys (Rother, 2007).

Unlike type 1 diabetes mellitus, type 2 diabetes (non-insulin-dependent diabetes) is most common in older age groups (over 40 years) although lately it has been observed among obese adolescents. Risk factors for type 2 diabetes mellitus include old age, increased body mass index (BMI) and a certain body fat distribution, weight gain in adulthood, ethnicity, family history of diabetes, low birth weight, sedentary lifestyle, higher systolic blood pressure, impaired glucose tolerance, impaired fasting glucose, and history of gestational diabetes. It is estimated that about 85-95% of all people living with diabetes in developing countries suffer from type 2 diabetes (Gerstein et al., 2001).

2.2.1.1 Diagnosis of diabetes mellitus

Diabetes mellitus is characterized by recurrent or persistent hyperglycaemia. The WHO diagnostic criteria (2006) for diabetes include the following:

- Fasting plasma glucose level at or above 7.0mmol/L (126mg/dL);
- Plasma glucose at or above 11.1 mmol/L (200mg/dL) two hours after a 75g oral glucose load as in a glucose tolerance test;
- Symptoms of hyperglycaemia and non-fasting plasma glucose at or above 11.1mmol/L (200mg/d); and
- Glycosylated hemoglobin (hemoglobin A1C) at or above 6.5.

It is also recommended that the oral glucose tolerance test (OGTT) should be used in individuals with fasting plasma glucose of 6.1–6.9mmol/l (110–125mg/dl) to determine their glucose tolerance status (WHO, 2006). Impaired Fasting Glycaemia (IFG) is an elevated nondiabetic fasting blood glucose level. It is defined by fasting plasma glycaemia (FPG) ≥ 6.1 – < 7.0 mmol/l, (and if measured) 2-hour plasma glucose

<7.8mmol/l. Impaired Glucose Tolerance (IGT) is defined by 2-hour plasma glucose \geq 7.8 to 11.1mmol/l (and if measured) fasting plasma glucose (FPG) <7.0mmol/l and diabetes is diagnosed by FPG \geq 7.0mmol/l and /or 2-hour plasma glucose \geq 11.1mmol/l (WHO, 2006). Both IFG and IGT are transitional stages in the development of type 2 diabetes. Table 2.1 below summarizes the WHO recommendations for the diabetes mellitus diagnostic criteria and intermediate hyperglycaemia.

Table 2.1: WHO Diabetes criteria (WHO, 2006)

Condition	2 hour glucose	Fasting glucose
	mmol/l(mg/dl)	mmol/l(mg/dl)
Normal	<7.8 (<140)	<6.1 (<110)
Impaired fasting glycaemia	<7.8 (<140)	\geq 6.1(\geq 110) & <7.0(<126)
Impaired glucose tolerance	\geq 7.8 (\geq 140)	<7.0 (<126)
Diabetes mellitus	\geq 11.1 (\geq 200)	\geq 7.0 (\geq 126)

2.2.1.2 Diabetes Management

Diabetes is a chronic disease with no cure to date. It is associated with an impaired glucose cycle and altered metabolism. The short-term management of this disease aims at lowering and stabilizing mean blood sugar levels, while long-term aims focus on avoiding hyperglycaemia and ketoacidosis as well as later complications, all of which result from high blood sugar levels (Gerstein et al., 2001; Teuscher, 2007). Management of sugar levels calls for strict adherence to a medical regimen which may include use of a special diet, exercising, taking oral diabetes medication and using some form of insulin. Management of blood sugar levels may be complicated by other external factors such as stress, illness, menses, injection site scarring, dietary habits and other physiological factors unique to individual patients (Gerstein et al., 2001).

Type 1 diabetes mellitus must be treated life-long with insulin replacement therapy. Treatment must be continued indefinitely. Treatment may not significantly impair normal activities, if there is sufficient patient training, awareness, appropriate care and discipline in testing — allowing self management of blood glucose levels (Teuscher, 2007). Type 2 diabetes mellitus is initially treated by adhering to recommended diet,

exercise, and by weight loss particularly among obese patients. The amount of weight loss which improves the clinical picture is sometimes modest (2-5 kg or 4.4-11 lb). This is almost certainly due to currently poorly understood aspects of fat tissue activity, for instance chemical signaling (especially in visceral fat tissue in and around abdominal organs). In many cases, such initial efforts can substantially restore insulin sensitivity. In some cases strict diet and physical activity can adequately control the glycaemic levels. However, in many cases oral anti-diabetic drugs are required, and in about 30% of cases insulin injection may be necessary (Gerstein et al., 2001).

Furthermore, WHO (2010) recommends the following guidelines for prevention, treatment and control of diabetes:

2.2.1.3 Prevention of diabetes mellitus

Simple lifestyle measures have been shown to be effective in preventing or delaying the onset of type 2 diabetes. To help prevent type 2 diabetes and its complications, people should:

- achieve and maintain a healthy body weight;
- be physically active – at least 30 minutes of regular, moderate-intensity activity on most days. More activity is required for weight control;
- eat a healthy diet of between three and five servings of fruit and vegetables a day and reduce sugar and saturated fats intake; and
- avoid tobacco use – smoking increases the risk of cardiovascular diseases.

2.2.1.4 Treatment and control of diabetes mellitus

Treatment of diabetes involves lowering blood glucose and the levels of other known risk factors that damage blood vessels. Tobacco cessation is also important to avoid complications.

Interventions that are both cost saving and feasible in developing countries include:

- moderate blood glucose control. People with type 1 diabetes require insulin;
- people with type 2 diabetes can be treated with oral medication, but may also require insulin;
- blood pressure control; and
- foot care.

Other interventions are also proposed including:

- screening for retinopathy (which causes blindness);
- blood lipid control (to regulate cholesterol levels); and
- screening for early signs of diabetes-related kidney disease.

The above measures should be supported by a healthy diet, regular physical activity, maintaining a normal body weight and avoiding tobacco use.

2.2.1.5 WHO (2010) planned activities to prevent and control diabetes

WHO also aims to stimulate and support the adoption of effective measures for surveillance, prevention and control of diabetes and its complications, particularly in low and middle-income countries. To this end, WHO:

- provides scientific guidelines for diabetes prevention;
- develops norms and standards for diabetes care;
- builds awareness of the global epidemic of diabetes, including partnership with the International Diabetes Federation in the celebration of World Diabetes Day (14 November); and
- conducts surveillance of diabetes and its risk factors.

2.2.2 Global Epidemiology of Diabetes

The growing incidence of diabetes mellitus is a widespread concern (Idemyor, 2010). The disease affects people worldwide and poses major public health and socioeconomic challenges (Mbaya et al., 2010). As mentioned before, the International Diabetes Federation (IDF) estimated in 2009 that the global number of adults with diabetes will increase by 54%, from 284.6 million in 2010 to 438.4 million in 2030. The same report (IDF, 2009) suggests that each year a further 7 million people will develop diabetes. These figures are clear evidence of the growing magnitude of diabetes mellitus as one of the major public health challenges in the 21st century.

At the beginning of the 21st century it was estimated that 5.2% of all deaths globally were attributed to diabetes mellitus. This ranks diabetes as the fifth leading cause of death after communicable disease, cardiovascular disease (CVD), cancer and injury (Roglic et al., 2005). Some studies have shown that diabetes has been responsible for

substantial morbidity and mortality, and could be responsible for reducing the rate of decline in population mortality (Thomas et al., 2003). However, assessing the global diabetes mortality burden has been difficult to quantify since more than a third of the world's nations do not have any data on diabetes-related mortality and the existing routine health statistics have been shown to underestimate mortality from diabetes (Roglic et al., 2005). The disease is frequently underreported on death certificates (WHO, 2003), since in many situations individuals with diabetes die from cardiovascular and renal disease and not from a cause uniquely related to diabetes, such as ketoacidosis or hypoglycaemia (Morrish et al., 2001). However, studies that have focused on interpreting diabetes mortality data based on death certificates have shown some limitations because they are basically 'surveys' of death certificates (e.g. national mortality data). Since individuals are not identified for these studies prior to death, the confirmation of diabetes status depends solely on whether or not diabetes is reported on the death certificate (Whittall et al., 1990; Will, 2001; Thomason, 2005; McEwen, 2006).

Furthermore, Ekoé and colleagues (2008) argued that type 2 diabetes is one of the great modern pandemics of the 21st Century. In some populations, more than half of adults either already have the disease or are at risk with evidence of IGT, IFG or metabolic syndrome. It can affect all populations but particularly some of the rapidly developing countries. For example, South Asians appear to have a particular predisposition to diabetes and the Indian subcontinent will have nearly one-third of the world's people living with type 2 diabetes (Ekoé et al., 2008). The prevalence of type 2 diabetes mellitus varies widely between different populations across the globe. There appear to be demographic variations among people suffering from type 2 diabetes between developed and developing countries. In developing countries, for example, most people affected with type 2 diabetes mellitus are between 35 and 64 years old, a group at its peak professionally and/or most economically productive (Roglic et al., 2000). Those mostly affected by type 2 diabetes mellitus in developed countries are over 60 years old (Idemyor, 2010). This age group variation of the population mostly affected by this disease undoubtedly has significant economic implications for the countries in the developing world (Narayan et al., 2000).

2.2.3 Epidemiology of Diabetes in Developing Countries

Several reports on global estimates and projections of diabetes (Roglic et al., 2004; IDF, 2006, 2009) have confirmed the prevalence of both diabetes and impaired glucose tolerance to be on the rise. Estimates show that by the year 2025, more than three-quarters of all people with diabetes will reside in developing countries (Roglic et al., 2004; Dagogo-Jack, 2006; IDF, 2006; IDF, 2009). Several studies have found a remarkable increase in the prevalence rates of type 2 diabetes in many developing countries (Amoah, 2002). This growing diabetes epidemic and its risk factors in developing countries have been attributed to a variety of social, cultural and economic factors coupled with increased population ageing and urbanization and/or westernization and changing lifestyles (Motala, 2002; Osei, 2003; Pradeepa, Deepa, & Mohan, 2002; Proctor, Sobngwi, Mauvais-Jarvis, & Vexiau, 2001).

The prevalence of diabetes in developing countries ranges from 0.5 to 2.5% in rural areas, to 4 to 6% in urban areas (Osei, 2003). The prevailing poverty, ignorance, illiteracy and poor health consciousness in developing countries account for less than half of people with diabetes being effectively diagnosed. Without timely diagnoses and adequate treatment, complications and morbidity from diabetes will rise exponentially among the populations in these countries (International Diabetes Federation, 2006). The prevalence rates of type 2 diabetes, and its associated long-term complications, continue to increase among the populations of developing countries (Osei, 2003). This increases the risk of developing macrovascular diseases and is the major factor behind the resurgence of heart disease and stroke in developing countries (Ekoé et al., 2008). Ekoé and colleagues further argue that people with diabetes also carry the risk of microvascular complications when glycaemic control is inadequate. Despite its deadly nature, diabetes has yet to attract the necessary attention from governments and policy makers particularly in developing countries (NCDs in East Africa editorial, 2005).

In most developing countries inadequate resources such as finance and specialized health professionals have been reported to be major barriers to addressing chronic diseases like diabetes (Osei, 2003). Other impediments are the failure to provide key decision makers with current evidence and data on the burden of chronic diseases coupled with the orientation of health systems toward acute care. Chronic disease management calls for more complex management approaches than acute diseases.

Effective management of chronic diseases like diabetes calls for an integrated approach, with patient, family and the community taking an active supportive role (Yach, Leeder, Bell, & Kistnasamy, 2005).

2.2.4 Epidemiology of Diabetes in sub-Saharan Africa

The prevalence and burden of non-communicable diseases due to type 2 diabetes are rising quickly in sub-Saharan Africa (Mbanya et al., 2010; Tuei et al., 2010). Although diabetes was previously thought to be rare or not documented in rural Africa, over the past few decades it has emerged as an important non-communicable disease (McLarty, Pollit, & Swai, 1990; Motala et al., 2008; Levitt, 2008). This is a shift from what Albert Cook, a medical missionary in Uganda, observed in 1901 when he noted that “... *diabetes is rather uncommon and very fatal...*” (Cook, 1901). The disease has been changing significantly over the past thirty to forty years and is currently regarded as a major public health problem throughout Africa (IDF, 2003).

Furthermore, the global diabetes trends show an increased incidence and prevalence of this disease in African populations (Sobngwi et al., 2001). For example, the International Diabetes Federation (IDF) estimated in 2009 that impaired glucose tolerance in sub-Saharan Africa would rise by 75.8%, from 26.9 million in 2010 to 47.3 million in 2030. This proportion is more than double the predicted global increase of 37%. The report further highlighted the paucity of data from Africa (IDF, 2009). Mortality attributable to diabetes in sub-Saharan Africa is estimated, in 2010, at 6% of total mortality, an increase from 2.2 to 2.5% in the year 2000. The report shows that the absolute and relative mortality rates are highest in the 20-39 years age group, significantly affecting the most economically productive population (IDF, 2009).

Mbanya and colleagues argue that the disease increase presents a substantial public health and socioeconomic burden in countries with scarce resources. They reported for example, that the rate of undiagnosed diabetes is high in most countries of sub-Saharan Africa, and individuals who are unaware that they have the disorder are at very high risk of chronic complications. It is for this reason they noted that the rate of diabetes related morbidity and mortality in sub-Saharan Africa could grow substantially in the near future (Mbanya et al., 2010).

The perceptions among patients and the general population in the region of the signs and symptoms of diabetes appear to contribute to delays in seeking medical care. The clinical combination of weight loss, polyuria and sepsis, for instance, is reported to be associated with erroneous diagnosis of AIDS in people living with diabetes, contributing to the delays in seeking medical care in sub-Saharan Africa, where HIV/AIDS is now endemic (Burdon, 1996). Further, there is fear currently that the antiretroviral drugs that are being widely used in African patients with AIDS, may lead to adverse effects of metabolic syndrome and type 2 diabetes. Furthermore, the existing socioeconomic inequalities are likely to contribute to inadequate access to healthcare services and other related material circumstances (Osei, 2003).

In sub-Saharan Africa the health care delivery agenda is overwhelmed by poverty (Idemyor, 2010). Diabetes management costs have to compete with other health demands such as antiretroviral drugs for HIV/AIDS, tuberculosis treatment, and malaria (Idemyor, 2010). These are intermediate factors that may contribute to delays and/or poor diagnosis of diabetes and/or its management. Cultural factors and health beliefs differ in sub-Saharan Africa, where under-nutrition and opulence coexist. Food remains a daily challenge and being overweight can thus be perceived as a sign of wealth. Indeed, being obese is often a deeply rooted status symbol, although there are wide geographical variations in these perceptions, in addition to differences between urban and rural environments. However, in a continent where there is a pluralistic and underdeveloped healthcare system with poor diagnostic facilities, and where poverty can be considered endemic, the atypical presentations of diabetes, coupled with health beliefs and the HIV/AIDS epidemic, can lead to difficulties in the diagnosis of diabetes (Osei, 2003).

The late diagnosis of diabetes in sub-Saharan Africa, coupled with inequality in accessing care, leads to early presentations of diabetes complications (Idemyo, 2010). In Africa for example, it was always thought that chronic complications of diabetes are rarely seen. Although there is some truth in this, there is no doubt that if carefully looked for, chronic complications are not infrequently seen, including retinopathy, cataract, nephropathy, hypertension, macroangiopathy and neuropathy (Mbanya et al., 2003; Rolfe, 1997). The acute metabolic complications of diabetes ketoacidosis,

hyperosmolar non-ketotic coma, hypoglycaemia and severe diabetes-related infections are all commonly reported to occur in Africa (Mbanya & Ramaiya, 2006; Lester, 1997).

Diabetes mellitus in the African continent is hugely affected by epidemiological factors and issues of health economics (Gill et al., 2009). Although accurate epidemiological studies are often logistically and financially difficult, the processes of rural-urban migration and epidemiological transition are certainly increasing the prevalence of type 2 diabetes in sub-Saharan Africa (Gill et al., 2009). Some studies have shown variations in diabetes prevalence between rural and urban African settings (Aspray et al., 2000).

Several studies reported that a major modifiable factor for diabetes prevalence in Africa is urbanization (Godfrey, 2005). There continues to be an increasing number of people moving into urban areas from rural environments, particularly in sub-Saharan Africa. This immigration is inevitably associated with a shift in lifestyle from a relatively healthy traditional pattern, to the urban scenario of increased food quantity and reduced quality, low levels of exercise, smoking and increased alcohol availability (Beaglehole, 2003). This rapid and dramatic epidemiological transition is driving the emergence of high and increasing prevalence rates of type 2 diabetes and hypertension (Aspray, 2000), with growing mortality implications (Gill et al., 2009).

According to Aspray and colleagues, rural dwellers have high levels of physical activity, which facilitate high energy expenditure compared to their urban counterparts. It is for this reason that obesity is reported to be four times higher among urban populations compared to rural populations in sub-Saharan Africa. Urban residents for instance, have a 1.5 to four-fold higher prevalence of diabetes compared to their rural counterparts. The estimated prevalence of diabetes in Africa is less than 3% in rural areas, up to 5-7% in urban sub-Saharan Africa, and between 8 and 13% in more developed areas such as South Africa and in populations of Indian origin (Amoah, Owusu, & Adjei, 2002; Motala, Omar, & Pirie, 2003; Sobngwi et al., 2001). These findings are supported by another study in Cameroon which showed an urban/rural ratio of 2:1 (Mbanya et al., 1997).

Apart from the influence of rapid demographic and epidemiological transition the growth of diabetes has been attributed to other factors including economic development.

Omar et al. (1994) and Levitt et al. (1999), for example, argue that the economic development in many countries in sub-Saharan Africa has led to increased life expectancy, lifestyle modifications and increased risk factor levels for type 2 diabetes. Parry et al.'s (2004) study appears to support these observations. In their study in Cameroon, life expectancy at birth in 1960 was at 35 years, but increased to approximately 55 years by 1990. According to this study diabetes in Africa is prevalent in older age groups due to the change in life expectancy.

Omar et al. (1994) and Levitt et al. (1999) argue that the risk factors for type 2 diabetes are not markedly different from those reported in other populations, such as age, ethnicity, positive family history, obesity, physical inactivity, urbanization, and westernized diet. Mennen and Mbanya (2000) categorized the risk factors into two groups: non-modifiable and modifiable risk factors. Mennen and Mbanya (2000) argue that modifiable risk factors such as obesity, physical inactivity, urbanization, and westernized diet (calorie-dense diets) appear to be major determinants for developing type 2 diabetes in sub-Saharan Africa. Their study also shows that non-modifiable risk factors such as age, family history and ethnicity appear to contribute to type 2 diabetes in the region. Ethnicity, for example, is a factor influencing the rate of diabetes among Indians, followed by Blacks and Caucasians in South Africa (Ramaiya et al., 1991). Among people of Indian origin in South Africa and Tanzania the prevalence is reported to be between 12 and 13% (Ramaiya et al., 1991).

Epidemiological data related to type 1 diabetes in sub-Saharan Africa are scarce (McLarty, Pollit, & Swai, 1990b; Motala et al.; Levitt, 2008). Mbanya and Gill (2004) argue that few studies have attempted to assess the incidence of type 1 diabetes in Africa. According to Parry et al. (2004), limited information was available on the prevalence of type 1 diabetes mellitus in Africa until the study by Elamin et al. (1992). Their study of nearly 43,000 school children (aged 7-11 years) in Sudan, found that 0.95 per 1000 had type 1 diabetes. In Tanzania, Swai, Lutale, and McLarty (1990) found the incidence of type 1 diabetes mellitus to be 1.4 per 100,000. According to their data, most people with diabetes in Africa (70-90%) were presenting with type 2 diabetes mellitus, although up to 25% of the patients presented with type 1 diabetes.

2.2.5 Epidemiology of Diabetes in Tanzania

Unlike other communicable and NCDs, qualitative studies on type 2 diabetes mellitus in Tanzania are limited. However, findings from most studies to date show type 2 diabetes mellitus to be very common. Surveys in the 1980s found age-standardised diabetes prevalence of less than 1 per cent. However, another survey found a prevalence of 1.3 per cent in a rural area and 4 per cent in an urban area (Aspray, et al., 2000). According to Aspray et al. community-based studies in rural-urban Tanzania show prevalence of diabetes of 3.8 percent for men and 2.9 percent for women. Apart from gender variations, diabetes also varies along ethnic lines. For example, there is at least a nine-fold difference in the prevalence of type 2 diabetes mellitus between indigenous Tanzanians and immigrant Asians (Ramaiya, et al., 1991). As in most sub-Saharan countries, diabetes in Tanzania continues to be under-diagnosed. In marking World Diabetes Day (2005) Dr. Kaushik Ramaiya, the Secretary General for Tanzania Diabetes Association (TDA) shared his concerns on this problem. As he put it:

Tanzania has more diabetic cases than previously estimated. Approximately 350,000 to 450,000 people are diabetic in Tanzania and this is mainly type 2 diabetes. The number could even be much larger because for every diagnosed person with this disease, there are two to three more undiagnosed persons who have the health condition but are unaware of it (Tanzania Diabetes Association, 2005)

These figures demonstrate an increase in the number of affected people compared with the ones in 2000, where Tanzania was estimated to have between 300, 000 -350,000 people with diabetes (World Diabetes Day Report, 2005). Earlier on, Tanzania was estimated to have over one million people with Impaired Glucose Tolerance (IGT) (Amos, et al., 1997), a state which often precedes diabetes. Furthermore, of the newly diagnosed people with diabetes, about 80 per cent had type 2 diabetes (Tanzania Ministry of Health and Socialwelfare Report, 1997).

In a five year cohort study of 1,250 newly diagnosed people with mixed diabetes in Tanzania, (1981 to 1987) McLarty, Kinabo & Swai (1990a) found out that 60 per cent of the patients would have survived if they were on insulin treatment, while 82 per cent would have survived if they were on oral agents. The results revealed that the causes of death were predominantly associated with the body's metabolic processes at five years and other related infections. The authors concluded that in sub-Saharan Africa including Tanzania diabetes was a serious disease with a poor prognosis. Interestingly, the

Tanzanian study showed that in five years from diagnosis about 40 per cent of those patients on insulin would die, while in Europe 40 per cent of similar patients would survive more than 40 years after diagnosis (Gill, 1997). The observed increase in mortality risk associated with insulin treatment may be attributed to two plausible causes: firstly, it may be a reflection of the dangers of insulin treatment itself without proper self-monitoring of blood glucose; and secondly, it may basically be that the patients involved in this study were coming from a high-risk diabetic subgroup (Gill, et al., 2009). As in many sub-Sahara African countries chronic diabetes complications such as neuropathy, nephropathy, hypertension, and retinopathy; and acute diabetes complications such as ketoacidosis and severe diabetes-related infections have been reported in Tanzania (Gill, et al., 2009).

2.3 Cost Implications of Diabetes at the Global Level

Diabetes mellitus is an increasingly common chronic disorder, which is associated with substantial costs in terms of life and demand on health budgets globally (Arnoldi, 2004). Arnoldi observed that up to 15 per cent of national budgets are spent on diagnosis, treatment and caring for people with diabetes in the developed world. Further, Williams and Pickup (1999) reported that diabetes is an expensive disease that accounts for at least 5 per cent of health care costs in the UK, while in the USA diabetes accounts for more than US \$10 billion a year in health care cost.

2.3.1 Cost Implication of Diabetes in Developing Countries

Given the chronic nature of diabetes, the age group affected is adults of working age, the severity of its complications and the resources required to manage the condition both by the health sector and the affected individuals and their families, diabetes is a costly disease (International Diabetes Federation, 2006). Further, the International Diabetes Federation, Diabetes Atlas (2006) reported that public mechanisms for financing health care are non-existent in most developing countries, hence, health costs typically represent out-of-pocket expenditure. Moreover, a WHO report (2003), indicate that 80 percent of people in developing countries pay directly for some or all of their own medicine. In many instances, the choice is between healthcare and food or clothing. Such financial constraints inevitably result in under-consumption of care services or spending a high proportion of income on health care. Studies in India, for example, have

shown that a low-income Indian family with an adult with diabetes may spend as much as 25 per cent of family income on the care of the patient (Shobhana, et al.,2000; 2002) Simpson's (2003) survey in Tanzania shows that as the number of patients with diabetes continues to increase in developing countries, there is a very real threat that excessive demand will be placed on already over stretched healthcare systems. It is for this reason that Simpson argues that a predominantly hospital-based model for diabetes care in developing countries is unlikely to cope with the increasing demand for diabetes services.

Dagogo-Jack (2006) supports Simpson's view by observing that once diabetes has developed, it is expensive to treat because of the costs associated with routine medications, repeated clinic visits, laboratory testing, supplies for home glucose monitoring, and treatment of complications. Further, according to Dagogo-Jack local manufacturing of drugs and devices used in the management of diabetes is nonexistent or limited in most developing countries. This is a major handicap, making availability of anti-diabetes medications including insulin insecure in local pharmacies. Dagogo-Jack (2006) complements these concerns by pointing out that the situation is even more serious in many developing countries since the costs of diabetes medication and medical supplies are not underwritten by government or by third-party insurers.

Poorly managed diabetes may lead to severe complications such as end-stage renal failure, blindness, amputation and heart disease that many developing countries are ill-equipped to manage (Dagogo-Jack, 2006). Similarly, Dagogo-Jack (1991) and Pettitt, Aleck, and Bai (1988) claim that complications of diabetes are rife among patients in developing countries. Sadly, many of these countries lack the wherewithal for adequate management of target-organ dysfunction such as renal replacement therapy, renal dialysis, surgery for retinopathy, invasive cardiology and coronary rescue (Dagogo-Jack, 2006).

2.3.2 Cost Implications of Diabetes in sub-Saharan Africa

Diabetes complications pose exorbitant management costs in most sub-Saharan African countries (Dagogo-Jack, 2006). For example, renal replacement therapy (either chronic dialysis or transplantation services), laser surgery for retinopathy, invasive cardiology

and coronary rescue procedures are not routinely available, even in tertiary care centres. Limb amputation, however, is available and performed frequently on patients with gangrenous diabetes foot ulcers (Dagogo-Jack, 1991). Once the lower extremity has been amputated in a patient with diabetes in poor countries, the economic contribution of that patient virtually ceases, because of poorly developed prosthetic and rehabilitation services (Pettit, Aleck, & Bair, 1988; Prentice & Moore, 2005). Based on this grim scenario, a strong case should be made for an aggressive focus on diabetes prevention and control as a top national priority in every developing and sub-Saharan Africa country (Dagogo-Jack, 2006).

Additionally, limited data are available on the actual costs of diabetes care and management in sub-Saharan Africa (Home, 1997). Available information shows that diabetes drugs and equipment for monitoring blood glucose for most people cost more than the average income (Home, 1997). Apart from costs at an individual level, diabetes in other parts of Africa is increasingly known to have cost implications for businesses and industrial production. In Egypt, for example, (Arab, 1992) has shown the country is losing about 47 million Egyptian pounds per year worth of national production due to absenteeism from work by the working diabetes population.

Ramaiya (2005) argued that diabetes is placing an increasing economic burden on the population and on the national budget for health care in Tanzania. Similarly, in Tanzania diabetes costs have been exacerbated by lack of access to health insurance (Mamdani & Bangser, 2004). A study done in the Kilimanjaro region on the northern part of Tanzania has shown that the total direct costs to patients related to the treatment of diabetes accounts for a quarter of the individual's minimum monthly wage. This has resulted in about 46 per cent of people with diabetes having permanent financial difficulties in managing this disease (Neuhann, Water-Neuhann, Lyaruu, & Msuya, 2002). In Dar es Salaam, the commercial capital city of Tanzania, only one in five people with diabetes receive government-funded treatment for the disease (Ramaiya, 2005). This ratio indicates that some patients might not be able to access treatment, which may increase their complication rates and deaths.

Finally, Simpson (2003) has shown that a patient who can afford to self-monitor their blood glucose levels has to pay 65,000 to 150,000 Tanzanian shillings (about US \$55 to

\$130) per year which is more than 20 per cent of an annual low income salary of a wage earner just for glucose monitoring. Likewise, Neuhann et al. (2002) have shown that a monthly cost for average insulin-treatment costs about 20 per cent of the minimum monthly wage in Tanzania. Apart from the costs of drugs and other medications there are costs of transport to and from the clinic which for many patients could be a major challenge in health care seeking. For example, in a study at Teule clinic in the Tanga region in Tanzania, Simpson (2003) observed that many patients could not attend their regular clinic appointments due to lack of financial resources to pay for public transport. In highlighting the problem of transport in health care seeking among patients Simpson cited a case of a patient who was given an appointment for diabetes treatment. According to Simpson the patient never made it back to the clinic basically because he could not afford the bus fare to the hospital. Simpson adds that a patient living 200 kilometres away from the Teule clinic, for example, not only has to pay for the travel costs but has to take into consideration the time it takes to reach the clinic. The cost implications are even higher if such a patient is to take an escort with them.

2.4 Section Three: Care and Management of Diabetes Mellitus

2.4.1 Global Management of Diabetes

Management of patients with diabetes aims to save lives, eliminate symptoms, and in the long term reduce complications and other risk factors which may shorten life (Watkins, et al., 1996). Care management refers to a set of activities which assure that every person served by the health care system has a single approved care and/or service plan that is coordinated, not duplicative, and is designed to enhance cost effective and good outcomes. Effective care and management of diabetes starts with early diagnosis. Globally however, there are significant levels of undiagnosed or delayed diagnosis of type 2 diabetes mellitus (Watkins, et al., 1996). Bilski, Perz, and Kara (2005) report that the latent onset of type 2 diabetes and its slow progression may delay the diagnosis and lead to numerous complications. Similarly, Watkins et al. (1996) observed that many population-based studies have shown that, even in western countries, as many as half of all diabetic cases remain undiagnosed, though these unidentified cases are all type 2 diabetes mellitus. In the UK, for example, close to 40 per cent of people with diabetes are unaware of their health status and delay diagnosis (Watkins, et al., 1996). Similarly

in the United States there are about a million people with the disease who are not aware of it, the majority of whom are diagnosed late (Hobson, 1997).

Furthermore, studies in the USA among minority populations have shown that diseases such as diabetes, whose symptoms are not readily identifiable by many people, may lead some not to seek health care unless their condition interferes with social or personal activities including their daily living such as work and household maintenance functions (Tripo-Reimer, Choi, Kelly, & Enslein, 2001). Seeking care when functionally impaired may be viewed as a self-indulgent luxury. There is often a fear of seeking professional care unless necessary (Tripo-Reimer, et al., 2001). In addition Boulton (1995) has noted a belief among immigrants in the USA that discussing a potential health problem before it occurs may increase its likelihood of occurrence. Such a belief may hinder early detection and health-seeking behaviour particularly at the household level.

Peyrot, et al. (2005) identified several important gaps in diabetes management across developed and developing countries (Asian and European countries). First, diabetes self-management is less than optimal and is often compromised by diabetes-related distress which is often not treated. Second, health care providers often lack a good understanding of the social and psychological problems that people with diabetes face. Thirdly, team care for people with diabetes is uncommon.

Van der Plicht (1998) proposed that the first line of treatment and management in diabetes is lifestyle adjustment in order to prevent complications (Anderson et al., 1995). The efficacy of treatment is highly dependent on the self-care behaviour of the individual. Patients are encouraged to modify their lifestyles, acknowledge their susceptibility to the various health risks involved, appreciate the severity of the disease and believe in the effectiveness of health protective behaviour.

The role of education in the management of diabetes is crucial not only with reference to information about the disease and its complications, but also for provision of practical elements such as skills required for injecting insulin, the ability to self-monitor and, most importantly, empowering patients with knowledge which will enable them to change their management and adjust their treatment safely (Watkins, et al., 1996).

Therefore research into the delivery of diabetes care should seek to determine the extent

to which the health care workers provide patients and their caregivers with adequate information on the management of diabetes and the related complications. Watkins and colleagues suggest that management plans should aim for active involvement of the patient in addressing their basic care needs at the household level supported by their family and/or social networks.

Health care providers may help the patient open up and share any stressful events or situations like a change in job, sexual problems, or the death of a family member that could have an impact on their care management. The patient needs to tell their health care providers whether they are getting adequate social and family support, as these are likely to influence their care (Anderson, et al., 1991).

Diabetes is a life-long challenge that needs behavioural change, most often through education and support offered by family members and health care practitioners (Anderson, et al., 1991). Self-care management in diabetes is crucial to keep diabetes under control (Anderson, Butler, Fitzgerald, & Feste, 1995). Anderson et al. (1995) proposed that as much as 95 per cent of diabetes self-care is usually provided by people with diabetes or their families. Self-care management involves self-monitoring of blood glucose, variation of nutrition to daily needs, as well as insulin dose adjustments to actual needs (De Weerd, Visser, Kok, & van Der Veen, 1990). Rubin, Peyrot, and Saudek (1989) claim that effective self-care can only be achieved when the person with diabetes is provided with skills such as injection techniques and other diabetes medication, and an awareness of how psychological factors affect their care. Rubin et al. (1989) emphasised that learning to master self-care in diabetes is highly important and this is achieved through a process where the patient attempts a variety of self-care strategies, according to their body's unique cues, until discovering what is effective for their lifestyle and contextual situation.

Self-care for people with diabetes is complex and influenced by various socioeconomic and cultural factors. Addressing these factors can enhance self-care practices of people with diabetes (Anderson, et al., 1991). These factors need to be known by the health care professionals to enable them to be more responsive to the needs of their patients. Although health care professionals may not be able to influence some patient's related factors such as age, gender, social class and the type of diabetes and its severity, they

can influence diabetes-related knowledge, physical skills, emotional aspects, and self-efficacy in relation to the four self-care areas: self-glycemic control; adhering to a prescribed diet and drugs; self-monitoring of blood glucose; regular exercise, foot care, and abstinence from cigarette smoking and alcohol (Anderson, et al., 1991).

O'Reilly (2005) warned that a perceived loss of control related to homebound status and the need for home health services, as well as previous life experiences and familiarity with the more traditional model of medical care, may cause people with diabetes to feel ill-equipped to manage their diabetes. However, according to O'Reilly, most patients can develop the skills and confidence needed to participate fully in their diabetes management. Patients who are self-directed but physically unable to fully participate in their self-management may be willing to have a family member or other caregiver assist with the process. According to O'Reilly, it is important to allow patients to determine the involvement of others in their care. This emphasises the importance of involving family, a caregiver and/or social networks in the self-management of diabetes.

2.4.2 Care and Management of Diabetes in sub-Saharan Africa

Care and management of diabetes includes carefully managing diet, exercising, blood glucose monitoring, taking oral diabetes medication, using some form of insulin, and foot care and maintaining proper circulation in the extremities. The main task of managing diabetes is to keep the blood glucose level within a specified range to avoid short-term emergency metabolic problems stemming from hypoglycemia (blood sugar too low) or hyperglycemia (blood sugar too high) and possible long-term complications due to chronic hyperglycemia blood glucose levels represent the amount of sugar, or glucose in a person's blood stream at a given time (Walker, 2007).

Health care systems in Africa including sub-Saharan Africa face challenges in the delivery of health care (Whiting, Hayes, & Unwin, 2003). According to Whiting and colleagues, resources in sub-Saharan Africa are limited and systems are strained. Further, Whiting et al. argued that health systems in sub-Saharan Africa have evolved to treat acute, infectious diseases rather than chronic diseases. This means that the training of health staff and health service organisations are not predisposed to effective and efficient treatment of people with diabetes. For example, people with chronic illnesses

like diabetes need long-term follow-up and treatment requiring continuity of care over many years which has implications, among other things, for record keeping. The role of the person with diabetes is crucial in diet, weight loss, physical activity, taking medication, and the involvement of multiple organ systems means that the care of patients often involves many services or specialties. These characteristics imply that diabetes care services must be more coordinated and integrated than that required for acute conditions.

According to International Diabetes Federation Africa Region Task Force (2006), most sub-Saharan Africa countries have no formal organised diabetes health care delivery system at the primary health care level. Insufficiently trained personnel and doctors at primary and secondary health facilities generally manage people with diabetes. Additionally, diagnostic equipment such as glucometers with appropriate strips and sphygmomanometers are frequently unavailable, and drugs are often not supplied in adequate quantities. International Diabetes Federation Africa Region, Task Force (2006) states that few health facilities can provide comprehensive tertiary care. The Federation's type 2 diabetes clinical practice guidelines for sub-Saharan Africa (2006) suggest that where diabetes clinics do not exist, clinics should be established and integrated into the health care system. Additionally, where the clinics do exist, an assessment of the quality of care provided should be done and changes instituted to rectify any deficiencies identified.

Further, the clinical practice guidelines observed that in certain countries in sub-Saharan Africa, traditional healers are integrated into the primary health care system. However, it was suggested that should the patient choose to utilize a traditional healer services, it is imperative that the patient be counselled by the health care provider to continue monitoring of glycaemic control and other process measures of diabetes management (International Diabetes Federation Africa Region Task Force, 2006)

Similarly, the clinical practice guidelines for sub-Saharan Africa proposed the minimum staffing and equipment requirements at each level of health care such as primary, secondary and tertiary for the appropriate management of diabetes mellitus. In addition, the clinical practice guidelines proposed what should be done and when at each health care level (Appendix 1). However, delivering anything like ideal diabetes care in sub-

Saharan Africa in particular presents enormous problems influenced by socioeconomic, cultural and geographical factors (Mbanya & Gill, 2004). Similarly, Tshabalala (2001) states that a wide diversity of beliefs, cultures, religions, traditions, educational backgrounds and economic structures have made management of diabetes in South Africa challenging. Mbanya and Gill remark that in Africa, socioeconomic considerations dictate that costs of diabetes treatment should be kept to a minimum. The aim should be to control plasma glucose with the least expensive but effective and not necessarily latest anti-diabetes drugs. Mbanya and Gill propose that the goal for diabetes management should be set for each individual based on the patient's clinical status, social, psychological, cultural and financial background, and willingness to participate actively.

Neuhann et al. (2002) state that diabetes care and management in developing countries and sub-Saharan Africa must address the specific background of the patient population, their needs, the medical problems and the social constraints. Moreover, they argue that active participation of the patients in diabetes management is required to help overcome some of these difficulties. Based on a survey finding in Tanzania, Simpson (2003) concluded that biomedical health systems in many developing countries and sub-Saharan African are undeveloped and would not be able to provide a service for monitoring and ensuring a constant supply of diabetes drugs (insulin) and other diabetes devices. Further, Simpson argues that diabetic care cannot just consist of dispensing more diabetes drugs and devices: "an increase in monitoring, education and general follow-up for patients is required to ensure that management is adequate" (Simpson, 2003).

2.4.3 Challenges in Care and Management of Diabetes in sub-Saharan Africa

2.4.3.1 Limited Financial Resources

One of the major challenges for diabetes care services delivery in sub-Saharan Africa is inadequate financial resources for purchasing diabetes drugs and related services and self-monitoring of blood glucose. (Mbanya & Gill, 2004; Smide et al. 2002). Mbanya and Gill claim that although blood glucose testing is more accurate than urine testing, and normally preferred, urine testing is still a useful tool in diabetes management in Africa. For example, on testing the reliability of urine glucose tests for monitoring

diabetes control in Ethiopia, Feleke and Abdulkadir (1998) concluded that urine glucose testing provides reliable information for people with diabetes who cannot afford the cost of blood glucose monitoring. Feleke and Abdulkadir went further to argue that management of diabetes poses a serious challenge in Africa because of inadequate health care systems and the cost of medications, especially insulin.

A study in Ethiopia showed that the main problems pertaining to diabetes care management are the recurrent shortages and rising costs of drugs, and illiteracy (Abdulkadir, 1997). The high cost of diabetes management has also been reported in Cameroon (Mbanya & Sobngwi, 1997). Measuring HbA1c, according to Gill (1997), is difficult and expensive, and few clinics in Africa have this facility. Home glucose testing has been successfully introduced in some parts of Africa (Gill et al., 1986) but is generally far too expensive.

Rolfe et al. (1992) have shown that glycaemic control is commonly poor and diabetes drugs are expensive among patients in Gambia. This problem is compounded by non-adherence, especially amongst type 2 diabetes mellitus patients. The researchers note that hot, humid conditions mean that tablets and strips for urine testing rapidly deteriorate and the cost of purchasing them from local pharmacists is prohibitive. In light of this observation they proposed forward planning to ensure a better supply of drugs and other related supplies for people with diabetes, while stepping up intensive patient education to reduce patient morbidity and mortality.

2.4.3.2 Poor Accessibility and Affordability of Diabetes Drugs

While healthcare coverage is important as can be seen in the next section, its effectiveness is limited unless there is accessible and affordable drugs, particularly insulin. Poor and erratic availability of drugs such as insulin in health facilities has been a problem in most sub-Saharan countries (Alberti, 1994; Gill, 1994; McLarty, Swai, & Alberti, 1994). Insulin is often unavailable in half of the large city hospitals in sub-Saharan Africa, and only five countries reported regular insulin availability in rural areas (International Diabetes Federation ForceTask, 1997). Supply of such drugs in most developing and sub-Saharan countries depends on where the patient lives and the affordability of insulin (Mbanya & Gill, 2004). According to Mbanya and Gill the

chronic lack of access to insulin is due to a number of factors. First, in some countries, insulin preparations are not included in the national formulary and are therefore not available on a regular and uninterrupted basis. In most sub-Saharan countries insulin is not one of the drugs on the essential drug list (Mbanya & Gill, 2004; McLarty et al., 1994; Savage, 1994). Secondly, in the absence of these drugs through the hospital pharmacies, patients have to buy them through the private outlets where they are far more expensive. In cases where there has been an introduction of cost-sharing, and in the absence of medical insurance, such costs are a burden on patients and their families. For example, the cost of outpatient health care for diabetes in Tanzania was estimated at US\$229 per person per year, of which some two-thirds (US\$ 156) was the cost of insulin (Chale, Swai, Mujinja, & McLarty, 1992). This is equivalent to about six months of a family's income in most developing and sub-Saharan African countries and may explain the problem of poor adherence to treatment, and lack of follow-up among patients, often leading to diabetic complications (Mbanya & Gill, 2004).

2.4.3.3 Access to Diabetes Care Services

Health care coverage is another major factor influencing timely accessibility to care and treatment for diabetes in sub-Saharan Africa. Amoah (2002) observed that in Ghana some people with diabetes had to travel more than 300 kilometers to receive care. Amoah state that it is not surprising, that many could not attend these centres and were therefore seen instead at facilities that had no trained diabetes healthcare personnel. He concludes that despite some advances in the management and treatment of diabetes, people in Ghana are still dying due to poor access to timely and appropriate medical treatment. Similarly, in a survey in Northern Ethiopia, Alemu et al. (1998) report that treatment for diabetes in Ethiopia is only available in hospitals, hence many patients must travel great distances to obtain diabetes drugs and education. The study observed that half of the patients coming from rural areas travelled more than 120 kilometres to a health facility while a quarter came from more than 100 kilometres away and a few from more than 180 kilometres away. Based on the findings, it is likely that patients from distant areas might have been seeking health care from somewhere else, most likely from traditional healers. Some may have basically died from the disease before reaching a health facility.

Further, studies in Uganda have shown that diabetic biomedical care facilities are inadequate due to increasing numbers of new patients and the fact that people with diabetes are living longer (Otim & Nambuya, 1997). Likewise a study in Ivory Coast, show the absence of appropriate infrastructure, diabetes education, and drug supply to be among the major issues in improving diabetes care and management (Lokrou, 1997).

Amoah et al. (1998) in Ghana and Levitt et al. (1996) in South Africa point out that although most patients are reported to be seeking care at primary health care clinics, in most areas these clinics are village dispensaries that are poorly equipped and staffed. The specialised diabetes clinics in some of the large cities are too expensive for the ordinary person. This poor coverage, inaccessible health care (Kagee, Le Roux, and Dick, 2007) and lack of government commitment to NCDs “due to the unfinished agenda on communicable diseases and the AIDS pandemic” (Levitt, et al., 1996) makes delivery of diabetes care services in most sub-Saharan African countries far from adequate. Moreover, both studies state that people with diabetes travel long distances to seek appropriate care from specialists who work mostly in large teaching hospitals. Mbanya and Gill (2004) argue that type 2 diabetes mellitus can usually be well managed in primary health care settings with properly trained staff and expertise in diabetes, using appropriate treatment protocols if the government has a strong commitment to make it happen.

Most diabetes clinics and specialists are usually at central and/or referral teaching hospitals, making them less accessible for the majority of the rural population. People with diabetes nevertheless travel hundreds of miles to such centres (Gill, Huddle, & Krige, 1993), or even move to local townships, basically to obtain care not available or not perceived as available locally. By contrast, in Malawi about 80 per cent of the population is estimated to live within eight kilometres of a care facility and utilisation is high (Harries et al., 1993).

Bensouda (1997) reports that primary care services for diabetes are highly inadequate in Morocco. Bensouda point out that screening is only occasional, and diagnostic criteria are not standardised. Further, the researcher notes that basic education is not given, particularly on prevention and control of diabetes. As in most sub-Sahara African countries researcher also noted great disparities between rural and urban communities in

access to quality care for people with diabetes. Constraints around access to health care due to lack of financial resources have also been reported in Cameroon (Mbanya & Sobngw, 1997). Similarly, Kiawi et al. (2006) in Cameroon observed that people often seek alternative or complementary treatment from folk healers and other sources, mainly because they cannot afford to pay for health services.

2.4.3.4 Inadequately Trained Care Providers for Diabetes

Another major obstacle in managing type 2 diabetes mellitus in sub-Saharan Africa is inadequately trained health care professionals and public health educators, although such personnel are beginning to appear in some referral and regional hospitals. However, they are still lacking at the district and primary health care level facilities where the majority of the rural population is likely to seek health care (Gill, 1997).

Other studies have shown that most health facilities in sub-Saharan Africa (Peyrot, et al., 2006) lack health care providers with trainings in diabetes management, thus compromising the quality of care for patients. Findings of low levels of professional competence in managing type 2 diabetes mellitus have been observed in Uganda by Otim and Nambuya (1997). They recommended that health care providers, particularly nurses, should be instructed in the proper method of routine blood pressure measurement for those people with diabetes with hypertension. Otim and Nambuya also recommended that education should be improved because many people with diabetes basically discontinue their antihypertensive treatment once they feel better, or basically because they have not been given correct instructions about the need for seeking treatment for their hypertension.

The traditional African diet is rich in carbohydrates (i.e. rice, corn or flour, sorghum and millet, roots and tubers, yams, plantains, potatoes and cassava) accompanied by meat, fish or vegetables, which is ideal for patients with type 2 diabetes (Mbanya & Gill, 2004). However, the traditional diet is changing to a more western influenced diet high in fat and kilojoules. Such changes in diet contribute to the diversity and complexities of diets across sub-Saharan Africa countries, which when coupled with a lack of dieticians in most health institutions, make it difficult to prescribe a standard for the management of people with diabetes. The nurses or doctors who are not adequately trained to provide

complex dietary advice to people with diabetes are therefore responsible for supervising the diet of patients (Beran & Yudkin, 2006; Kaushik, 2005). Successful adherence depends greatly on the acceptability of the prescribed diet and on continuous counselling. Watkins et al. (1996) note that diets need to be tailored to suit individual patients and their habits in terms of physique, occupation, cultural habits and religious beliefs.

2.4.3.5 Inadequate Health Education

Inadequate provision of patient education, to help those with diabetes to look after themselves is also reported to pose a major challenge in most sub-Saharan countries (Gill, 1997). Diabetes education is the cornerstone of successful diabetes treatment. It is particularly important in a continent where diabetes is believed to be caused by supernatural forces and evil spirits (Kofi & Anarfi, 1997). Parry (2004) and his colleagues argue that lack of diabetes educators in most African countries, scarcity of diabetes specialists and multidisciplinary support teams, low patient education levels along with low literacy, poor treatment adherence, adverse cultural beliefs, and a lack of reliable and affordable supplies of medication and monitoring equipment, all combine to limit good diabetes management outcome.

Tshabalala (2001) proposes that diabetes education in South Africa should be done in a holistic manner to empower people affected with diabetes—for example, patients, relatives, and the community—with relevant information, knowledge, skills, and motivation for self-care, as well as freedom of choice and responsibility. Education can be started informally either at outpatient clinics or on admission to hospital, as well as during urine or blood glucose testing, and when giving medication (Mbanya & Gill, 2004). Mbanya and Gill emphasise that patients should be encouraged to join existing diabetes associations or given help in creating one through which continuing diabetes education and counselling can be provided. Diabetes education in Africa should involve people with diabetes, families, health care staff and communities, and should be considered as an integral and vitally important component of diabetes treatment and management.

According to Gill (1997), if diabetes care is to reach the “grassroots”, then care needs to be focused at the primary health care level, along with efficient administration and education of primary health care staff. Likewise, Gill (1990) proposes that training, particularly on type 2 diabetes mellitus, should come down the diabetes care and management pathway, that is from teaching hospital experts to district hospitals and from there to primary health care. Studies in Cameroon report that the absence of trained diabetes health care providers and affordable health services has led to the forfeiture of the rights of people with diabetes to relevant education, leading to high diabetes related morbidity and mortality (Mbanya & Sobngwi, 1997).

2.5 The Health Care Delivery System in Tanzania

The health care delivery system in Tanzania is organised according to government administrative structures consisting of seven key layers, starting with treatment abroad, national referral/ consultant hospital, followed by regional hospital, district hospital, the health centre, the dispensary and the village levels as described below and summarised in the pyramid in Figure 2.3. According to this structure diabetes services has been non-existent at the village, the dispensary, health centre and district level. The regional hospital level have been providing diabetes services as apart of their routine out-patient services, which were not adequate in meeting the patients needs.

1. The Village Health Post: This is the lowest level health care delivery facility in the country. It essentially provides preventive services which can be offered in homes. Usually each Village Health Post has two Village Health Workers chosen by the village’s government and given brief health care training to help them with their responsibilities.

2. The Dispensary: This is the second level of health care service delivery which caters for one ward consisting of about 6,000 to 10,000 people. Dispensary staff also provides first aid treatment and supervisory services to all the Village Health Posts in the ward.

3. The Health Centre: A Health Centre is expected to serve 50,000 people, approximately the population of one administrative division. Structurally a division has

a number of wards. As in the case of the dispensary, the health centre staff provides supervisory services to all the dispensaries in their division.

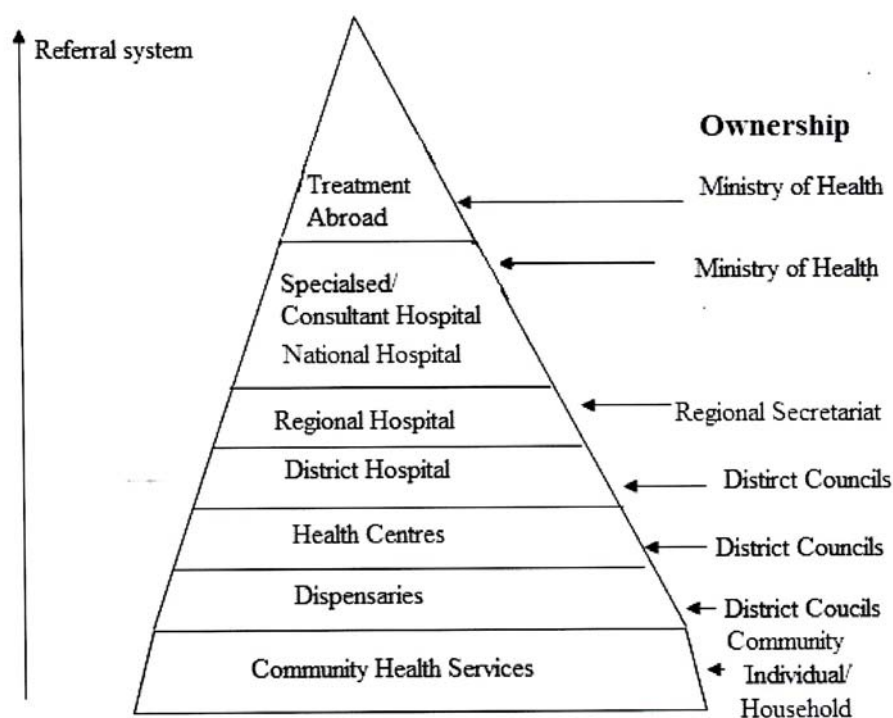
4. District Hospitals: The health sector reform initiatives have decentralised the coordination of health care delivery services to the districts, giving their leadership both the technical and managerial oversight. For effective provision of referral health care services each district has one designated hospital managed by a district medical officer and mandated to support health care centres in the district. For those districts which do not have a government run hospital with defined referral status, the government normally negotiates with existing religious organisations to designate one of their hospitals in the district to deliver these services. Once designated these hospitals then receive government financial support for their activities.

5. Regional Hospitals: Every government administrative region is supposed to have a designated regional hospital managed by the regional medical officer. These regional hospitals provide supervision and referral care for the district hospitals. Although the regional hospitals have for a long time been providing diabetes services as a part of their routine out-patient services, these have been far from adequate in meeting the needs of the patients. The health care providers have inadequate diabetes training (Ramaiya, 2006) and because diabetes services have been provided within the general care services some of the patients needing attention did not receive any. This structure of health care access to diabetes services is limited in urban areas and almost non-existent in semi-urban and rural areas (Ramaiya, 2006).

6. National Referral/Consultant Hospitals: These hospitals provide medical consultants with highly specialised skills that are rarely available at the regional and district hospitals. They provide the highest level of referral services in the country. Currently there are four referral hospitals—Muhimbili National Hospital, Kilimanjaro Christian Medical Centre, Bugando Hospital, and Mbeya Hospital—which serve the east, north, west and south of the country respectively. Prior to 2004, special diabetes services were only available at these four main referral hospitals on the Tanzania mainland and one in Zanzibar and Pemba. However, as mentioned earlier, in 2004 a project run by the Tanzania Diabetes Association established diabetes clinics in these referral hospitals and stocked them with diabetes drugs and related services.

7. Treatment Abroad: In cases where the patient's medical condition requires more specialised skills and equipment beyond that which is available in the country, a referral for treatment abroad may be recommended. Since treatment outside the country is always expensive, and thus beyond the individual's or their family's resources, the government normally provides funding. However, before the government can do that it has to be convinced that the patient's condition requires referral outside the country. To this end, the government has developed guidelines that must be followed before a patient can be sent abroad for treatment. These include a strong recommendation from a panel of medical specialists from the National Referral Hospitals.

Figure 2.1 Tanzania Health Referral System



Source: Tanzania Ministry of Health and Social Welfare (2007)

The Ministry of Health and Social Welfare (MoHSW) remains the principal institution for the delivery of health care services. The ministry of health is responsible for coordinating, monitoring and evaluating health services provided through its health facilities at all levels, and those provided by non-governmental organisations (NGOs) and private institutions. The ministry of health for the mainland has four major directorates: Preventive Health Services, Curative Health Services, Human Resource Development and the Directorate of Planning. Within the ministry of health, the

management of diabetes mellitus and hypertension is under the mandate of the NCDs Unit, which is situated in the Directorate of Preventive Health Services. The health care structure in Zanzibar has more or less similar structures with minor variations at the national, regional and district levels due to the size of the region (Tanzania Ministry of Health and Social Welfare Report, 2007).

Following the various reforms that have been going on in Tanzania, the Ministry of Health and Social Welfare and the Ministry of Regional Administration and Local Government (MRALG) have found much in common, particularly in the implementation of the Health Sector Reform, the major thrust of which is to decentralise the delivery of health services to the districts. Through these reforms, health management is placed under the elected District Councils and District Health Boards, which in turn are answerable through the regional government structure to the Ministry of Regional Administration and Local Government. Under the ongoing Health Sector Reform and Local Government Reforms, the Ministry of Health is responsible for running the consultant and referral hospitals while the regional administration and local government authorities have the responsibility of running regional and district hospitals, primary health facilities, and hospitals and health centres operated by NGOs and individuals from the private sector (Tanzania Ministry of Health and Social Welfare Report, 1999).

Over the years, the public/private mix in the provision of care services has been growing. In both Tanzania mainland and Zanzibar, NGOs, including those operated by religious organisations, supplement services provided by the government health care structure. For example, around 40 per cent of care services are provided by NGOs, particularly those operated by religious organisations under the umbrella of the Christian Social Services Commission. The private and public sectors provide 15 per cent and 45 per cent of the remaining care services respectively. Estimates show that 72 and 92 per cent of Tanzanians live within five and ten kilometres of a health facility respectively, although there are some variations in terms of the quality and the range of services provided (Tanzania Ministry of Health and Social Welfare Report, 1999).

Following the economic recession of the late 1980s and early 1990s, the care services provided by the government health facilities deteriorated significantly, while those

provided by NGO facilities continued to remain strong. Over the years, the structural state of the buildings and associated infrastructure, and the quality of services being provided by the existing 195 hospitals, 302 health centres, and 3,500 dispensaries deteriorated significantly hence requiring major renovations. The laboratory services, for example, have received scant attention and most blood bank services in some regions like Shinyanga are far from adequate. However, realising the poor quality of care services being provided by the public sector, the government, through the poverty reduction initiative, running parallel with the health sector reform, has placed care services on its priority list, followed by education and agriculture (Tanzania Ministry of Health and Social Welfare Report, 1999).

Tanzania has a wide range of health care workers appropriate to the specific levels of service delivery. All the health facilities are provided with regularly supplied essential drug kits that are intended to have the entire range of required drugs for common community health problems with limited diabetes drugs. However, shortages of drugs, equipment and other essential supplies are reported in some health facilities for a number of reasons, including poor drug management. The recent introduction of a cost sharing system for care services has also made care services inaccessible to some community members (Tanzania Ministry of Health and Social Welfare Report, 1996, 1999).

2.5.1 Challenges in Delivery of Diabetes Care Services in Tanzania

The overall objective goals of diabetes management in Tanzania are: to keep blood glucose levels as close to normal as possible; to relieve symptoms and prolong life of people with diabetes; to prevent infections, and acute metabolic complications and long-term complications such as retinopathy, neuropathy, and nephropathy. However, delivery of diabetes services in Tanzania has been facing a number of challenges as highlighted below.

2.5.1.1 Limited Financial Resources

Simpson (2003) in Tanzania noted that 88 per cent of patients did not monitor their own blood glucose levels, and even those few who did, did so once a week on average. The

remainder of the patients usually attended a pharmacy or an outpatient dispensary at a cost ranging from 800 to 2,500 Tanzania shillings (US \$0.08 to \$2.50). Due to the high cost of drugs and related services, patients reported that they did this once a month or even less frequently. According to Simpson, this is a far cry from the recommendations that patients should be self-monitoring their blood glucose levels at least four times per day. Blood glucose monitoring in Tanzania is expensive and basically not feasible to do at home. As Simpson stated, urine testing remains the simplest, cheapest and least invasive method of blood monitoring. However, she observed that despite this, the vast majority of patients neither tested themselves at home nor had their readings taken at a pharmacy or dispensary. Simpson (2003) also highlighted the fact that in Tanzania basic information was lacking among patients including an understanding and acceptance of what diabetes entails.

Further, in Tanzania, only about 100,000 out of 450,000 people with diabetes have access to affordable treatment (Ramaiya, 2005). It is believed that the cost of medical care deters some patients from seeking care for diabetes (McLarty, Phillitt, Swai, & Alberti, 1997) forcing others to seek alternative care services from the traditional healers (Simpson, 2007). This behaviour is reported to have a negative effect on the overall management of diabetes mainly because these patients only turn to the biomedical care services in a crisis after failing to get relief from traditional healers. Unfortunately, this move is made at a time when their health conditions have significantly deteriorated making treatment highly difficult.

2.5.1.2 Poor Accessibility and Availability of Diabetes Drugs and Related Services

Persistent shortages of drugs and equipment for diagnosis and treatment of diabetes and other diseases are common in most public health facilities in Tanzania (Green, 2000). This is due to many factors, including: a shortage of imported drugs due to lack of foreign exchange; a lack of locally produced drugs for similar reasons; poor storage and distribution facilities and lack of quality assurance (Kasilo & Mwaluko, 1992). Most dispensaries and health care centres in Tanzania are not well stocked with relevant drugs (Ngonji, 2001). Consequently some patients go straight to a referral hospital for diabetes care rather than seeking care at dispensaries or health care centres, while others seek care through traditional healers (Walraven, 1996). In Zanzibar, people with

diabetes were reported to seek care for diabetes at referral hospitals because there were no blood glucose measuring strips in the village dispensaries or pharmacies (Simpson, 2003). Similarly, in a survey carried out in Tanzania, Simpson, (2003) observed that access to required diabetes drugs was a significant problem:

Mr. K. is a 49 year old man who was diagnosed with diabetes in 1992. He himself acknowledged that money was not a problem: the problem was basically that he could not get hold of insulin often enough due to lack of supplies in medical centres.

In Pemba, the sister island of Zanzibar, Yudkin (1998) found that there is no system in place to ensure drug purchasing and monitoring of drug availability. He noted that due to poor stock-keeping about 6,100 bottles of 100 iu Actrapid insulin were found in stock but had expired. Similarly, according to the Tanzania Food and Drug Authority (TFDA), in 1999, 1,000 vials of insulin were found to have expired in Ilala hospital in Dar es Salaam (Tanzania Food and Drug Authority Report, 2000). Storage of insulin was found to be a problem for patients, during transport, and at the clinic level (Simpson, 2003).

A survey in Tanzania (Smide, Lukwale, Msoka, & Wikblad, 2002) reported that people with diabetes were dissatisfied with the lack of drugs and wanted more diabetes education. Their study revealed that few Tanzanian people with diabetes could monitor their own blood glucose. The study suggested that diabetes education in Tanzania should concentrate more on providing basics diabetes information and knowledge. Likewise Simpson (2003) observed that little time is devoted to providing information and educating patients about diabetes care as illustrated by the following description of a patient from Mnazi Moja Hospital in Zanzibar, Tanzania:

He is a 24-year old man who works as a vegetable farmer and was first diagnosed with diabetes two months ago. He is first time attending at the clinic. After waiting in the clinic for two hours to be seen, he was handed one vial of free 40IU actrapid insulin and told to come back in a week's time. He received no information regarding his diabetes and its management. When she asked him specific questions it became apparent that he had not been shown properly how to inject himself, and certainly did not know what to do if he had a low or a high blood sugar level. In addition, he had not been told what normal blood glucose should be. He was only told that he was required to take insulin three times a day and the doses to take. He had no needle and the syringe he had was a 10mls. Yet, he had not been taught how to use it (Simpson, 2003).

As far as storage is concerned, the vial remained in his pocket until the following visit because he had not been told otherwise (Simpson, 2003). Further, most patients do not

have refrigeration facilities hence they are unable to store insulin at home. To improvise, some patients are reported to use clay pots filled with cold water to store insulin, which are not as effective in ensuring the quality of the drug.

2.5.1.3 Inadequately Skilled Diabetes Health Care Providers

Inadequate skills among health care providers have also been found to contribute to delays in the diagnosis of diabetes (Ramaiya, 2005) in Tanzania. Although new diabetes clinics have been established in all regional hospitals through funding from the World Diabetes Foundation and other partners including Novo Nordisk and the Vienna Diabetes Association, the capacity of health care workers to diagnose and manage diabetes at the primary health care level remains very limited (Ramaiya, 2005).

Insufficient skills, for example, have been reported to contribute to the failure of health care providers to properly diagnose diabetic ketoacidosis in patients, resulting in many patients needing to be put under insulin treatment (Rwiza, Swai, & McLart, 1986). This and other related findings led Simpson (2003) to conclude that in some sub-Saharan African countries including Tanzania, simple models of diabetes management may need to be established at the primary care level to guide health care providers on proper diagnosis and management of this disease. Similarly, Simpson (2003) and Rosenquist and Luft (1988) noted that the health care focus on communicable diseases may have led Tanzania to provide care services for NCDs like diabetes on an ad hoc basis, often through community workers with limited knowledge and training in diabetes care.

Furthermore, there are insufficient numbers of trained health care professionals who can handle diabetic cases in most of the health facilities. For example, the Diabetic Clinic at Muhimbili National Hospital (MNH) in Dar es Salaam, which was opened in March 2003, is staffed with only three nurses and very few diabetes specialists. This number of staff is far from adequate to cope with the large number of patients who flock into the centre with serious complications (Personal communication with Nurse Diabetes Educator MNH, 2007).

In Pemba, Tanzania, Yudkin (1998) noted that there is only one qualified pharmacist in the whole island, which has a population of one million people (Bureau of Africa Affairs, 2008). In Tanzania Ramaiya reported that in early 2004 only about a third of

health care providers at regional hospitals were sufficiently conversant with key components of the diagnosis and treatment of diabetes and its complications. Health care workers also had limited knowledge about the nature of the education they needed to provide to their patients about diabetes (Ramaiya, 2005).

2.6 Health-seeking behaviour in developing countries and sub-Saharan Africa.

“To begin to picture the resources and constraints ... the way the actor experiences them, is to take a crucial step towards understanding why, and how people do what they do” (Wallman and Baker, 1996, p.678).

The term health-seeker refers to a person who goes from place to place in the interest of their health (Craigie & Hulbert, 1940). Health-seeking behaviour refers to any activity undertaken by individuals who perceive themselves to have a health problem or to be ill, for the purpose of finding an appropriate remedy (Kasl & Cobb, 1966). Health-seeking behaviour should be distinguished from the broader concept of “health behaviour”, defined by Kals and Cobb (1966) as any activity undertaken by individuals who see themselves as healthy for the purpose of preventing disease or detecting it at an asymptomatic stage.

Although specific studies on health-seeking behaviour for type 2 diabetes mellitus may be limited, findings from many studies on health-seeking behaviour on acute and chronic diseases in developing countries, sub-Saharan Africa and Tanzania have been used to guide the current study. Researchers have long been interested in what facilitates the use of health services, and what influences people to behave differently in relation to their health. Health-seeking behaviour is important because it is one of the factors determining uptake and outcomes of health care. This has led to a plethora of studies addressing particular aspects of this debate within various social and cultural settings (MacKian, 2002). MacKian states that health-seeking behaviour concerns factors which enable or prevent people from making ‘health choices’ in their lifestyle and in their use of medical care and treatment. Health-seeking behaviour is not just a one-off isolated event (Uzma, Underwood, Atkinson, & Thackrah, 1999). Uzma et al. observe that the process of responding to ‘illness’ or seeking care involves multiple steps and can rarely

be translated into a simple one-off choice or act, or be explained by a single model of health-seeking behaviour. Health-seeking behaviour is specifically a response to perceived ill-health and it should be looked at within its cultural context, since it and related activities are influenced by culturally recognised signs and symptoms and their associated interpretations. This section examines the influences behind health-seeking and health related behaviour among patients with type 2 diabetes mellitus.

2.6.1 Awareness and Knowledge about Diabetes Mellitus

Among the many factors that influence health-seeking behaviour for diabetes care and management is the overall awareness and knowledge that the patient and their caregivers and/or social networks have about diabetes signs and symptoms. Low levels of awareness and knowledge about chronic health conditions have been blamed for delays in seeking care in biomedical care facilities. The level of awareness and knowledge about diabetes is noted to be low among many patients. In marking World Diabetes Day in 2003 the president of the International Diabetes Federation noted with great concern that in a world of expanding waistlines, increasing urbanisation, and rising health costs, awareness and knowledge of diabetes and its complications, particularly in developing countries, remained low among many populations. He went on to state that awareness was also low among health care providers, and people who live with the condition.

Furthermore, in a qualitative study of people without diabetes in Cameroon, Kiawi et al. (2006) noted that awareness and knowledge about diabetes, its causes, clinical course, and complications were limited. Additionally, perceptions of the threats associated with diabetes were reported to be low and lifestyle modifications required for diabetes management were also unknown (Kiawi, et al., 2006). In Tanzania, Ramaiya (2005) reported that more than two thirds of patients with diabetes at a regional hospital were unaware that their problems were related to high or low concentrations of glucose in their blood and did not know that they could or should monitor their sugar levels themselves. McLarty's (1990) survey in Tanzania noted that out of the 213 patients with duration of classical symptoms ranging from one week to five years, only 9 percent suspected that their symptoms might have been related to diabetes. About 91 percent of the patients said that they did not know what was wrong or attributed their symptoms to

such conditions as old age, intestinal worms, anaemia, fever and accompanying general malaise, as well as witchcraft. In Athaide's (1986) survey involving newly diagnosed people with diabetes with classical symptoms such as polyuria, polydipsia and weight loss, the patients were not aware of diabetes before their diagnosis.

A survey conducted by Simpson (2003) in Tanzania revealed that people with diabetes were at times unaware of the complications and seriousness of diabetes if left untreated. In the same vein, late diagnosis due to delayed health care seeking has also been attributed to poor patient knowledge about diabetes and associated misconceptions (McLarty, et al., 1997). McLarty et al. for example, noted that most people with diabetes in tropical Africa including Tanzania present with classical symptoms of diabetes, but often seek help only when infection or other complications have developed. Sometimes the clinical combination of weight loss, frequent visits to the toilet and or presence of an abscess may lead to the erroneous conclusion that the patient has AIDS. This erroneous conclusion may delay patients and relatives seeking health care as McLarty observed in the following case:

A 45-year old businessman, living in one of the regions in Tanzania where AIDS is highly prevalent, noted that he was losing weight and passing large volumes of urine. When his friends observed his obvious weight loss they assumed that he had the "New" disease (AIDS), and this feeling was communicated to the patient. As a result the patient became extremely depressed and contemplated suicide. One friend went to visit the patient and witnessed his frequent visits to the toilet, not knowing if he was going to urinate or because of diarrhoea. He tried to persuade the patient to go to the hospital but he refused, probably because he was afraid or felt that nothing could be done. The friend then brought a local teacher who was able, eventually, to persuade him to go to the hospital, where diabetes was diagnosed (McLarty et al., 1997).

McLarty et al. (1990) and Rwiza et al.(1986) surveys in Tanzania found the low level of awareness about diabetes has major implications for the overall management of diabetes. Their findings show that most deaths related to diabetes could be prevented through public education about diabetes while improving patient detection, management, and follow-up.

Simpson (2003) suggested that health facilities and/or clinics should aim at educating patients on a whole range of topics about diabetes mellitus within six to eight months of diagnosis. Public awareness and knowledge about diabetes in Tanzania is limited, and

as a result, there are many Tanzanians in the urban /rural areas who may have diabetes without being aware of it. Like any other disease, managing diabetes becomes more difficult when diagnosis is delayed. When this is coupled with limited patient education at the health care facilities particularly on proper drug use, many patients end up facing great problems in adhering to their medical regimens and consequently consider the use of alternative care services (Personal communication with TDA, 2007).

In South Africa a qualitative study aimed at gaining in-depth information about patients' knowledge and attitudes about diabetes. Van Rooijen et al. (2001) reported low levels of awareness and knowledge about diabetes among people with low education levels. Van Rooijen and colleagues suggested that health care providers need to be well informed about diabetes and pass on such information to their patients to enhance prevention, control and/or better management of diabetes after diagnosis. In their study patients reported substantial psychosocial problems in coping with diabetes, indicating the need for counselling by health care providers. The study recommended that patients should be educated about the basic physiology of diabetes, insulin action and causes of hypoglycaemia. Similarly, patients should be motivated to increase physical activity on a continuous basis. Finally, the study called for further culturally sensitive studies aimed at identifying health beliefs, motivation for the control of diabetes and environmental and personal barriers to exercise and physical activity.

Other studies have indicated that lack of awareness and knowledge in other chronic diseases influences health-seeking behaviour. For example, in their qualitative study of patients with breast lumps in South Africa, Mdongolo et al. (2003) found that lack of knowledge and misconceptions associated with breast lumps influenced patients to seek care through traditional healers prior to seeking biomedical care services. According to Mdongolo et al., by the time patients sought medical treatment their condition had progressed to advanced stages of cancer with a poor prognosis and outcomes. A qualitative study in Tanzania on health-seeking behaviour for TB diagnosis and treatment (Nguma, 2003) revealed that health-seeking behaviour was influenced by a range of factors which can be categorised into themes including: awareness, perceptions and knowledge about TB; stigma; socio-economic factors and/or access to health services; and patients' perceptions of biomedical care.

2.6.2 Social and Cultural Beliefs

Culture refers to the organised system of knowledge and beliefs through which people structure their experience and perceptions, formulate acts, and choose between action alternatives (Keesing & Strathern, 1998). Hollinger (2005) in Tanzania noted that beliefs regarding disease causality tend to be consistent with cultural and personal values, which consequently shape patients' decisions for action. Disease causality may be linked to an action of a family member, something in the community or to a supernatural agent. Therefore, health-seeking behaviour clearly varies for the same individuals or communities when faced with different illnesses (MacKian, 2002). For example, Bedri (2001) highlights contrasting pathways to care for women in Sudan when faced with abnormal vaginal discharge, as opposed to malaria. For the former, the woman is bound far more by rituals and obligations, such as shaving prior to examination, and being accompanied to a medical consultation by a husband.

It is believed that cultural factors influence health-seeking behaviours in chronic diseases. For example, in South Africa a qualitative study among the Xhosa women with breast lumps (Mdongolo, et al., 2003) found that the cultural perceptions of the significance of the female breast, the meaning of a breast lump and the cause of illness influenced health-seeking behaviours.

Type 2 diabetes is asymptomatic or has relatively non-specific symptoms. Thus, symptom recognition and consequent action is only one part of the picture, while health seeking for screening for asymptomatic people is another. Who is consulted once symptoms are recognised will depend on pre-existing beliefs about the likely meaning of the symptoms, disease causation, and the efficacy of different approaches such as traditional healers, spiritual methods, or biomedical medicine for the condition and the availability and accessibility of the various potential sources of help. Studies in Swaziland, Nigeria and Mozambique suggest that where symptoms are thought to signify natural imbalances, infidelity or some form of spiritual intervention, traditional healers may be viewed as the most appropriate initial point of contact for help (Green, 1992; Piot and Tezzo, 1990; O'Toole, 1993). However, there is no simple model relating to beliefs and actions. People frequently seek more than one form of health care during the course of an illness.

Steen and Mazonde (1999) found that about 95 percent of patients with TB in Botswana visited a biomedical care facility as a first step. However, after initiating biomedical treatments, 47 per cent then went on to visit a traditional or faith healer as well. They emphasised the importance of social and cultural factors in contributing to the outcomes of TB control. They state that for these patients, TB is seen as a ‘European disease’ that will respond well to ‘biomedical medicine’. Nonetheless, a traditional healer is also consulted to explain the ‘meaning’ of the disease for that particular person. As they put it:

There is an increasing tendency to use biomedical medicine as a ‘quick fix’ solution, whereas traditional medicine is utilised for providing answers that may be asked about the meaning of the misfortune, and to deal with ‘real’ causes of the illness” (Steen and Mazonde, 1999, p. 170).

Similarly, Pronyk et al. (2001) found that TB patients in South Africa attended government facilities more readily than for some other conditions. About 72 per cent present initially to a hospital or clinic, with only 15 per cent presenting to a spiritual or traditional healer, and 13 per cent to private doctors. Nonetheless the authors recognised a significant failure of official clinical services to diagnose symptomatic individuals, adding to the already substantial problem of late presentation.

2.6.3 Stigma and/discrimination

Existing public awareness and knowledge about diabetes is reported to influence the way the disease is perceived at the community level and acted on (WHO, 2003). Some studies have revealed that Africans suffer from a preponderance of myths and misinformation about diabetes and its treatment (Fokumlah, 2005). Fokumlah argues that misinformed patients may not make the necessary adjustments in lifestyle or receive proper medical treatment and may rely on herbal treatments and alternative therapies exclusively. Further, De-Graft in Ghana (2006) observed that misinformation and myths about diabetes also feed the feelings of disgrace that are associated with being diabetic. She states that for individuals who suffer extreme weight loss because of this disease, the stigma may result from assumptions made by neighbours and community members that the weight loss is due to HIV/AIDS and/or TB.

The concept of ‘stigma’ was first elaborated in the classic work of Erving Goffman (1963). Goffman defined stigma as “an attribute that is significantly discrediting” and

which serves to reduce the person who possesses it, in the eyes of society. Herek (1999) states that stigma includes prejudice and can lead to active discrimination directed toward persons either perceived to be or actually infected with HIV and the social groups and persons with whom they are associated. Campbell et al. (2005) argue that stigma prevents the delivery of effective social and medical care, enhances the number of HIV infections and diminishes the public health effects of anti-retroviral treatment (ART) because people living with HIV/AIDS (PLWHA) are not able to interact with their families and the communities which would make them feel complete and a part of society.

In her study in Tanzania, Simpson (2003) noted that there was some discrimination against people with diabetes when it comes to employment, insurance, social life, marriage and adoption. Simpson suggested that it is not surprising then that people with diabetes tend to become anxious and depressed, and use a series of defence mechanisms to cope, some of which may include not seeking care at the medical care facility.

2.6.4 Disease Understanding and Perceptions

People's perceptions of illness are complex and are influenced by traditional and cultural beliefs and attitudes. Simpson (2003) argues that it is not just the classification of illness that determines the course of action but also the people's perceptions of its cause. In Tanzania, Muela et al. (2000) have shown that in African societies, disease aetiology is the main element according to which illness are broadly classified. People distinguish between 'normal illness or 'illness of God' as opposed to illness caused by witchcraft and spirits, which is referred to as 'out of order illness' or 'abnormal illness'. 'Normal illnesses or 'illnesses of God' are a natural creation by God and are part of normal human life and suffering. Such diseases include malaria, schistosomiasis, flu, diarrhoea diseases or worms. The most efficient treatment for such diseases is through hospitals with 'biomedical medicine' or 'white man's medicine'. 'Out of order' or 'abnormal illness' includes afflictions such as barrenness, impotence, mental disturbances and chronic disorders. The distinctive characteristic of 'out of order' or 'abnormal illness' is that they are not treatable at the hospital but are treated through traditional healers who have the appropriate skills to enter into contact with the invisible

world. Diagnosis is normally done through divination, using the power of spirits to identify the cause of the illness (Muela et al., 2000).

In South Africa, Tshabalala et al. (1997) observed that often an individual perception of illness has a significant influence on a person's course of action. In most traditional African countries the action taken against any disease is based on the beliefs and perceptions that people have on the actual disease causation. The power of beliefs and preconceptions related to disease, and particularly type 2 diabetes mellitus, seems to lead to strange courses of action. Fortune-tellers and 'sangomas' (witch-doctors or traditional healers) are extremely popular in most African countries. Type 2 diabetes mellitus may be perceived to emanate from a vengeful god or ancestors and successful treatment may, therefore, be perceived to be placation with sacrifice, prayers or even self-punishment. The authors recommended that health care workers should be aware of the guilt, confusion and self-blame which frequently haunt patients with newly developed diabetes.

Based on perceived disease causation, health-seeking behaviour may involve among other things the execution of traditionally prescribed rituals believed to get rid of the health problem. According to Tshabalala et al. (1997), in one part of South Africa a diabetic patient may basically scoop out pineapple flesh, pour urine into the remaining shell and bury it in the garden. The health belief model here is that diabetes is also 'buried' through this ritual and therefore, the patient is cured! The same study noted that in parts of Natal in South Africa there is a widespread use of 'flowers', which is used to make some tea which is believed to cure diabetes.

The use of traditional rituals in the treatment of diabetes cuts across all social classes irrespective of gender, economic status or educational levels. Tshabalala and Gill (1997), for example, reported having known a University graduate Black African in South Africa who used cinnamon to control his diabetes. Bopape and Peltze (2002) in South Africa also observed widespread use of combined traditional and biomedical therapies in managing diabetes and noted the need to consider using different counselling strategies to motivate patients to comply with biomedical treatment regimens. Similarly, Simpson (2003) in Tanzania noted that about 40 percent of type 1 people with diabetes sought alternative care services from a traditional healer,

consequently compromising insulin intake. What is the extent of this problem? Is it also a problem with non-insulin dependent diabetic therapies?

2.6.5 Nature of Health Care System and Health Providers

The health care system and the way in which health services are provided have been noted to influence health care seeking for such services. Often, patients choose private doctors over public facilities, as they believe their service to be more polite, more effective, more sympathetic and respectful of privacy (Auer, Sarol, Tanner, & Weiss, 2000). Auer et al. in Philippines stress that in the case of TB, with its lengthy treatment period, the fostering of a good doctor-patient relationship is crucial. Information is also needed regarding the availability of free drugs. Many patients in their study continued to purchase privately prescribed drugs and were unaware that these drugs were available free of charge at public facilities.

In Tanzania Simpson (2003) has shown that the setting of the health facility, and the interactions between the health care providers and the patient also influence the patient's health-seeking behaviour. One of the patients in Simpson's study had the following to say:

There were so many people at the clinic. I hardly got a chance to open my mouth to explain what was wrong with me. Even the doctor did not tell me what was wrong with me. He basically told me to take these pills. I still don't know what they are for (Simpson 2003).

Simpson found that physicians at the clinics are extremely busy, and very little time is devoted by the doctor to listen to patients' problems. The type of relationship between the patient and health care providers has been reported to be a factor in the patient's decision to consult and could be attributed to the tendencies of people with diabetes to seek care from alternative sources including traditional healers and/or herbalists. Hospital personnel have been accused of being rude and giving very little information to patients, hence losing the rare opportunity to educate their clients about the health problems at hand (Astrom, Awadia, & Bjorvatn, 1999; Feierman, 1981).

2.6.6 Use of Alternative Sources of Care

In their TB study in the Philippines, Auer et al. (2000) noted that “multiple health seeking” may account for delayed case finding. Only 29 per cent of patients in their study presented first to a health centre, with 53 per cent consulting a private doctor initially. They found that 69 per cent of patients had been told by a member of the household to seek medical advice for their symptoms, and those who felt ostracised because of their TB delayed seeking medical help. As they put it:

Effective health seeking and case finding are influenced by the health system, community, family, and other personal issues (Auer et al., 2000, p. 648).

Yamasaki-Nakagawa et al. (2001) found that women in Nepal were more likely than men to first seek help from traditional healers. The scale of this may be reflected in findings from a study by Rahman (2000) in rural Bangladesh, where 86 per cent of women received health care from non-qualified health providers. In urban Zambia and Nepal this has an implication for diagnosis, and women have been found to have significantly longer delays to diagnosis than men (Needhama, Bowman, Foster, & Godfrey-Faussettd, 2004; Yamasaki-Nakagawa, et al., 2001).

Non-Western practitioners remain a favourite source of care for many diseases including STIs. In Tanzania, Outwater et al. (2001) found that respondents pursue several different avenues of treatment for sexually transmitted infections (STIs) including self-treatment with herbs, traditional healers and/or herbalists, injections, pharmacies, government hospitals, and private clinics. Further, interviews with traditional healers about their knowledge and relationships with ‘biomedical’ medicine, as well as health-seeking behaviour among their clients revealed that some patients appeared to ‘wander’ from one service to another also known as ‘healer shopping’ (Aikins, 2005).

Despite the ongoing evidence that people do choose traditional and folk medicine providers in a variety of contexts which have potentially profound impacts on health, recommendations have been made on ways to build bridges to enable individual preferences to be incorporated into a more responsive health care system. For example, Ahmed et al. (2001) concluded that effort should be made to raise community

awareness regarding the importance of seeking care from the trained, and the availability of services.

2.6.7 Summary

The findings from these studies are informative and inspired the current study to explore the levels of awareness, understanding and knowledge about diabetes among people with diabetes, their caregivers and community members. The current study focuses not only the factors influencing their health-seeking behaviour but also on their health behaviour following diagnosis and initiation of therapy. Furthermore, while the Cameroon study (Kiawi et al., 2006) reported lack of knowledge, lay cultural beliefs and attitudes about the causation and treatment of diabetes as the causes for delaying health care seeking at the health facility, the study did not capture the full range of lay beliefs and attitudes that patients and their families and/or social networks have towards diabetes. The current study takes an in-depth look at the lay socio-cultural beliefs and attitudes of asymptomatic people with diabetes in relation to diabetes, their health-seeking behaviour, treatment and management of the disease following diagnosis.

As observed, in the current literature awareness, understanding and knowledge about diabetes is lacking for many, and some are unaware of their role in diabetes management and monitoring the therapeutic process. The reasons behind these observations however are not clear. Is it because of patients' ignorance about the disease? Have health care providers been effective in educating and counselling their patients on what they should do in enhancing their therapeutic processes? These and similar questions are addressed in the current study in an effort to develop recommendations which will enhance the overall delivery of diabetes services in Tanzania.

2.7 Health-seeking behaviour Models

A number of models have attempted to look into what causes individuals to behave the way they do when confronted with health related problems (MacKian, 2002). Health-seeking behaviour models as applied to public health mostly serve as a catalogue of relevant factors that need to be considered in applied research (Hausmann-Muela,

Ribera, & Nyamongo, 2003). Hausmann-Muela (2003) and colleagues in Kenya argued that data obtained using these models permit the evaluation of the relative weight of different factors influencing health-seeking behaviours such as use of preventive or therapeutic measures, choice between different health resources, non-compliance with treatment, or the consequences of behaviour for delayed care seeking. The principle objective is to identify problematic areas in order to intervene with specific health system strategies.

A range of health-seeking behaviour models were identified and examined with the aim of identifying key possible factors influencing health-seeking and health related behaviour for type 2 diabetes. While some of the models have been useful both in the initial development of this study, during data collection, analysis and interpretation of the findings, others appeared limited as described below.

2.7.1 The Health Belief Model (HBM) (Sheeran & Abraham, 1995)

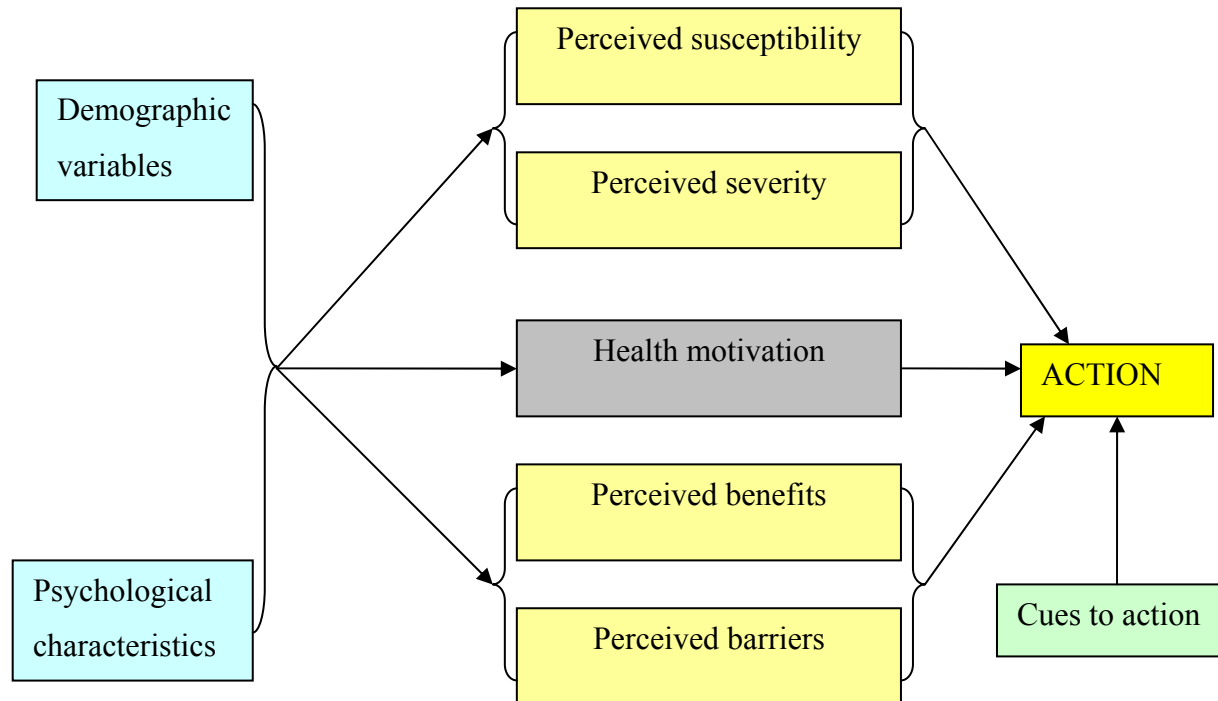
The health belief model is a widely applied behavioural model in several disciplines including public health (Figure 2.2). The model can be used to explain individual's health-seeking behaviour. In this model action is guided by the following five factors: (1) Beliefs about the impact of illness and its consequences (threat perception) which depend on perceived susceptibility, or the beliefs about how vulnerable individuals consider themselves in relation to a certain illness or health problem, and perceived severity of illness or health problems and its consequences.

(2) Health motivation or degree of concern about health matters.

(3) Beliefs about the consequences of health practices and the opportunities and barriers to putting them into practice. This depends on perceived benefits of preventive or therapeutic health practices, and perceived barriers, both material and psychological (for example 'will-power'), with regard to the implementers of certain health practice.

(4) Cues to action, which includes different internal and external factors which influence action. For example, the nature and intensity of disease symptoms, mass media campaigns, advice from significant others or social networks (family, friends and health staff). (5) Finally, beliefs and health motivation are conditioned by socio-demographic variables (class, age, gender, and religion) and by the psychological characteristics of individuals (personality and peer group pressure)

Figure 2.2: The Health Belief Model (Sheeran & Abraham, 1995)

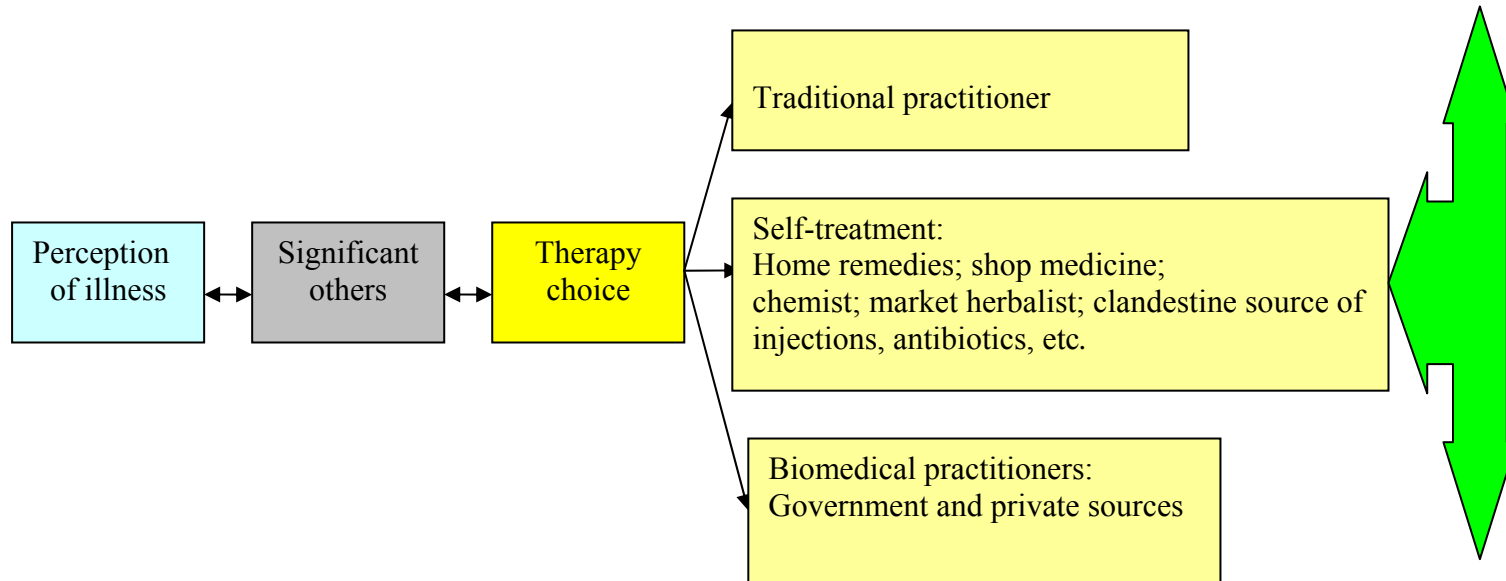


As useful as it, the health belief model has been criticised for various shortcomings. First, the model focuses on individual decision-making does not take into account broader societal influences such as social norms. Secondly, the model is linked to the general assumption that those who believe they have control over their health are more likely to engage in health promoting behaviours (Norman & Bennett, 1996). Third, the model does not allow any understanding of how people make decisions, and does not provide a description of the way in which people make decisions (MacKian, 2002).

2.7.2 Good's Model (1987) –The Pathway Model

The model starts with the recognition of symptoms. It describes the path that people normally follow in their use of care services (home treatment, traditional healers/herbalists, and biomedical facilities) as shown in Figure 2.3. Unlike the health belief model, the Pathway Model stresses the importance of 'significant others' in the decision-making process in health care. This approach challenges the health belief model's strong emphasis on the individual and stresses the social context under which the individual operates including a pivotal role of extended family members, relatives and friends in illness negotiation and management. The model also acknowledges the dynamics of illness and decision-making and looks at health seeking as a dynamic process, because perception of illness and social networks may change over time.

Figure 2.3: Good's Model, 1987



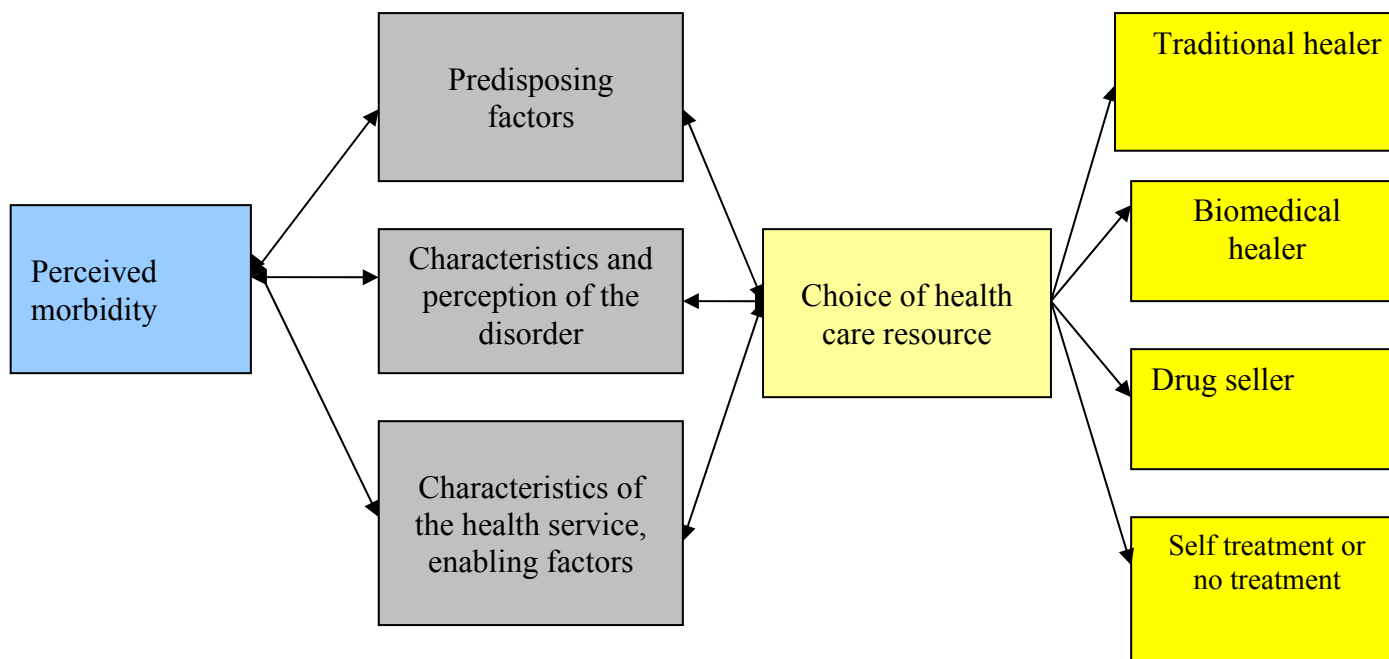
Note: The arrow at the extreme right of the diagram (green arrow) indicates that people can move from one sector to another.

2.7.3 Kroeger's Model, 1983

Kroeger's (1983) model proposes a framework of interrelated explanatory factors (Figure 2.4), all of which are affected by perceived morbidity. These factors are:

- (i) An individual's traits or predisposing factors: age, sex, marital status, status in the household, household size, ethnic group, degree of cultural adaptation, formal education, occupation, assets (land, livestock, cash, and income), and social network interactions.
- (ii) Characteristics of the disorder and patients' perception: chronic or acute, severe or trivial, aetiological model, expected benefits of treatment (biomedical versus traditional), and psychosomatic versus somatic disorders.
- (iii) Characteristics of the service (health service system factors and enabling factors): accessibility, appeal (opinions and attitudes towards traditional and biomedical healers), acceptability, quality, communication, and costs. The interaction of these factors influences the selection of health care resources which could either be through the traditional or biomedical healer, self treatment or treatment through medicines from the drug seller.

Figure 2.4: Kroeger's Model, 1983

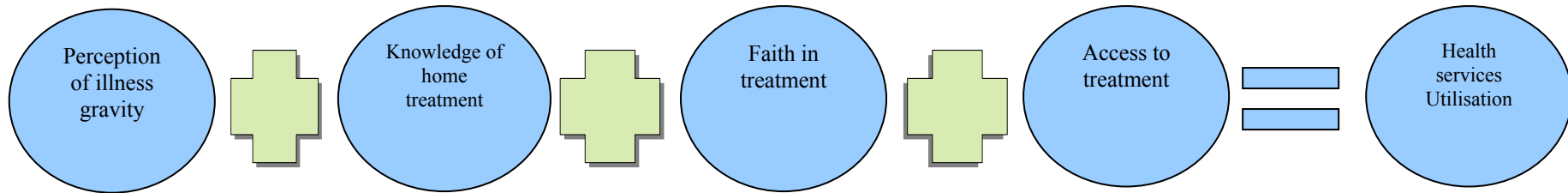


2.7.4 Young's Model (1981)—“A Choice-making Model”

Young's (1981) model which is referred to as “A Choice-making Model” is based on his ethnographic studies of health services utilisation in Mexico. This model incorporates four components which are likely to influence an individual's health service choice (figure 2.5).

- 1) Perceptions of illness gravity. This category includes both the individual's perception and their social network's consideration of illness severity. Gravity is based on the assumption that the culture classifies illnesses by level of severity.
- 2) Knowledge of a home treatment. If a person knows of a home remedy that is efficacious, they will be likely to utilise that treatment before utilising a professional health care system. Home remedy knowledge is based on lay referral.
- 3) Faith in the remedy. This component incorporates the individual's belief in efficacy of the treatment for the present illness. An individual will not utilise the treatment if they do not believe the treatment is effective.
- 4) The accessibility of treatment. Accessibility incorporates the individual's evaluation of the cost of health services and the availability of those services. According to Young, access may be the most important influence on health care utilisation (Wolinsky, 1988b).

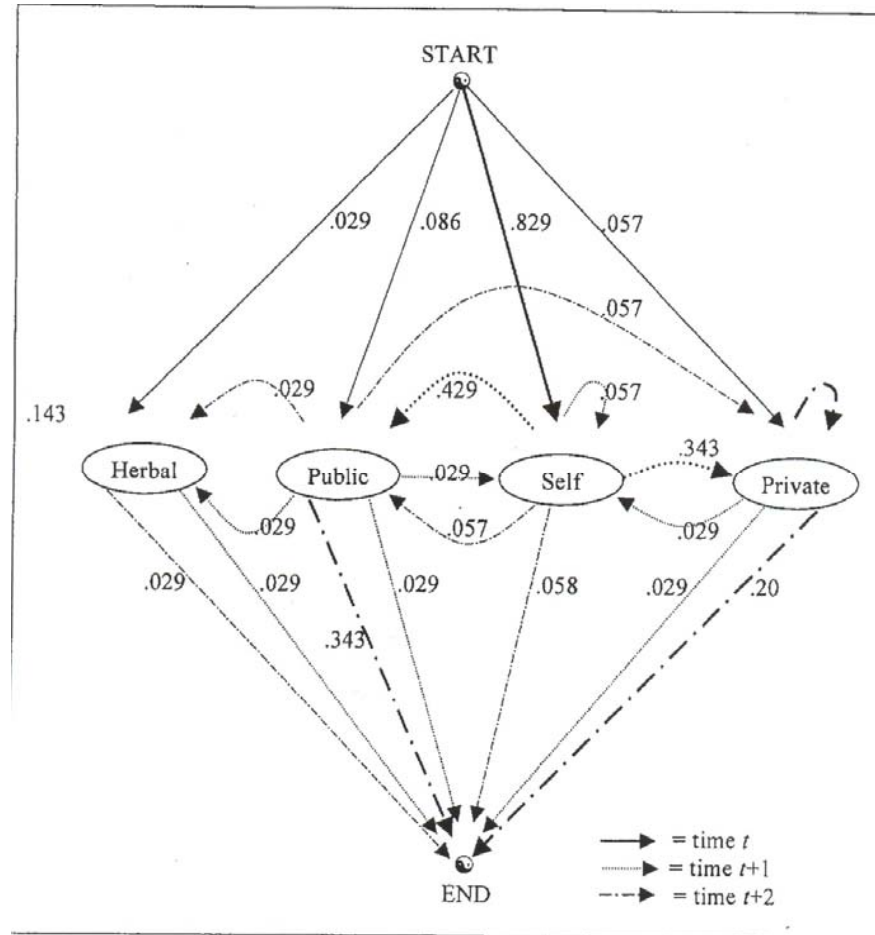
Figure 2.5: A Choice-Making Model (Young, 1981)



2.7.5 Nyamongo's (2002) Health Care Switching Behaviour Model

There has been an increasing emphasis on successive therapy choices. Nyamongo (2002) model elaborated a descriptive model (Figure 2.6) which includes treatment sequences for malaria in a Kenyan community. Nyamongo argues that delay in seeking care is caused by a number of factors ranging from expenditure, duration of illness, knowledge of illness and its treatment, and individual patients and their social networks' attitudes towards the illness. These factors are often reflected in the community's overall attitudes towards illness including the notion of "wait and observe the progress" when faced with symptoms of illness. According to Nyamongo, people consequently go through different alternative treatments when looking for a cure. These may range from self-treatment and/or home remedies, consulting a traditional healer and/or herbalists, to the use of public and private health facilities

Figure 2.6: Nyamongo's (2002) Health Care Switching Behaviour Model



Note: Likely movements between care and treatments with likelihood estimates (N=35, arrows in bold indicate higher probabilities) (Nyamongo, 2002).

2.7.6 McKinlay–Health-seeking Behaviour in Context

In his review of studies of health-seeking behaviour in the developed countries, McKinlay (1972) identifies six analytically distinct and culturally orientated approaches that guide decisions about when, where, and how to seek help and/or treatment (Table 2.1)

Table 2.1: Analytical orientation and/or Approaches to Health-seeking behaviour

Economic	Financial barriers such as income, health insurance cover, the cost of health services and availability of free medical drugs
Geographic	The geographical proximity of health services
Socio-demographic	Characteristics like gender, age, social class and education
Social-psychological	Individual motivation, perception and learning
Socio-cultural	Values, norms, beliefs, definitions of situations, and lifestyles of different socio-economic groups
Organisational or health delivery system	Aspects of health care organisations and those working in them

Source: McKinlay, cited in Fitzpatrick at al., 1984, p.37.

2.7.7 Reflections on Health-seeking behaviour Models

Overall, the models presented above describe a variety of factors likely to influence health-seeking behaviour patterns. These range from knowledge and perceptions of disease signs and symptoms, social and cultural beliefs, family and/or social networks, geographical proximity, and finance, to organizational and service delivery factors. Health-seeking behaviour, according to these models, appears to be a product of interactions between an individual and one's family and/or social network, as well as the health care system. Although the area of focus varies from one model to another, they all appear to overlap, showing the interactions between these factors in influencing the health-seeking behaviour patterns that we see in the patients' pathways to care and treatment.

The pathway to care and treatment for any disease starts with presenting signs and symptoms (Nagv et al., 2009). While the Health Belief Model (HBM) (Sheeran & Abraham, 1995) focuses on individual patients' perceptions of the severity of disease signs and symptoms as a trigger to seek care, Young, Good, Kroeger and Nyamongo's models also focus beyond the individual, on the family and social networks. These models argue that although the individual perceptions of disease signs and symptoms and their severity are important, by themselves they might not be enough to trigger action to seek care. According to these models, the perceptions that the family and /or social networks have about these signs and symptoms are equally if not more important in patients' decisions to seek care. The family and/or social networks not only have an influence in determining "what" the patient might be suffering from but also on the nature of care and treatment he/she might need "*when*" and "*where*". Hence, by virtue of being able to determine "what" the patient is suffering from, the family and/or social networks set the patient on the pathway to care and treatment. Although the concept of "perceptions" of signs and symptoms appears to be central among most of these models, it is the level at which the decision is made to seek care that distinguishes the HBM from the rest. The individual approach taken by the HBM in explaining the decision making process to seek care as opposed to the family and/or social networks approach used by the Young, Good, Kroeger and Nyamongo models has weakened the HBM since individuals' behaviour can only be explained effectively within the context in which they live. The approaches of Young, Good, Kroeger and Nyamongo are even more valid in explaining patients' health-seeking behaviour particularly in developing and sub-Saharan African communities where response to illness is a family affair.

Despite their varied approaches, the HBM and Young, Good, Kroeger and Nyamongo models all suggest that the perceived "severity" of signs and symptoms influences patients' decisions to seek care. Nyamongo, for example, argues that persistence or growing severity of the signs and symptoms are what normally prompts the family to take action. While the argument presented by these models appears to be valid in explaining "when" a decision is made to seek care they fail to explain "why" some patients faced with similar disease severity may respond by seeking care early while others do so later or do not seek care at all.

In addressing this question McKinlay's model introduced the structural factors such as geographical proximity and economic factors such as financial resources to explain the varying health-seeking behaviour among patients. According to McKinlay, for example, decision making on whether or not to seek care for some patients is influenced by the distance between the patient's residence to a health care facility and the transport costs involved. This factor, however, does not appear to be valid in explaining why some of the patients living close to the health care facility or those who can afford transport to the health care facility still do not seek care at the facility. Furthermore, the distance factor cannot explain why some poor patients and their family members and/or social networks still manage to seek care at distant places despite transport costs involved.

The financial resources factor, however, appears to provide a more valid explanation of the patients' decisions to seek care, particularly in meeting the costs for medical consultations, medical tests and drugs. McKinlay's and Nyamongo's models, for example, argue that patients' decisions to seek care or not are dependent on whether they have the financial resources to cover the costs of transport, medical consultations and tests as well as medication. Where these resources are lacking, the patient is likely to resort to staying at home or seeking alternative sources of care. Still, it is not clear from this or other models whether given access to financial resources all the patients would seek care at health facilities.

Cognizant of the limitations of the various factors (i.e. patients' perceptions of severity of signs and symptoms, geographical proximity, availability of financial resources) used to explain the patients' decisions to seek care, the McKinlay, Kroeger and Young models went further to explore other factors that might explain other health-seeking behaviours observed among patients. For example, which factors explain why patients seek care from a traditional healer and/or herbalist as opposed to going to a biomedical health facility? It is at this juncture that they introduce the characteristics of the health care services including quality of care services, accessibility and affordability. As mentioned earlier, family and/or social networks have a significant role not only in determining when care is sought but where it should be sought. Unlike the other models, the McKinlay, Kroeger and Young models have managed not only to provide more valid explanations of the observed health-seeking behaviour among different patients, but have also brought to light the role of socio-cultural context and belief

systems in the utilization of the health care services. Given his use of studies carried out in the “western cultural” context, McKinlay’s model understandably emphasized the role of health care workers and the nature of biomedical services delivered through the health care facilities. Kroeger’s and Young’s models similarly look beyond the “health care facility and health care workers” within the “biomedical services” delivery. Since most of their studies were carried out in “non-western” cultural context, their models appear to focus on the services provided beyond the confines of a “health care facility” and “biomedical services”. They looked at the care services provided by the traditional, herbalist and/or faith healers and the influence these have upon the patient, their family members and/or social network’s decisions on “where” care services are sought.

While all these models appear to approach the concept of health-seeking behaviour from different perspectives, they nevertheless tend to overlap, particularly in their recognition of the role of the social, cultural and economic context under which the individual operates. Further, they all recognize the socio-cultural perceptions attached to different disease signs and symptoms, their interpretation and resulting course of action. These observations provided me with some “pointers” on the things that I might need to look into during this study. They also challenged me to look beyond the individual patients and people around them (family and/or social networks) and beyond the confines of a “health care facility” and “biomedical services”. Furthermore, these observations challenged me to delve deeper into factors behind the use of “alternative” care services and their implications to policy and improved care and treatment services for people with diabetes in Tanzania.

2.8 Evidence of Importance of McKinlay’s (1972) Theoretical Framework

McKinlay model seemed to incorporate many of the key influences on health-seeking behaviour identified in the literature review. This section highlights some evidence on how the six key factors in McKinlay’s theoretical framework have been applied in explaining the observed health-seeking and health related behaviour for various diseases under varying socio-cultural and economic contexts in developing countries and sub-Saharan Africa. Whether in western, developing countries or sub-Saharan Africa, a fuller understanding of health seeking behaviour is likely to follow McKinlay’s approaches which include socio-economic conditions, geographical, socio-

demographic, social-psychological, socio-cultural, and organisational factors with variations based on the specific cultural and societal context.

2.8.1 Economic Factors

The economic factors of McKinlay's model have been extensively used in describing health-seeking behaviour in many studies carried out in developing countries and sub-Saharan Africa. Nyamongo (2002) in Kenya and Okyere (1998) in Ghana for example, noted that the economic polarisation within the society and lack of a social security system for care services make the poor more vulnerable in terms of affordability and choice of health care providers. In his study on malaria in Kenya, Nyamongo noted that the high costs of biomedical care services have been forcing patients into the use of alternative care services including those of traditional healers.

In Mozambique the costs for diabetes tests at the health facility have been found to constitute an important constraint to diabetes care (Beran, Yudkin, & De Courten, 2005). Similarly, in their studies in Vietnam, Berman, Ha, and Larsen (2002) observed that the magnitude of household out of pocket expenditure on health is at times as high as 80 per cent of the total annual expenditure on health care. This trend of expenditure challenges the ability of a person or a family as a whole to seek health care even in view of a threatening health condition. Apart from the costs of care services, the economic factors have also featured in other areas of health-seeking behaviour as well. The costs of transport have undoubtedly been a major barrier in health-seeking behaviour in many developing countries (Fatimi & Avan, 2002). In their studies in Pakistan, Hunte and Sultana (1992) argue that not only do consultation fees or the expenditure incurred on medicines create a barrier in health-seeking behaviour but another problem is the actual cost of transport to reach the health facility. In Tanzania poor clinic attendance among people with diabetes was attributed to the lack of financial resources to meet the transport costs (Simpson, 2003). In making decisions to seek care most households take into consideration both the costs of transport to the health facility, consultation fees and medical costs for drugs including other incidentals. Often the sum total of these costs is far above what the family can afford consequently limiting the choices and opportunities for health care seeking.

Sachs (2001) has observed that diseases like diabetes place a large financial burden on individuals and their families in many sub-Saharan countries, often leading the household into poverty. In Ghana, one of the reasons for “healer shopping” by people with diabetes was the high cost of biomedical drugs and recommended foods (Aikins, 2005). Similarly, Awah, Unwin, and Phillimore (2008) in Cameroon observed that financial constraints are a major factor in the use of alternative as opposed to biomedical care services in the management of diabetes. Studies in Senegal also have shown that cost of treatment is the main barrier to adherence to medical treatment for chronic diseases such as AIDS (Lanièce, Ciss, & Desclaux, 2003). In Tanzania Simpson (2003) observed that many people with diabetes were not adhering to their treatment regimen mainly because they could not afford to purchase insulin from private pharmacies when they failed to get any from the public hospital whose prices are subsidised by the government. Cost implications were similarly observed to contribute to barriers for health seeking behaviour among patients with stroke conditions in Tanzania (Mshana, Hampshire, Panter-brick, & Walker, 2007).

2.8.2 Geographical factors

Distance to the health facility coupled with poor public transport and associated costs have been noted to influence health-seeking behaviour in many developing and sub-Saharan African countries. In Pakistan, for example, a combination of these factors was reported to contribute towards increased the costs of clinic visits (Bhuiya, 1995; Islam & Tahir, 2002; Noorali, Stephen, & Rahber, 1999). Health care shopping has been linked with proximity and/or accessibility of health services (Uzma, et al., 1999;). Poor availability of transport, physical distance to the health facility and the time taken to reach such facilities have been found to influence health-seeking behaviour and health service utilization (Fatimi & Avan, 2002; Stephenson R & Hennink, 2004). While distance to the health facility may be a constraint due to the travel and waiting time at the bus stop, the costs for such transport is also reported to influence the decisions to seek care. In Tanzania, Simpson (2003) observed that the sum total of the money spent on diabetes drugs coupled with the travel cost had a significant influence on patients’ decisions to seek care. She noted that some of the patients were travelling more than 200 kilometres to Teule Hospital in the Tanga region, a distance which was quite costly to most of them in terms of both time and money. It is therefore not surprising that some

patients could not afford to attend a diabetes clinic and resorted to other traditional forms of care. Long distances to health facilities are also reported to be a disincentive to health care seeking especially among women in some developing countries in which they need to be accompanied there (Islam & Tahir, 2002; Mumtaz & Salway, 2005). Similarly, in South Africa long distances to and from the care facility were associated with delays in health-seeking behaviour for treatment among TB patients (Pronyk, et al., 2001). In Ghana some people with diabetes had to travel more than 300 kilometers to receive diabetes care (Amoah, 2002). According to Amoah, many could not attend diabetes clinics and were therefore seen instead at facilities that had no trained diabetes healthcare personnel.

2.8.3 Socio-demographic factors

In developing countries and sub-Saharan Africa demographic variables such as age, gender and marital status including educational status and occupation of the head of the family have been reported to influence health-seeking behaviour (Goldman & Heuveline, 2000 ; Nyamongo, 2002; Yip, Wang, & Liu, 1998). Studies in Pakistan have shown significant variations between men and women in access to nutrition and education where women are overburdened with reproductive and child care responsibilities, making them highly vulnerable and disadvantaged in accessing health care (Hasan & Khanum, 2000; Hunte & Sultana, 1992). Other studies have observed that men in Pakistan play a paramount role in determining the health needs of a woman which include deciding when she can seek care (Shaikh & Hatcher, 2005). In their study, Rani and Bonu (2003) for example, argue that since men are decision makers and have control of all the family resources, they decide when and where a woman should seek health care. Under this arrangement women suffering from an illness may less frequently seek health care compared to men (Ahmed, Adams, Chowdhury, & Bhuiya, 2000). Similarly, studies in India, Pakistan and Mali have observed that the low status of women prevents them from recognizing and voicing their concerns about health needs (Fatimi & Avan, 2002; Navaneetham & Dharmalingam, 2002; Uchudi, 2001). Fatimi and colleagues state that women are usually not allowed to visit a care facility or health care provider alone or to make the decision to spend money on health care. They further conclude that women generally cannot access health care in emergency situations (Fatimi & Avan, 2002). Other studies in Pakistan have shown that the gender

of the health care provider is an important factor for women's decisions on where to seek care (Shaikh, Haran, & Hatcher, 2008). According to Shaikh and colleagues, women generally tend to seek care at health facilities with a female health care provider with whom they can easily discuss their problems.

The overriding household responsibilities among women in developing and sub-Saharan countries have also been reported to significantly influence women's health-seeking behaviour. In Tanzania, for example, Green (2000) found that women were highly limited in their ability to seek care even when they had the resources to do so mainly because of the overriding demands of household chores. According to Green the married women were known to delay seeking medical treatment longer than their single counterparts because of their household chores and social obligations to their husband's relatives. Other studies in Tanzania have reported that men with resources tend to seek treatment earlier than women (Tanzania Ministry of Health Report, 1997). Additionally, in Tanzania Muela, Mushi, and Ribera (2000) observed that socio-economic obligations of women within the family severely limit their opportunities to seek care compared with their husbands.

2.8.4 Social-psychological factors

Health-seeking behaviour is known to be influenced by a variety of socio-psychological factors most of which are embedded in the cultural context of the patient. A study in Pakistan shows that traditional beliefs tend to be intertwined with peculiarities of the illness itself consequently dictating the path of action that should be taken to address it (Shaikh & Hatcher, 2005). Shaikh and Hatcher argue that the cultural interpretation of the signs and symptoms of the disease often dictate the health-seeking behaviour path which includes use of home-prescriptions, which at times lead to delays in seeking biomedical treatment. Lack of awareness and basic knowledge about the disease has been reported to contribute to delays in health-seeking behaviour in Pakistan (Shaikh, et al., 2008). Shaikh and colleagues state that the perceived quality of care is always a consideration for many patients. Some patients who reported using alternative care services for example, underscored the quality of care they were getting from the faith healer in their neighbourhood. According to these patients the faith healers were accessible hence they did not have to travel far. Further, the healer was reported to listen

to their problem and give them “satisfactory advice and treatment”. The best part of this relationship according to the patients was the fact that they did not have pay him right away.

Qualitative studies in Cameroon (Awah, Unwin, et al., 2008; Kiawi, et al., 2006) have shown that people with diabetes and community members’ with good knowledge and understanding of the treatment for diabetes are more likely to adhere to care seeking. However, Awah et al. (2008) observed that different understandings of diabetes cause tension between biomedical and traditional medicine in the patient’s quest for a cure. For example, patients feel that instead of going to purchase medicine at the clinic, it is better to harvest some leaves behind their house, boil and drink the juice every morning. Psychologically then, these patients find themselves struggling to answer the question: “If they can heal using leaves, why go to the clinic to buy medicine?” Awah et al. found out that when people do not know what is happening to their bodies they will seek care anywhere. Similarly, in Tanzania, Simpson (2003) showed that individual perceptions of illness influence health-seeking behaviour. Some respondents in Simpson’s study were unaware of the complications and seriousness of diabetes if left untreated. According to Simpson there seems to be a culture that ‘being ill’ is a taboo subject. She reported that one of the respondents happened to say ‘diabetes is not an illness; it is inability of the body to cope’. Based on these findings, Simpson found that patient attitudes to treatment are influenced by their perceptions of where the responsibility lies for their health outcome.

2.8.5 Socio-cultural factors

According to McKinlay’s model, health seeking behaviour is influenced by a number of socio-cultural factors. Nyamongo’s (2002) qualitative study of patients with malaria in Kenya found that socio-cultural beliefs and practices influence patients in the non-use of biomedical services in favour of self-care, home remedies and consultation with traditional healers. In Pakistan socio-cultural beliefs and practices are reported to influence not only the patients’ acknowledgement of the severity of an illness but also the availability and acceptability of appropriate care services (Shaikh & Hatcher, 2005). Pakistan is typical of many societies in developing and sub-Saharan countries, where family members and social networks play a culturally significant role in the patient’s

decision to seek care, and where and when to seek it. Shaikh et al. (2008) found that community members and/or members of social networks appear to hold strong opinions about certain services, consequently becoming a decisive factor in health care seeking (Shaikh, et al., 2008). Shaikh and colleagues observed that when confronted with an ailment, family members and social networks tend to collect information quickly on remedies available in the area and the decision to seek care was based on the news of any other person who might have been cured by the khalifa's [faith healer] treatment. Similar observations were made in another qualitative study in Tanzania where Mshana noted the significant role of family members and social networks in the decisions on where and when to seek care for a stroke patient (Mshana, et al., 2007).

Peoples' perceptions about a disease and the modality of its treatment are influenced by the existing socio-cultural context. In Tanzania for example, Simpson observed that people's perceptions of their illness are complex and influenced by cultural differences (Simpson, 2003). Also in Tanzania, Muela et al. (2000) observed that diseases and their causes are culturally classified (i.e. 'normal illnesses' or 'out of order or abnormal illnesses'), as previously discussed. Muela and colleagues observed the cultural role that the structure of the family plays not only in the decisions on the type of care that should be sought for the patient but also in the overall family support throughout the treatment process. In particular, they noted that 'out of order' illness is perceived to be affecting the whole extended family or social group, therefore it tends to involve the whole family and in some cases the wider community group (Muela, et al., 2000).

2.8.6 The organisation of the health system

Apart from looking at the factors outside the biomedical health care system which put off patients from attending these facilities (push factors), Mckinlay's model also looked at the factors within health care system which attract the patients towards the care services (pull factors). By nature, the health care systems in developing and sub-Saharan African countries are mostly organised for the treatment of acute rather than chronic conditions (Whiting, et al., 2003). Over the years these systems have faced an immense challenge in tackling communicable diseases like HIV/AIDS, tuberculosis, malaria, diarrhea, and respiratory infections (Ezzati, Lopez, Rodgers, Vander Hoorn, & Murray, 2002). However, Zimmet (2000) argues that chronic disorders such as diabetes and

hypertension share with HIV/AIDS and tuberculosis several common features. These include the need for diagnostic tools and trained personnel able to initiate and sustain treatment of a life-long condition, a referral system for management of complex regimens or complications, and the need for an effective organised system for regular supply of medicines throughout the country. Beran et al. (2005) assert that proper organisation and availability of diabetes services play an essential part in the provision of health care for diabetes conditions in sub-Saharan Africa. This is a challenge that most health care systems have been facing in many countries in developing and sub-Saharan Africa. For these reasons Zimmet has argued that for type 2 diabetes, primary prevention will need organised political action, to deal with a tide of globalisation and its effect on both urban migration and obesity.

Further, under-utilisation of the health services in the public sector has been a universal phenomenon in developing countries (Green, 2000; Shaikh & Hatcher, 2005).

According to Shaikh and Hatcher in Pakistan and Green in Tanzania, public health clinics in most developing countries including sub-Saharan Africa tend to have fixed opening hours and even when they are open they tend to lack adequate equipment, medications and health care providers. In some situations health care providers are either limited in number or poorly trained to cope with the health care demand (Shaikh, et al., 2008). Shaikh and colleagues have pointed out that this system of health care is inconvenient compared with the services provided by Pakistan's khalifas (faith healers) who are available around the clock in the community.

An anthropological study in Tanzania (Green, 2000) revealed that the public health facilities were in fact barriers to people's early care seeking for diagnosis and treatment. Citing the case of malaria, for example, Green showed that these health facilities had neither diagnosis nor testing equipment let alone the drugs to treat the disease. Furthermore, he observed that even when the drugs happen to be available the patients who were given medication were not strongly advised of the importance of completing their course of treatment.

Newman et al.(1998) in Mozambique and Stephenson and Hennink (2004) in Pakistan respectively reported that the attitude of the health care providers and patients' satisfaction with the treatment play a role in health-seeking behaviour. Similarly,

Mshana et al. (2007) in Tanzania reported that good interactions with health care providers (i.e. doctors and/or nurses) play an important part in treatment seeking. For example, they noted that patients often complained about the attitude of the doctors particularly when communicating their medical test results to them. The patients reported that they were highly uncomfortable with the phrase “no problems” often used by the doctors when reporting these results. According to the patients this type of communication amounted to trivialisation of their medical condition particularly when such comments were made by the doctors without adequate explanation as to why there is “no problem”.

The international literature (Pruitt & Epping-Jordan, 2005) suggests that health care workers in most sub-Saharan Africa health care systems need to be organised in coordinating treatment and educate people with diabetes in self-care while carrying out active initiatives in diabetes prevention. According to Pruitt & Epping-Jordan, health care workers need up to date training on diabetes management in order to handle the care demands of their patients.

2.9 Key findings and gaps

2.9.1 Findings

The literature reviewed in this chapter examined an array of studies on diabetes mellitus around the world which raised a number of questions whose answers might not be within the scope of the current study. However, some of the areas covered by these studies and the gaps identified are highly relevant to the current study in Tanzania. Most of the studies in developing countries and sub-Saharan Africa show that there are inadequate financial resources and availability of trained staff in diabetes contributing to the poor diabetes quality services provision (Beran & Yudkin, 2006). The economic factors were found to pose a major challenge in the patient’s management of diabetes. This includes costs of transport to and from the health facilities, and the costs of medical tests and medication. In making decisions to seek care most households take into consideration both the costs of transport to and from the health facility, consultation fees and medical costs for drugs and other incidentals (Abdulkadir, 1997; Mbanya & Sobngwi, 1997). As observed in many studies from sub-Saharan African countries the major challenge facing many people with diabetes in adhering to their treatment

regimen is poor and erratic availability of diabetes drugs such as insulin in public health facilities (Alberti, 1994; Gill, 1994; McLarty, et al., 1994; Simpson, 2003). Other studies on the health care system in Tanzania have noted that health facilities have neither the diagnosis nor testing equipment let alone the drugs to effectively treat diseases including diabetes (Green, 2000). While acknowledging the costs of drugs and treatment for different communicable and NCDs diseases is a major problem in the Tanzania health care system, the current study was interested in determining the nature and the extent of this problem, and its impact on the care and management of type 2 diabetes mellitus.

Geographical distance from patients' homes to the clinic coupled with shortages and poor public transport and associated costs have been noted to influence health-seeking behaviour in many developing and sub-Saharan African countries. In Tanzania, Simpson (2003) observed that many patients could not attend their regular clinic appointments due to lack of financial resources to pay for public transport. Additionally, health care coverage is another major factor influencing timely accessibility to care and treatment for diabetes in sub-Saharan Africa. Amoah (2002) noted in Ghana that despite a few advances in the treatment and management of diabetes, people are still dying due to poor access to timely and appropriate medical treatment. Further, diabetes treatment and drugs are reported to be available mainly in the large city hospitals, forcing many patients to travel great distances for diabetes care services. Poor clinic attendance among people with diabetes has been attributed to distance (Simpson, 2003). This information is worth noting and challenged the current study to examine whether patients' adherence to their regular clinic appointments following their diagnosis and subsequent medical treatment was influenced by geographical distance and coverage of health care facilities. Specific question includes: are the transport and medical costs the only or main factors influencing patients' decisions to attend clinic or to seek alternative care services?

The issue of communication between health care providers and patients along with the overall organisation of the health care system and service delivery was also an area of interest in the current study. In his studies in Tanzania, Green (2000) observed that even when the drugs are available at the health facilities there appears to be inadequate communication between the health care providers and the patients on the use of diabetes

drugs and other associated disease management skills. In her case studies in Tanzania, Simpson (2003) also made similar observations. Other studies (Makani, et al., 2003; McLarty, et al., 1997; Rwiza, et al., 1986) have noted some skill deficiencies among health care workers in the overall diagnosis and management of diabetes. These studies appear to raise some questions: For example, what is the nature of the information the patients need and to what extent is this need met by the health care workers at the clinic? How conversant are the health care workers are with the overall diagnosis and management of diabetes? While evaluating the health care workers skills in the diagnosis and management of diabetes was beyond the scope of this study, this information was interesting and led the study to explore the extent to which the health workers are equipped with relevant management skills for diabetes, particularly in the provision of relevant education to their patients and their caregivers and/or social networks on the care and management of this disease. This was explained briefly but the results were not presented because it was not the aim of this study.

The literature also showed limited levels of awareness and knowledge about diabetes. In Tanzania, more than 50 percent of people with type 2 diabetes are reported not to be aware of having the disease (Ramaiya, 2005). This situation leads to late care seeking with consequent complications in the care and management of diabetes. Given the chronic nature of diabetes, patients' knowledge and skills in its management become essential. However, as observed by Smide et al. (2002) in Tanzania, most patients lack the basic knowledge and skills for diabetes self-care and management. These findings inspired the current study to explore the existing levels of knowledge and skills among patients and their caregivers in the management of diabetes. In particular, the study explored the role of family members and/or social networks in the overall care and management of diabetes within the family context.

Finally, the studies reviewed suggested a significant influencing role of socio-cultural beliefs and practices in the peoples' perceptions of the signs and symptoms of disease and the course for care and management. A combination of limited knowledge about the disease, lay beliefs and attitudes about disease causation and treatment has been reported to contribute to significant delays in seeking care (Kiawi, 2006). People's perceptions of illness are complex and are influenced by a range of traditional and cultural beliefs and attitudes. Simpson (2003) for example, argues that it is not just the

cultural classification of illness that determines the course of action but also the people's perceptions of disease causation. Based on perceived disease causation, health-seeking behaviour may involve the utilisation of various traditionally prescribed rituals believed to get rid of the health problem, some of which may influence early health care seeking. These observations inspired the current study to delve into the socio-cultural factors influencing health-seeking behaviour among people with diabetes in Tanzania. For example, are there other lay and cultural beliefs and attitudes that may be influencing the health-seeking behaviour among our study population besides those already observed by other studies elsewhere as shown in this literature review? If so, what models can be used in explaining such behaviour? Further, to what extent are the existing 'traditional health belief' influencing the different perceptions that people form based on the manifestation of the signs and symptoms of diabetes? How do such perceptions influence the nature of care services sought by the patients and their respective families?

2.9.2 Observed gaps in the reviewed studies

Most of the diabetes studies reviewed in this chapter are from developing countries, including sub-Saharan Africa and Tanzania. However, the majority of these studies are quantitative and based on clinical and/or hospital observations. Many of these studies also collected data from patient and/or health care workers in urban and/or rural areas. With some exceptions, such as studies from Cameroon and Ghana, there are few qualitative studies from sub-Saharan Africa. Of those, the Cameroon and Ghana studies mainly collected data through in-depth interviews and/or focus group discussion with people with diabetes at the hospital settings. Studies exploring health-seeking and health related behaviour among people with diabetes in sub-Saharan Africa, including Tanzania, do not exist. The current study, therefore, was intended to fill this gap. The study also moved beyond the confines of the hospital setting to the community setting to explore an array of factors likely to influence health-seeking and health related behaviour for type 2 diabetes mellitus.

Unlike other studies carried out so far in sub-Saharan Africa and in Tanzania, the current study is multifaceted and employed multiple qualitative methods including in-depth and key informant interviews and FGDs in generating information not only from

the patients and health care workers but from the patient caregivers, the community and key national health officials. Triangulation of information from all these sources aimed to give the study's findings exceptional richness and rigour in its contribution to better understanding of the factors influencing health care seeking and health related behaviour including management of diabetes in Tanzania.

2.10 Summary

This chapter presents an overview of the literature related to the key concepts and issues covered in this thesis. It is divided into five major sections. The first section describes the literature reviewed and the methods used. The review covers an extensive amount of secondary data sources from various journals, books, published and unpublished reports. The focus here was to identify and evaluate the various studies on health-seeking and related behaviour for type 2 diabetes mellitus, particularly from sub-Saharan Africa and Tanzania in particular.

The second section looks at the epidemiology, definition and state of diabetes mellitus including risk factors and mortality associated with diabetes globally and in sub-Saharan Africa. The available data show the prevalence of diabetes mellitus varying widely across the globe and across different populations. The disease appears to be influenced by a number of factors including age, obesity, genetic background, racial group and geographic region. The growing prevalence of diabetes among the developing countries and sub-Saharan Africa has been attributed to variety of social, cultural and economic factors coupled with increased urbanisation and changing lifestyles. Similarly, low levels of understanding and knowledge about diabetes are reported to significantly contribute to the high observed levels of diabetes. The cost implications for the management of diabetes are highlighted.

The third section describes the care delivery and management of diabetes mellitus globally and in sub-Saharan Africa including Tanzania. Care and management challenges for diabetes in developing countries, sub-Saharan Africa and in Tanzania in particular are highlighted. Provision of quality care and management of diabetes appears to be facing structural and administrative challenges coupled with an overwhelming problem of financial resources to meet the day to day costs of managing this disease.

Lack of or inadequate, financial resources for purchasing diabetes drugs and related services are reported to be a significant problem for individual patients and their families. These challenges are further complicated by limited or inadequate knowledge about diabetes among some patients and many caregivers, family members and/or social networks.

Section four describes studies of health-seeking behaviours, pathways for diabetes. Health-seeking behaviour is among the important factors determining uptake and outcomes of health care services for diabetes. Health-seeking behaviour is influenced by peoples' perceptions about the disease within the context of traditional and cultural beliefs and attitudes. Cultural classification of illness and the people's perceptions about the diseases within such classifications are noted to determine not only the course of action in terms of health care seeking but also when and from where it should be sought. Health-seeking behaviour is also reported to be influenced by the health care system and the nature and manner in which care services are provided. Patients are often reported to choose alternative health care services through traditional practitioners over public facilities for many reasons but more specifically due to their cultural beliefs about the nature of their service.

The chapter ends with section five which present reflections on reviewed health-seeking behaviour models. The models have been refined through a number of studies both in developed and in developing countries. Syntheses of how these models interact in explaining the observed health-seeking and health related behaviour for various communicable and NCDs are made.

Chapter 3–Methodology and Methods

“Knowing what you want to find leads inexorably to the question of how you will get that information” (Miles & Huberman, 1984)

3.0 Introduction

This qualitative study provides in-depth exploration of an array of issues related to health-seeking and health related behaviour and the overall provision of care and management services for type 2 diabetes mellitus. The conceptualization of the study, the development of the study’s objectives and tools, as well as data collection, analysis and interpretation were informed by McKinlay’s (1972) theoretical framework. In so doing the current study used both descriptive and interpretive approaches as highlighted below in section 3.8.

Since the intended study outcome was to provide information likely to influence health policy, health seeking and care service provision, selection of subjects for the study was done carefully to capture the perspectives of the patients and health care providers including the perspectives of key stakeholders such as key national health officials. The study further collected information from the patients’ caregivers and community members who by virtue of living with people with diabetes are better positioned to provide relevant perspectives related to care seeking and management.

This chapter is divided into three sections. Section one starts by positioning the current study within the health care services research paradigm. Section two presents the rationale for the use of a qualitative research methodology and McKinlay’s theoretical frameworks in the development of the study tools, analysis and interpretation of the study findings. Finally, section three focuses on the research process and the methods used for data collection and analysis.

3.1 Health Services Research

Health services research is defined as a multidisciplinary field of scientific investigation which studies how social factors, financial systems, organisational structures and processes, health technologies, and personal behaviours affect access to health care

services, the quality and cost of health care, and ultimately our overall health and well-being (Academy Health, 2000). Its main research domains include individuals, families, organisations, institutions, communities and populations.

Bowling and Ebrahim (2005) propose that health services research seeks knowledge and evidence that will lead to improvements in the delivery of care services. It aims to provide reliable and valid research data on which to base appropriate, effective, cost-effective, efficient and acceptable health services at the primary and secondary care levels. Amongst its objectives is research into how behavioural change to enhance prevention might be achieved and how to improve care of people with chronic diseases. Therefore, health services research generally focuses on:

- the relationships between the population's need and demands for health services, and the supply, use and acceptability of such services;
- the process and structures, including the quality and efficiency, of health services delivery;
- the appropriateness and effectiveness of health service interventions, their cost-effectiveness, and patients' perceptions of outcomes in relation to the effects on their health, health-related quality of life and their satisfaction with health care outcomes (Bowling & Ebrahim, 2005).

The current study aims to generate information to inform policy frameworks and guide public health interventions focused at improving the quality of care and management of diabetes in Tanzania. Quality of care is clearly relevant to health care services research. Donabedian (1980) describes quality of care in relation to its effectiveness in improving the patient's health status, and how well it meets professional and public standards about how the care should be provided. Therefore, quality of care includes efficiency, effectiveness, acceptability, humanity and equity. Patient empowerment is undoubtedly central and necessary to increase patient control over the services provided (Higginson, 1990).

3.2 Rationale for Qualitative Research

Qualitative research was chosen as a strategy of choice in studying the factors that influence health-seeking and health related behaviour among adult people with diabetes. This approach allows an in-depth exploration of patients' own perceptions, attitudes and behaviour in relation to health care seeking. It also enables in-depth views of patients' caregivers, health care workers and community members in relation to the overall process of health care seeking and service delivery in their natural settings. Qualitative research is an approach which encompasses many disciplines, fields and subjects. It has neither a theory that is distinctly its own nor a single method that is given priority over another. Denzin and Lincoln (2005, p.3; 2005, p.3) for example, give the following definition in their seminal textbook on qualitative research:

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.

The current research applies qualitative methods aimed at informing intervention strategies and policy frameworks for type 2 diabetes in Tanzania. According to Patton (1990), qualitative research enables researchers to get particularly close to the problems under study during field work and brings their personal insights and experiences into any recommendations that may emerge from the data. Indeed, in this research, as I became more familiar with the challenges in health seeking and care management of type 2 diabetes I was able to develop some tentative structural solutions and cultural recommendations which may enhance health care seeking and provision of quality care services in Tanzania. Further, Denzin and Lincoln as well as Guba and Lincoln (Denzin & Lincoln, 2005, p.10; Guba & Lincoln, 1994, p. 112) had this to say about qualitative research:

Qualitative research methods are able to expose contextual information that is often missed or lost in quantitative designs. The dominant paradigms of quantitative research are to apply methods that measure exposure as simple, independent variables so as to maximize the study's rigor in identifying causation. However, this reductionism approach results in a loss of information about meaningful context and may tend to investigate how exposures influence outcomes in interaction with other outcomes. Inherent to those exclusionary designs is the loss of the human factor, which often

injects the small quantity that gives meaning and purpose to an outcome. Equally so, the quantitative paradigm of objective of enquiry by the ‘disinterested scientist’ may often have the unintended result of producing results that have no meaning to the studied or affected group”.

Guba and Lincoln’s (1994) approach to qualitative research has certainly influenced the current study. Their observations were influential on my decision to use qualitative methodology, as was their focus on human behaviour in generating information and knowledge that has meaning to the group being studied in this thesis – people with type 2 diabetes. The use of qualitative methods enabled me to explore why people with diabetes and their caregivers behave the way they do. The approach enabled me to engage the patients to describe their experiences of living with diabetes and the challenges they face in its management. Through qualitative methods the present study was able to generate information which provides a better understanding of people’s beliefs and attitudes that influence the use of biomedical care services as well as alternative care services in managing type 2 diabetes.

3.3 Theoretical framework

Traditionally public health researchers have been called upon to provide a description of the theoretical framework for their research, the methods used to collect and interpret data, and the process for analysis of research results (Frohlich, Mykhalovskiy, Miller, & Daniel, 2004). This section presents the theoretical framework employed in the current research. Over the years, researchers have developed theoretical models of the influences on health-seeking behaviour. These models vary in scope and assumptions depending on the disciplines in which the researchers are trained (Torres-Gil & Kuo, 2001, p.18). McKinlay’s (1972) theoretical framework, for example, takes a broad approach which shares assumptions developed through other models (Chapter Two), which are associated with health-seeking behaviour. The popularity of McKinlay’s model is due to its inter- and multi-disciplinary research approaches to health-seeking behaviour (Pescosolido, Gardner, & Lubell, 1996).

McKinlay’s theoretical framework has provided an overall foundation for the current research starting from the literature review to the formulation of research objectives and questions. It allowed me to develop methodological approaches to the overall exploration of factors influencing health-seeking and health related behaviour for people

with type 2 diabetes. McKinlay's theoretical framework, which resulted from extensive analysis of various studies on health service utilisation behaviour, highlights six major approaches that can be used in understanding health-seeking behaviour, as follows.

1) ***The economic approach:*** According to McKinlay this approach focuses on the factors that transform needs into demand, such as income, health insurance cover, the cost of health services and availability of free medical care. Financial costs for medical care services to McKinlay are pre-determinants of health-seeking behaviour. Consequently, the nature of individual and family income and cost of accessing services are highly linked to the level of health-seeking behaviour and the use of hospital facilities. Similarly, the method of payment may influence health-seeking behaviour and the quality of the health care provided. Nevertheless, McKinlay argues that the removal of costs for health care services by themselves, might not make a difference to the health-seeking behaviour among other individuals. These observations led him to conclude that cost is not the only and/or necessarily the most important factor affecting health-seeking behaviour in some settings.

2) ***The geographical approach:*** According to McKinlay the proximity and locality of health care services in relation to a target population plays an important role in influencing health-seeking behaviour. There is a significant relationship between health-seeking behaviour and the distance to the clinics from the patients' homes. However, as in the economic approach McKinlay argues that even when lack of geographical accessibility is addressed, certain groups will still tend to routinely under-utilise medical certain care services. Based on these observations he suggests that much more work is needed to determine the precise effect of geographical proximity in relation to health-seeking behaviour.

3) ***Socio-demographic approach:*** In this approach McKinlay describes the research that has looked into demographic variables and/ or individual traits such as age, gender, social class, marital status, occupation and education. Various studies have found that these traits and/or factors also influence health-seeking behaviour. For example some researchers have found that women seek care earlier than men but in other studies it has been argued that men seek care earlier because they control resources as heads of

households. Similarly, young people in other settings have been reported to seek care earlier than older people and vice versa. McKinlay however, cautioned that this approach alone might not offer adequate answers to a range of questions related to health care seeking behaviour.

4) **The social-psychological approach:** The focus here has been on the work that has approached health utilisation behaviour in reference to motivation, perceptions and learning. McKinlay added that this approach should include various fears based on uncertainty about the medical outcomes or findings: fear about the nature of treatment, or fear of the medical condition getting worse. Other relevant factors might include knowledge and perception of the illness; recognition of medical care need; perceptions of medical care urgency; and degree of alienation from health care organisations. Equally, McKinlay states that relationships with health service personnel have also been cited to influence health-seeking behaviour. He states however, that given the same medical care needs, some people may turn to different sources of health care services.

5) **The socio-cultural approach:** In this approach McKinlay directed his attention to the studies that have focused on values, norms, beliefs, definitions of health situations, and lifestyles associated with health-seeking behaviour. McKinlay noted that this approach is based on the idea that within certain communities one will find beliefs about when action related to seeking health services should be taken. McKinlay commented that people are ordinarily symptom free, get symptoms at a specific time, and either act or fail to act. He challenged researchers to examine the role of families and/or social networks in decision making particularly in chronic illness and health-seeking behaviour. According to McKinlay the concept of families and/or social networks in the research of health-seeking behaviour may provide more detailed and sensitive information on specific and inter-related influences in health care seeking behaviour.

6) **The organisational approach:** Here McKinlay refers to the impact of organisational factors on health-seeking behaviour, in particular the assumptions and responses of the health care system and staff to people using health services. He focuses on the conflicts between the values and beliefs of health care personnel and the structures of health care services delivery systems and the users of care services. According to McKinlay the main concern in this approach is that there may be organisational or health care delivery

system barriers which may cause client dissatisfaction that in turn may affect health-seeking behaviour. McKinlay states that organisational or health care delivery system phenomena may be important influences on health-seeking behaviour as well as personal characteristics. He concluded that there is an ever-widening gap between biomedical care services and certain groups of the population who continue to cling to their traditional beliefs. There is a need for health care systems to tailor their services to meet the particular needs of their clients.

McKinlay emphasises that it is only through examining the interactions and interrelationships between the six approaches highlighted above that one will be able to answer the question “*what are the factors influencing health-seeking and health related behaviour*”. This theoretical framework has been used to structure the subsequent investigation of influences on health-seeking and health related behaviour among people with type 2 diabetes in the current study.

3.4 The Research Process

This section describes the research process and methods employed in the current research. According to Ken (2003) research methods include specific research techniques used to collect and analyse data.

3.4.1 Ethics approval and local consultation

Ethics approval for the present research was first sought through the University of Otago Ethics Committee in New Zealand and the Research and Publications Committee at Muhimbili University of Allied Health Sciences (MUHAS) in Tanzania because the data collection was carried out in Tanzania. After ethics approval was granted by both bodies (Appendix 3.1 & 3.2), I then travelled back to Tanzania to work on the preliminary logistics for the present study.

Back in Tanzania I visited the three districts in Dar es Salaam municipality where the study was conducted. I met separately with the District Medical Officers of the three districts of Kinondoni, Ilala and Temeke. I introduced myself, presented a copy of the study's ethics approval letters and briefly presented the purpose of the intended study. Furthermore, I responded to all the questions raised by the District Medical Officers

regarding the proposed study. The District Medical Officers then issued me with formal letters officially permitting me to carry out the study in their respective districts (Appendix 3.3, 3.4, 3.5). With these letters at hand, I was able to set up meetings with the medical officers in charge of the diabetes clinics in the three districts.

The meetings with the medical officers in charge of the three diabetes clinics addressed and clarified a number of logistical issues related to the data collection process. The meetings were followed with other official letters permitting me to carry out the main study in the respective clinics (Appendix 3.6, 3.7). The whole process from the applications for ethics approval to the final permits from the doctors in charge of the respective diabetes clinics took almost three months. I started data collection in March 2007 and finished in June that year.

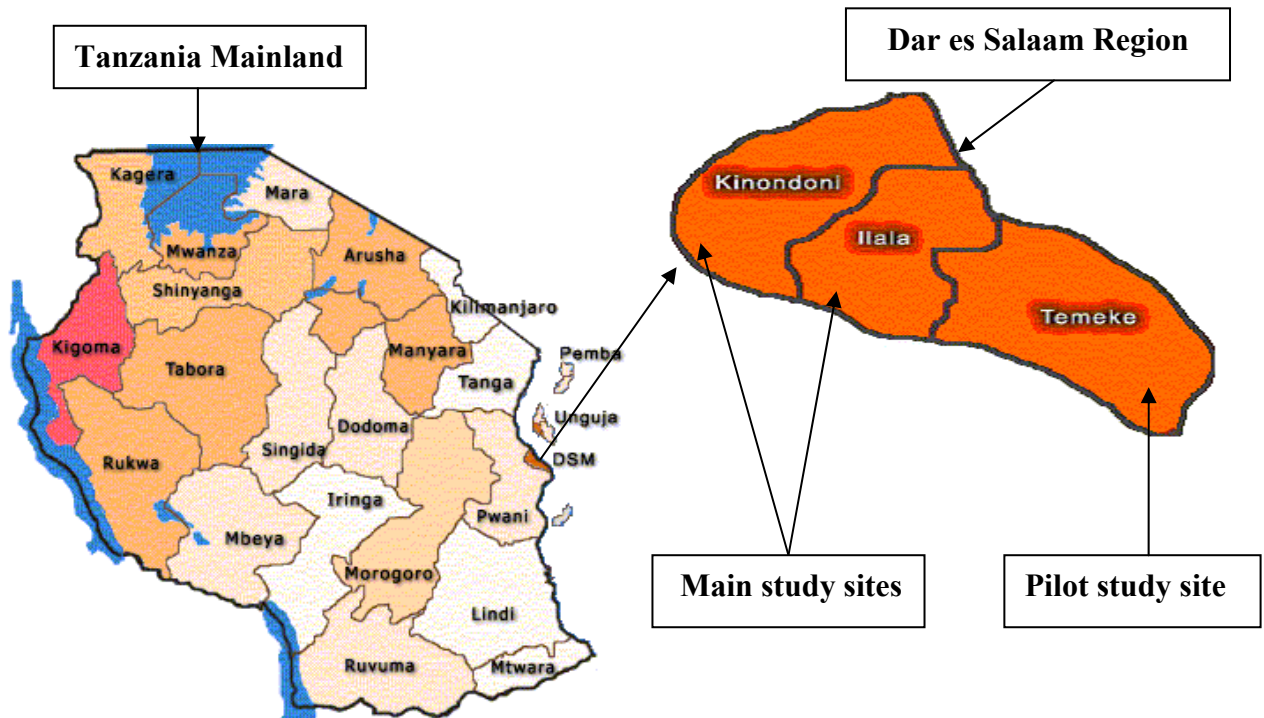
3.4.2 The study setting and justification

Dar es Salaam is now estimated to have more than 10, 000 people with diabetes (TDA personal communication, 2007). The city is divided into three major districts of Ilala, Temeke and Kinondoni. The pilot study was carried out in one of the most urbanised wards in Temeke district with a public primary health care diabetes clinic. The main study was carried out in the two most urbanised wards purposively selected from a list of wards in the two districts of Ilala and Kinondoni respectively. The two wards hosted the Amana and Mwananyamala public hospitals respectively and each hospital had one diabetes clinic. Unlike the Temeke district, the two districts of Ilala and Kinondoni had relatively good infrastructure and a good mix of public and private health care services for diabetes patients. The two public primary health care diabetes clinics were also selected because of their accessibility and affordability of services for the vast majority of people in the city. They both received government subsidised diabetes drugs. Two research sites of Ilala and Kinondoni districts were selected to increase the range of the data collected. Specifically, it increases the richness of data available for analysis and therefore can facilitate a more complete understanding of the issues (Travers, 1995, p.27).

Dar es Salaam City has about 2,497,940 inhabitants (National Bureau of Statistics Tanzania, 2002). The population is distributed among the three districts in the city as

shown in the map below, with Kinondoni district having 1,088,867 residents and Ilala district having 637,573. Kinondoni district has 27 wards, 22 of which are urban based, while three are mixed wards and the remaining two are mainly rural communities. Ilala district has 22 wards of which 17 are urban based, three are mixed and two are rural based.

Figure 3.1: Map of the Study Site



3.5 Pilot study

The pilot study for the present research was carried out in Temeke district. In each interview session after introducing myself I shared the information sheet and/or its contents for those who could not read, after which consent to participate in the study was obtained. Similarly, in each interview permission was sought from the respondent before using a tape recorder to document the conversation. Through this process oral and/or written consent from all the participants was granted.

For this component of the study, in-depth interviews were carried out: one with a diabetes patient who attends the clinic regularly and her caregiver, and one with an infrequent clinic attendee and his caregiver at their home. Similarly, in-depth interviews were carried out with two health care workers at their workplace: a registered nurse and a doctor. Overall, this study component went well with the exception of problems I had

in locating patients and their caregivers' homes. Given the lack of defined street names and absence of house numbers it was difficult to locate the majority of the patients not only in the pilot phase but also during the main study. In an effort to get to the homes of the patients and their caregivers I had to be escorted by other patients at the clinic who knew where they lived. This was a method I designed during the pilot study to get around the problem.

3.5.1 Data analysis

The pilot study interviews of the six participants (i.e. two patients and their caregivers including two health care workers) were transcribed in the first week of March 2007 followed by translation into English. I met with my research assistant to double check the translation. The research assistant was a social scientist, a native Swahili speaker fluent in English with extensive experience in transcription and translation. I analysed all the pilot study data manually and had a meeting with the research assistant to review the raw information. The following main themes emerged from the data:

- Lack of money for bus fares, buying drugs and recommended food
- Distance from home to the clinic
- Poor availability of affordable drugs at the public clinic
- Poor organisation of diabetes clinic services such as opening time, long waiting time and long queues
- Absence of a diabetes specialist at the clinic
- Lack of escort to the clinic
- Inadequate and poor public transport
- Social and cultural beliefs

Based on this data I prepared a brief report which was sent to my supervisors at the University of Otago, Wellington in New Zealand to share the issues emerging from the study. Following their comments on this report I then proceeded with the main data collection for the study.

3.5.2 Lessons learnt from the pilot study

3.5.2.1 Study instrument

- The pilot study helped me to test the appropriateness and clarity of the study data collection instrument.
- The in-depth study instruments for patients, their caregivers and health care workers turned out to be far too long. On average each interview took about two hours.
- Some of the questions were repetitive which made the questionnaire unnecessarily long. The instrument was revised to eliminate the repetitive questions.

3.5.2.2 Data collection

- Lack of house numbers and street names in the city of Dar es Salaam made the task of visiting patients and their caregivers at home highly problematic. I had to enlist the assistance of other patients who knew where these patients resided.
- The original idea of making two visits to the patient's home (i.e. one visit for introducing the study and soliciting their consent to participate, followed with another visit on an appointed day for the actual interview) was not realistic. My experience was that these two visits were not necessary since most patients were willing to have the interview done the same day once they had agreed to take part in the study. All participants in the pilot study were willing to have the interview sessions tape recorded, making the process of documentation easier.

3.5.2.3 Data management

Given the size of the study instruments and the lengthy nature of the responses that were provided by the participants, the exercise of transcribing the contents was time consuming. The first transcription was made in Swahili and translated later into English. This needed to be done carefully to ensure that the content and meaning of the responses were well represented.

3.5.2.4 Methodological responses to the experience from the pilot study

- Following the pre-testing of the study instruments my research assistant and I incorporated the relevant changes into the study instruments including

rewording or eliminating some of the questions that were repetitive. The study tools were now more realistic and ready for use in the main study.

- The highlighted ambiguities in the study instruments were adjusted to ensure comprehension of the questions by all study participants.
- To maintain data quality for the main study I decided to do the transcription and translation myself.
- Clinic patients were enlisted to help locate addresses of study participants

3.6 The Sampling Strategy for the Main Study

The current study sought to recruit a wide range of subjects utilising a purposive sampling strategy to gain in-depth knowledge and understanding of the factors influencing health- seeking and health related behaviour for type 2 diabetes mellitus. According to Patton (1990; 2002) a purposive sampling technique is used to select participants for a study to ensure that the information collected is rich and clearly addresses the issues in question. Similarly, Glaser (1978) states that purposive sampling is often used to select people with different backgrounds (different sexes, ages, education levels, employment status, duration of disease, experiences with the health care system) to enrich the nature of information gathered.

An equal number of subjects were selected from these clinics. The Amana and Mwananyamala clinics are located in wards that encompass two different socio-economic populations. The former consists of a lower to middle class population while the latter appears to fall in the middle to upper levels. The majority of the residents in the two wards are known as “Watu wa Pwani” or “Waswahili” (the Coastal people or Swahili people).

3.6.1 The Diabetes Patients and their Caregivers

Through the cooperation of the health care workers at the selected diabetes clinics I identified 15 people with type 2 diabetes. I purposely recruited a mix of patients’ gender, those who were aged 35 years and above and those who were diagnosed at least one year before this study. People with diabetes were categorised into two groups consisting of regular or infrequent attendees. Regular attendees in this study were

mainly people with diabetes who attended more than 50 per cent of their scheduled clinic appointments during the past year before the study. The infrequent attendees referred to people with diabetes who attended less than 50 per cent of their scheduled clinic appointments during the past year before the study. Further, I identified a mix of these participants' caregivers gender. This method was applied from each clinic (ten people with diabetes who were regular clinic attendees and five who were infrequent clinic attendees). Regular clinic attendees included patients who had attended the diabetes clinic frequently as scheduled. This group was selected to elicit experiences and patterns of health seeking and health related behaviours and challenges of utilisation of biomedical diabetes care services. The infrequent clinic attendees included patients who had not attended the diabetes clinic for more than a year. This group was selected to elicit the experience of people who had used and then stopped using the biomedical services. The focus here was not only to find out the reasons for stopping the use of services but to identify what alternative services were used. Residence information for the infrequent clinic attendees was obtained through health care providers or other people with diabetes who knew them. Once contact was established with the patients I sought an appointment to meet and interview them. I also enlisted their support in identifying caregivers whom they perceived to be providing them with care and social support. On the appointed day and time, I visited both the patient and their caregiver and introduced myself to them explaining the purpose of my visit and the nature of the study that I was doing. I then went on to ask them if they had time for an interview or would they rather I came back on another day. Where feasible I interviewed the subjects individually on the same day at their home (Figure 3.2).

Figure 3.2: Researcher conducting in-depth interview at patient's residence 2007



The purpose of trying to do the interviews on the first day of our meeting was to save me both a trip and the escort's time, since the majority of patients were staying in unmarked streets and houses (Figure 3.3). The only assured way of getting there was to have an escort who knew the place well.

Figure 3.3: View of some streets and houses without names and numbers in Dar es Salaam 2007



Fortunately, most patients and their caregivers gave their consent to be interviewed the same day and were also agreeable to having our conversations tape recorded.

Figure 3.4: Researcher trying to locate Patient's residence in Ilala District, Dar es Salaam 2007



3.6.2 The Health Care Workers

Since each of the diabetes clinics involved in this study was run by a handful of health care workers (i.e. one or two registered nurses, one enrolled nurse, and one doctor specialist in diabetes), I decided to interview all clinical staff at each clinic irrespective of their age, sex, gender and grade. The only exclusion criterion was if the health care worker had worked at the clinic for less than six months. The aim was to obtain their clinic experiences in working with people with diabetes and the nature of the challenges they faced in providing care services to their patients at the respective clinic. Following my brief introduction of the study I sought their consent for participation in the study and made an appointment for a formal interview day and time.

3.6.3 The Diabetes Clinics

Amana clinic is located in the west while the Mwananyamala clinic is located in the eastern part of Dar es Salaam within the district council/public hospitals. The two

diabetic clinics are located in an urban area of each district. Each of the clinics provide care services to patients three times a week and are run by one medical officer qualified in general medicine but who has also received short training in diabetes.

Figure 3.5: Mwananyamala Diabetes Clinic in Kinondoni District, Dar es Salaam 2007



Figure 3.6: Ilala Diabetes Clinic in Ilala District, Dar es Salaam 2007



When patients arrive at the clinic the registered nurse or enrolled nurse carries out a physical assessment and refers them to the medical officer who offers more assessment

before prescriptions. The doctor prescribes appropriate treatment after which the patient goes to the pharmacy to get the drugs before they go home. Neither clinic had equipment for an oral glucose tolerance test or HbA1c (glycosylated haemoglobin) test. The clinics mostly used urine test and strips; blood with strips and glucometer for measuring casual glucose. Patients who needed this test were normally referred to Muhimbili National Hospital or private hospital.

3.6.4 The Community Members

A sample of community members without diabetes, aged 35 years above was purposively selected to achieve a mix of gender. They were selected from the communities in the catchment areas of the diabetes clinics. The selection of the community members for this component of the study was carried out by moving west from the main gate of the hospital. With the assistance of the local community leaders about 11 households were selected from the list of households under the Ward Chairperson (Mwenyekiti wa kata). Moving in one direction from the hospital gate one family was selected from each of the houses that had a minimum of five tenants and from each family a man and a woman over the age of 35 were selected until the number of ten respondents for each sex needed for FGDs was reached. All households with people with diabetes were first excluded from the list. During the house to house visits I took the opportunity to introduce myself and the purpose of my study to the selected families and following their agreement to participate in the study I informed them about the venue, the day and the time for the FGDs. On the day for interviews the men and women were separated to ensure more open and free communication during the discussion.

Figure 3.7: Focus Group Discussions (FGDs) with Community Women in Ilala District in Dar es Salaam 2007



During the FGDs, I was the moderator and the research assistant took notes. I was able to conduct two FGDs (one for men and one for women) in each of the two catchment areas for the two diabetes clinics involved in the main study, bringing the total number of FGDs among community members to four.

The purpose for doing FGDs with community people was to gain information on the awareness, knowledge and understanding that people without diabetes have about the disease. The interviews also provided an opportunity to explore their experience with the health care system and the nature of various health care services and community cultural norms. The group further provided some insights into factors which influence health- seeking and health related behaviour for other diseases including diabetes at the community level.

3.6.5 The Key National Health Officials

According to Patton (2002) key informants are people knowledgeable about the subject under study and who can give informed opinions on broad questions and issues pertinent to the subject. The key national health officials in the present study were

identified according to their specialised knowledge of diabetes care and management in Tanzania. The decision to interview key informants was made after all other participants were interviewed. The intention was to generate additional data to enrich the information already derived from interviews with other participants. These key informants were used also as a sounding board in clarifying the key issues raised by the participants, particularly patients, with regards to accessibility to quality care services and affordability of drugs. Some of the tentative policy-related recommendations raised by the participants in the study were also discussed with these key informants. One of the key informants included in the list that was developed in consultation with my supervisors was the Chief Medical Officer of the Ministry of Health and Social Welfare. All the key informants on the list were contacted by phone and appointments for face-to-face interviews were made. The list of key national officials interviewed during the study is presented in Table 3.1.

Table 3.1: Key National Health Officials Interviewed

Position	Organisation
Chief Medical Officer and member of Tanzania Diabetes Association of Tanzania	Ministry of Health and Social Welfare
Head-NCDs	Ministry of Health and Social Welfare
President of Tanzania Diabetes Association (TDA)	Muhimbili National Hospital
Vice-president and chairperson of International Diabetes Federation (IDF)–African Region	Hindu Mandal Hospital
Coordinator of community diabetes management in Dar es Salaam	Temeke Hospital
Director of National Food and Drug Authority	National (Tanzania) Food and Drug Authority (NFDA)

Unlike the people with diabetes, their caregivers and health care workers the key national health officials provided verbal consent only. This was in compliance with their wishes.

3.7 The Sample Size

It was difficult to decide how many participants to include in a study of this nature. Existing literature varies widely on the recommended size for a sample to be used in qualitative studies. Some have suggested that interviews for qualitative studies may be carried out until data saturation has been achieved (Patton, 2002). Proponents of this argument state that after reaching data saturation no further participants should be approached and the process of data collection should come to an end. Others argue that in order to gather a sufficiently wide range of experiences one needs to interview about 30-60 people in a carefully selected “maximum variation” sample (Bernard, 2000). In the final event the sample size for the current study was largely predetermined before data collection began for logistical reasons. However, data saturation was noted when there was repetition of themes. This indicated that there were no major new themes emerging during the interviews with various study participants, including patients and their caregivers.

The sample size for the current study consisted of a total of 20 people with type 2 diabetes (i.e. ten regular clinic attendees from Amana and Mwananyamala clinic in Ilala and Kinondoni districts respectively). As it turned out, the 20 regular attendees did not all have caregivers, so only 14 caregivers were recruited. Further, I interviewed ten people with type 2 diabetes who were reported to be infrequent clinic attendees (five from each clinic) with their six caregivers. I also interviewed seven health care workers from the diabetes clinics, and six key national health officials. Additionally, my research assistant and I carried out two focus group discussions with people with type 2 diabetes from each diabetes clinic during the study (i.e. one for men and the other for women). Similarly, we carried out two focus group discussions with community members selected from the study catchment areas (also divided by gender). In total, we carried out eight focus group discussions (four among people with type 2 diabetes and four among community members) bringing the total number of participants involved in this study to 148 as presented in the breakdown in Tables 3.2a and 3.2b.

Table 3.2a: Breakdown for in-depth and key informant interviews in the current study

SERIAL UMBER	SITES	GROUP DESCRIPTION	SEX		SUB - TOTAL	TOTAL
			MALES	FEMALES		
1.	A-Clinic	Regular clinic attendees people with type 2 diabetes	5	5	10	20
	M-Clinic		5	5	10	
2.	A-Clinic	Caregivers of regular clinic attendees people with type 2 diabetes	2	5	7	14
	M-Clinic		3	4	7	
3.	A-Clinic	Infrequent clinic attendees with type 2 diabetes	3	2	5	10
	M-Clinic		4	1	5	
4.	Amana Clinic	Caregivers of infrequent clinic attendees people with type 2 diabetes	1	2	3	6
	M-Clinic		0	3	3	
5.	A-Clinic	Health care workers	1	3	4	7
	M-Clinic		1	2	3	
6.	National	Key national health officials	5	1	6	6
GRAND TOTAL						63

Key: A-clinic=Amana clinic; M-clinic=Mwananyamala clinic

Table 3.2b: Breakdown for Focus Group Discussion (FGDs)

SERIAL NUMBER	SITES	GROUP DESCRIPTION	SEX		SUB - TOTAL	TOTAL
			MALES	FEMALES		
1.	A-Clinic	FGDs for people with type 2 diabetes	12	10	22	45
	M-Clinic		12	11	23	
2.	I-District	FGDs for community members	10	9	19	40
	K-District		10	11	21	
GRAND TOTAL						85

Key:

I-District = Ilala ; K-District = Kinondoni

A-clinic=Amana clinic; M-clinic=Mwananyamala clinic

3.8 Study Methods

As mentioned in the introduction to this chapter, this qualitative study adopted both descriptive and interpretive approaches in the data analysis. Qualitative studies include both descriptive and interpretive approaches (Maxwell, 1992; Lopez & Willis, 2004) and will answer questions about “what” or “how” (Chenail, 1995). A descriptive approach focuses on describing meanings and/or experiences of individuals. The interpretive approach, on the other hand, focuses on human experience rather than what they consciously know (Solomon, 1987). The latter approach also examines how individuals’ meanings influence the choices they make and how they assign meanings to them (Orlikowski & Baroudi, 1991).

Furthermore, Smith (1987) argues that the interpretive approach does not negate the use of a conceptual framework. According to Smith the approach helps in the interpretation of the narratives described by respondents in relation to various contexts. In the current study I utilized McKinlay’s (1972) framework to interpret the narratives described by respondents in relation to their diabetes experiences.

Several studies have shown how descriptive and interpretive approaches have been applied in research (Lopez & Willis, 2004). For example, in his study on the experiences of women with postpartum depression, Beck (1992) used a descriptive approach to answer the question “*what is the essential structure of postpartum depression?*”. The narratives were analyzed according to Colaizzi’s (1978) method. The findings were reported according to themes with examples of respondents’ comments that supported the themes. In the current study, I analyzed respondents’ narratives according to Miles and Huberman’s (1994) method. I reported the findings under each theme with examples of respondents’ quotes that supported the themes. Furthermore, Svedlund et al.’s (1994) study on the other hand used an interpretive approach to describe women’s subjective experiences during the acute stage of myocardial infarction. The research used Ricoeur’s (1976) conceptual framework for the study. This framework was used both for the study orientation and methodology for data analysis. Respondents’ narratives were analyzed and interpreted, resulting in a description of what women experience during acute myocardial infarctions with some clear directives for practice.

As was the case with Svedlund et al.'s study, the current research was guided by a specific theoretical framework – McKinlay's (1972) framework – during the data collection and interpretation of the findings. Similarly, Miles and Huberman's (1994) approach was used during data analysis. Respondents' narratives were analyzed and interpreted based on what they described as influencing their health-seeking and health related behaviour for type 2 diabetes. In an effort to capture the experiences described by different respondents in the current study specific verbatim quotations were used to present respondents' perspectives. To this end some lengthy quotations were also used as needed.

Data collection in the current study was carried out using multiple qualitative methods such as focus group discussions, and in-depth and key informant interviews. The literature suggests that qualitative methods provide the most appropriate research tools for gathering meaningful data about human behaviour (Ken, 2003; McKinlay, 1972). Through the use of semi-structured open-ended questions and non-leading prompts the current study was able to engage participants into free discussions that enhanced sharing of their understanding, beliefs, attitudes and knowledge related to type 2 diabetes mellitus. The approach also enabled me to gain access to other pertinent socio-cultural factors that may influence health-seeking and health related behaviour for type 2 diabetes. Semi-structured interviews allowed maximum flexibility and coverage of the subject matter consequently capturing the richness of the themes emerging from the interactions with the participants (Drever, 1995). Efforts were made to ensure that the wording of the questions encouraged the participants to talk freely. To this end, words and phrases like: "what", "how", "tell me" or "describe to me" as opposed to "why" were mostly used because they tend to elicit more personal expressions from participants (Kvale, 1996). The current study aimed at generating as much information as possible both to describe health-seeking and health related behaviours for type 2 diabetes mellitus and to highlight the challenges faced by the patients and their caregivers in accessing care and treatment.

The in-depth interview technique was used to collect information from patients and their caregivers and health care workers. In-depth interviews allowed most participants in this study to respond to specific questions, yet tell their stories about the problems of

diabetes (Flick, 1998). It also allowed each participant to discuss their individual thinking about diabetes without being influenced by group dynamics (Patton, 2002). This is in contrast to FGDs whose the ideas of one respondent may influence the thoughts of another participant (Patton, 2002). Also, depending on the nature of the question some patients in this study were more willing to discuss personal issues during in-depth interviews than they would be in FGDs (Patton, 2002). Similarly, on certain occasions in this study some participants were less willing to open up in one-on-one interview compared with the relaxed atmosphere of FGDs (Patton, 2002). In view of these uncertainties efforts were made throughout the study to maintain trust and good rapport with all the respondents in order to generate as much information as possible from each one of them.

Key informant interviews were used to collect data from national health officials. According to Patton (2002), key informants are useful in helping the researcher to understand what is happening and why. In the current study key informants were useful in understanding what is happening in the Tanzanian health care system particularly in highlighting the challenges related to the provision of quality care and management of diabetes. Through the key informants this study was more informed about the Tanzania Diabetes Association and its ongoing contribution to care and management of diabetes in Tanzania. Given the limitations of relying on information from key informants as mentioned by Patton (2002), I decided to diversify the data collection methods, approaches and sources of such data to ensure its objectivity.

The study carried out focus group discussions with people with diabetes and selected community members separately using a semi-structured open-ended interview guide. To ensure more open and free communication men and women in each of these groups were interviewed separately. According to Dawson, Maderson, and Tallo (1993), focus group discussions are valuable for exploring a community's socio-cultural norms and beliefs associated with NCDs. FGD produce a lot of information more quickly while using less resources than individual interviews (Dawson et al., 1993). As suggested by Dawson and colleagues some of the illiterate respondents in this study were able to participate effectively in the focus group discussion providing significant contributions to the issues related to diabetes care and management. Similarly, most participants in the current study found the group discussion to be an opportunity for learning from each

other about diabetes and its management. To avoid the limitations associated with FGDs such as “groupthink” as observed elsewhere by (Krueger, 1994) I made sure that all the participants in the FGDs were given equal opportunity to air their views thus limiting the chances of some participants to sway the group’s thinking. I was equally conscious of the risks of a facilitator influencing participants into a certain way of answering questions (Dawson et al., 1993) as well as participants’ reluctance to discuss personally sensitive issues during FGDs (Bowling & Ebrahim, 2005). To this end, efforts were made to ensure that discussions of personal issues were limited to the in-depth interviews.

3.8.1 Respondent validation

Several limitations are known to be associated with qualitative methodology. Respondent validation, or “member checking”, includes techniques in which the researcher’s account is compared with those of the research subjects to establish the level of correspondence between the two sets. Study participants’ reactions to the analyses are then incorporated into the study findings. Although some researchers view this as the strongest available check on the credibility of a research project (Morse, Barrett, Mayan, Olson, & and Spiers, 2002) it has its drawbacks. For example, the account produced by the researcher is designed for a wide audience and will, inevitably, be different from the account of an individual informant mainly because of their different roles in the research process. As a result, it is better to think of respondent validation as part of a process of error reduction which also generates further original data, which in turn requires interpretation (Bloor, 1997, p.221-238). In the current research respondent validation was done immediately after each interview. Participants were asked to indicate if they felt that the content was consistent with the summary I presented at the end of our interview and/or discussion. A few respondents identified some issues, omissions and errors which were corrected then included in the interview notes.

3.8.2 The triangulation strategy

Triangulation in research has been described as a process of combining multiple data collection methods (method triangulation), sources (triangulation of sources), theories or theoretical approaches (theoretical triangulation) and multiple analysts (analyst

triangulation) to review the findings in a study of a single phenomenon (Patton, 2002). According to Patton, triangulation provides different ways of looking at the same phenomenon. This study has adopted several strategies to ensure triangulation. First, it employed different methods of qualitative data collection such as in-depth and key informant interviews as well as FGDs. Secondly, the study used different sources of data including patients and their caregivers, health care workers, key health officials and selected community members. Thirdly, the study used a multifaceted theoretical model (McKinlay, (1972) in the development of objectives, questions, and data analysis. This was adopted to ensure issues were addressed in multiple dimensions. Further, other recent models from developing countries such as Nyamongo's Health Care Switching Behaviour Model (2002), Sheeran and Abraham's Health Belief Model (1995), Good's Pathway Model (1987), Kroeger's model (1983), and Young's Choice-Making Model (1981) (Chapter 2) were adopted during the interpretation of the current findings to address issues where McKinlay's model appeared to be limited. Finally, I was able to triangulate the data that was coming from the different data collection methods during the data analysis whose interpretations were further enriched through consultations with my two research supervisors. These different types of triangulation according to Patton (2002) reduce systematic biases and distortions that could arise during data analysis thus enhancing the credibility and validity of the current study findings.

3.9 Data Management and Analysis

3.9.1 Data management

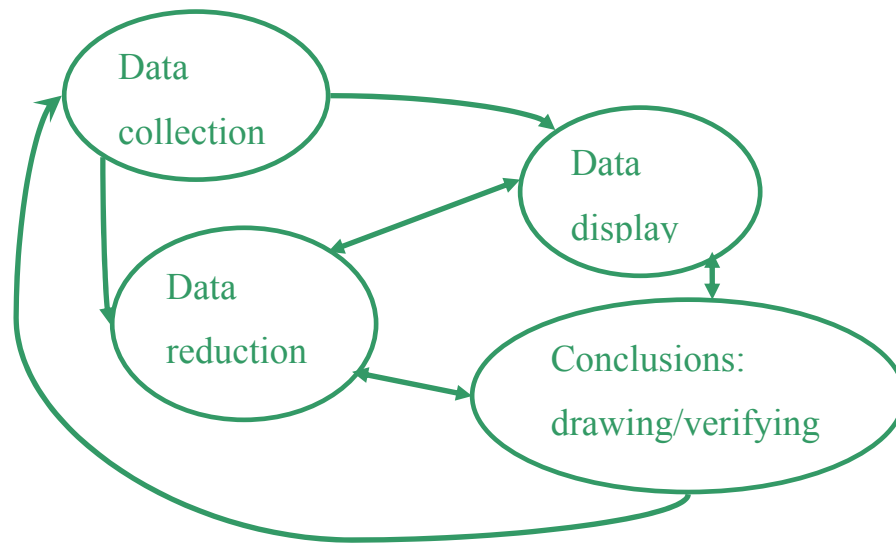
Most participants consented to the use of a tape recorder during the in-depth interviews and focus group discussions. Use of a digital voice recorder allowed me to capture all the details of the interviews and discussions while enhancing my rapport with the participants during the interviews. Further, the use of a digital camera helped me to capture a variety of data which could not be so easily documented in written form. I was able to document the environmental problems such as poor access difficulty in accessing the patients' households due to lack of street names and house numbers in some of the communities where patients came from (Figure 3.3). Similarly, I was able to document through photographs the hassles of travelling in public transport in the study area.

The interviews were all carried out in Swahili except among some of the key health officials and health workers who were more comfortable being interviewed in English. The recorded interviews were all transcribed into Swahili (except those conducted in English) and later translated into English. Due to time constraints I could not finish all the transcription and translation while in Tanzania, so this work was completed after getting back to New Zealand. Conscious of the risks of losing the meaning and the content of the data due to the use of two languages which often requires a professional interpreter (Stejskal, 2009, p.29-30) I decided to carry out the task myself. During the process, however, I frequently communicated with my research assistant, exchanging transcripts for review to ensure language consistency and interpretation. Occasionally, some Kiswahili phrases have been left without any translation purposively to retain the unique contents and expression. In such cases an English word or phrase was normally attached in brackets to provide the closest interpretation possible.

3.9.2 Data analysis

Data analysis refers to making sense of data collected so as to present findings and draw specific conclusions at the end of the study by answering the research questions (Miles and Huberman, 1994). The data analysis and interpretation of the findings of the current study were informed by multiple theoretical models, particularly the theoretical approaches of (Miles & Huberman, 1994). Miles and Huberman's theoretical approach provided me with an early step-by-step analytic strategy for managing the mass of qualitative data generated from this study, and McKinlay's (1972) theoretical approaches appear in many respects to mirror Miles and Huberman's framework particularly with the emerging themes from the data.

Miles and Huberman describe the analysis of qualitative data as being organised into three concurrent flows of activity—data reduction, data display, and drawing of conclusions based on the data. According to Miles and Huberman these three processes are interwoven before, during and after data collection in parallel, comprising a general domain called “analysis” as shown in Figure 3.8 below.

Figure 3.8: Components of Data Analysis: Interactive Model

Source: Miles and Huberman (1994)

As reflected in Figure 3.8 above, Miles and Huberman advise researchers to initiate data analysis concurrently with data collection. They argue that early data analysis can be very helpful in allowing the researcher to reflect on the meaning of the various statements and the issues whole work. In the current research the development and identification of themes was very much an evolving process and began during the data collection phase. The data analysis process was extensively enhanced by the interpretive summaries I wrote during individual interviews and focus group discussions during the data collection in the field. These notes reflect the emerging themes that were starting to take shape from the data.

Below is a summary of Mile and Huberman’s method of data analysis and how this has informed the analysis of the data in the current study.

3.9.3 Data reduction and/or coding

According to Miles and Huberman (1994), data reduction refers to the process of selecting, focusing, simplifying, abstracting, and transforming data. They argue that the data reduction process entails sharpening, sorting, focusing, discarding, and organising data in such a way that “final” conclusions can be drawn and verified. In addition, data coding reviews a set of notes, and transcribes or synthesises data into a meaningful format while keeping the relationships between the parts intact. In the current study the

hand-written field notes, audiotapes, and interview transcripts provided the key raw data sources to which the coding process was applied.

In an attempt to transform the raw data into theoretical narratives a “transcripts-based analysis” (Morgan, Krueger, & King, 1998) was used. To do this I did multiple readings line -by-line of each individual and focus group interview transcript. This allowed me to familiarise myself with the data and started me thinking about structuring and organising it into meaningful parts. This process heightened my awareness of the “patterns, themes and categories” emerging from the data (Patton, 2002). I carried out all data analysis manually instead of using electronic software because as it has been observed elsewhere (Denzin & Lincoln, 2003, p.268), manual analysis enabled me to gain a sense of the whole interview, the whole story, and the whole body of data themes as they emerge. I entered the transcripts into a word processing program after which I highlighted relevant passages and text including verbatim quotes, naturally occurring commonalities and differences in experiences, beliefs, attitudes, perceptions, knowledge, opinions and practices as well as emerging themes. Along with highlighting passages of relevant text I wrote a memo to myself as to why I thought a particular passage of text was important and any related new ideas that might have been stimulating from the text.

This activity was accompanied by the coding process. In this I produced a hard copy of each transcript and made codes (important categories) on the transcript margins in order to keep written records. The process enabled me to filter the data and pick out relevant information which was then included in the next step of data analysis (i.e. data display). While doing this I kept in mind Auerbach and Silverstein’s (2003) argument that it is important at times to keep and report specific experiences even if they happened to only one person because in qualitative research individual differences could have significant implications for the subject under study. To this end as the coding process continued I selected a new code and opened a new file for information that was not related to my research concerns and theoretical framework, but was mentioned by more than one participant in the transcripts or more than one focus group discussion.

Separate files were made in a word processing program for each individual interview and each focus group discussion, into which all the highlighted passages for each

individual and focus group discussion were copied, labelled and dated. All these files were finally saved into my larger project folder. To safeguard against missing important but unexpected information, I sent the coded transcript files to my research assistant and to my supervisors for review. Records of subsequent discussions were also kept in the larger project folder.

3.9.4 Data display and/or data organisation

Data display means taking the reduced data and displaying it in an organised, compressed way so that conclusions can more easily be drawn from study findings (Miles & Huberman, 1994). At this stage I developed several data display matrices and transferred all the stored data from the different subjects and FGDs into them (Table 5). The first column of the matrix contained the question together with the précis of the quote. The second column contained the quotes while the third column contained the participant's number and the fourth column identified repeating ideas. The fifth column was used to note rare ideas while the sixth column contained identified overarching themes. The last column includes the memos and/or notes that I made during the data reduction process. The data display matrices were very useful and at this stage I could see clearly what was happening within the data and, as (Auerbach & Silverstein, 2003) put it, "the wheat was now clear from the chaff".

Through the matrices I was able to identify a list of repetitive and/or rare ideas, grouping similar and different ideas together, followed by formulation of concepts based on their commonalities and differences. I further developed another table (Table 3.4) where core categories, major themes, sub-themes and concepts were entered. With this table I went on to summarise the concepts into sub-themes and then paraphrase these to major themes. It was at this stage that I turned to McKinlay's theoretical model for the interpretation of concepts and themes emerging from the data analysis process.

Table 3.3: Example of Data Display Matrix

Question & Précis	Quotes	Participants	Repeating ideas	Rare ideas	Theme	Memo/notes
Tell me about type 2 diabetes prevention						
Cannot prevent	You cannot prevent yourself from getting this disease	P1	Not preventable		Knowledge and perceptions about type 2 diabetes mellitus and whether it is preventable	Some patients are confident that diabetes is not preventable while some are not sure. However, one patient believes a traditional healer can prevent it.
Not preventable	No...it is not preventable	P3	Not preventable			
Don't think preventable	I don't think it is preventable	P2	Don't think it is preventable			
Not sure ...preventable	Not sure if diabetes is preventable	P4	Not sure if preventable			
Traditional healer ... prevent	Yeah...I believe a traditional healer can prevent it.	P5		Traditional healer can prevent		

Table 3.4: Example of developed Major themes, Sub-themes, and Concepts

Core Category	Sub-themes	Concepts
Health seeking and health related behaviour for type 2 diabetes mellitus	Understanding & views about type 2 diabetes	<ul style="list-style-type: none"> -Too much sugar and oily food causes of type 2 diabetes -Not transmitted -Experience all signs and symptoms -Type 2 diabetes cannot be treated, cured and prevented -Adhere to medical treatment, diet, do exercise and attend clinic regularly
	Growing consequence of diabetes in the community	<ul style="list-style-type: none"> -Type 2 diabetes is a big problem in the community -Every one at risk -Rich, old and overweight people are at risk to get diabetes
	Risk perception for contracting type 2 diabetes & its complications	<ul style="list-style-type: none"> -Everyone is vulnerable nowadays -Every patient develop diabetes complications -Delay seeking care early from the clinic -Failure to adhere to medical treatment and diet
	Attitudes and perceptions towards type 2 diabetes & its services	<ul style="list-style-type: none"> -Felt bad, sad, shocked and disappointed when first diagnosed -Did not hide from anybody

Health seeking and health related behaviour for type 2 diabetes mellitus		<ul style="list-style-type: none"> -People relate normally after knowing it is diabetes -HIV & AIDS and TB -Never thought of getting the disease -Relatives advise to use herbal drugs -Don't believe in traditional healers medicine to heal diabetes
	Influence on decisions to seek care at the health care facility	<ul style="list-style-type: none"> - Signs and symptoms -Family or social network influence -Accessibility of financial resources -Distance from home to the clinic -Knowledge of the illness -Knowledge of the services available at the clinic
	Barriers/constraints in care seeking and management for type 2 diabetes at biomedical care facility	<ul style="list-style-type: none"> -Lack of money -Inadequate and poor public transport -Poor understanding of the importance of regular check-ups (individual influence) -Dissatisfied with long queues and waiting time at the clinic

Health seeking and health related behaviour for type 2 diabetes mellitus		<ul style="list-style-type: none"> -Dissatisfied with poor patient's centred services delivery -Annual seasonal weather -Scattered diabetes services at the clinic -Unavailability of drugs from the public hospital pharmacy -High price of diabetes drugs at the private pharmacies -Distance from residential area to the clinic -Impact of diabetes complications
	Family and/or social network influence	<ul style="list-style-type: none"> -Advise on sources of care services -Children and spouse support financially and emotionally. -Escort to the clinic -Assistance in house chores
	Perceptions of health workers and delivery care system	<ul style="list-style-type: none"> -Satisfied with some health care workers' answers and explanations -Poor patient's centred service delivery -Had problems with initial prescribed drugs -Unavailability of diabetes drugs from biomedical public hospital pharmacy several times

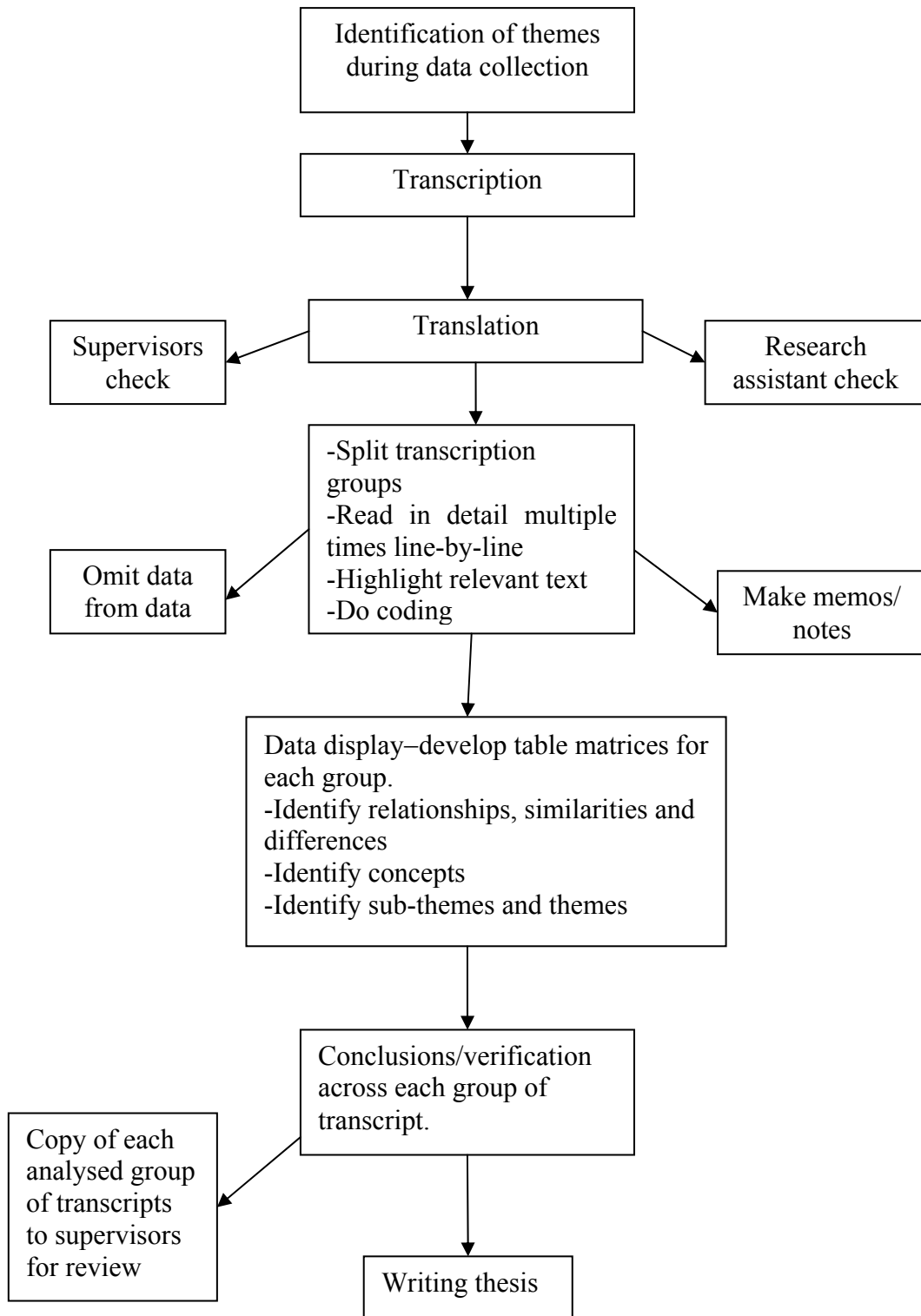
Health-seeking and health related behaviour for type 2 diabetes mellitus		<ul style="list-style-type: none"> -Unavailability of diabetes equipment at the diabetes clinics -Bought drugs from a private pharmacy across the hospital fence very expensive
	Multiple utilisation of care services for type 2 diabetes	<ul style="list-style-type: none"> -Herbalist -Traditional healers -Private health care facility -Public health care facility -Spiritual and/or faith healers -Did not seek care any where
	Effect of diabetes management costs on family welfare	<ul style="list-style-type: none"> -Squeeze family welfare to afford diabetes drugs -Burden on the family budget -Sacrifice family needs -Family lack necessary needs

3.9.5 Conclusion and Verification

Miles and Huberman (1994) state that research conclusions are a product of data analysis. In the process of drawing relevant conclusions for the current study, participants' subjective ideas and experiences were organised into coherent stories accompanied by reflective narratives. Throughout this process I kept verifying issues by reading from transcripts and/or re-listening to tape recordings for clarification and authenticity.

The process of writing reflective narratives enabled me to triangulate and compare both the information arising from the different themes as well as the information coming from different sources (i.e. people with diabetes, health care workers, caregivers, key health officials and community members). I was able to draw conclusions, and in consultation with my supervisors, developed models to explain the health-seeking and health related behaviour for type 2 diabetes mellitus at a primary health care setting in Tanzania (Chapter 7). Figure 3.9 below summarises the process of data analysis used in the current research.

Figure 3.9: The process of data analysis



Special codes and numbers were used for identification of each participant where the quote was used. These were divided into four categories including:

1. Type of interviewee

- PtI-Patient Interview
- Pt FG-Patient Focus Group
- CgI-Caregiver Interview
- CmFG-Community member Focus Group
- Hcw-Health care worker
- Go-Government Official
- Ac-Academic
- Cl-Clinician

2. Additional details

- RA-Regular Attendee
- IA- Infrequent Attendee
- KI-Key Informant

3. Gender

- F-Female
- M-Male

4. Participants Identity Number

- 10, 05, 31, 03...

The codes and numbers for participants' references were presented in table 3.5.

Table 3.5: Special Identification Codes for the study Participants where the quote used

Codes	Participants
	Patients Interviews Regular Attendees
PtIRAF10	Patient Interview Regular Attendees Female 10
PtIRAM05	Patient Interview Regular Attendees Male 05
	Patients Interviews Infrequent Attendees
Pt IIAM31	Patient Interview Infrequent Attendees Male 31
Pt IIAF62	Patient Interview Infrequent Attendees Female 62
	Patients Focus group Regular Attendees
PtFGRAM03	Patient Focus Group Regular Attendees Male 03
PtFGRAF01	Patient Focus Group Regular Attendees Female 01
	Caregivers Interviews Regular Attendees
Cg IRAM07	Caregiver Interview Regular Attendees Female 07
Cg IRAF34	Caregiver Interview Regular Attendees Male 34
	Caregivers Interviews Infrequent Attendees
CgIIAF45	Caregiver Interview Infrequent Attendees Female 45
CgIIAM112	Caregiver Interview Infrequent Attendees Male 112
	Community Members Focus Group
CmFGF02	Community Members Focus Group Female 02
CmFGM06	Community Members Focus Group Male 06
	Health Care Workers Interviews
HcwRN04	Health Care Workers Registered Nurse 04
HcwTN13	Health Worker Care Worker Trained Nurse 13
HcwDr 40	Health Care Worker Doctor 40
	Health Officials Key Informant Interviews
GoKI 58	Government Official Key Informant 58
AcKI 88	Academic Key Informant 88
CIKI 36	Clinician Key Informant 36
A-clinic	Clinics: Amana clinic
M-clinic	Mwananyamala clinic
I-District	Districts: Ilala District
K-District	Kinondoni District

3.10 Selection of illustrative quotes

Inclusion of verbatim quotations from research participants enhances the quality of the qualitative research report (Corden & Sainsbury, 2006). Also, according to Corden and Sainsbury use of verbatim quotes makes research participants feel that their ideas are important and valued. However, much as all the information gathered from the respondents is important data, the current study is limited in terms of how many of these quotations can be used. As such seven criteria for the selection of verbatim quotes (Corden, 2007; Corden & Sainsbury, 2006) to be used were developed, as follows.

1. Quotes which provided direct evidence of a theme, belief or attitude. For instance, in the current study patients reported poor availability of diabetes drugs at the public health clinic as a factor that led them to seek alternative care from traditional healers.

...the lack of diabetes drugs at the public hospital pharmacies is really a chronic problem and to me this has been the reason why some of the patients have been turning to traditional healers for local herbs... [PtFGRAM87]

2. Quotes that illustrate how patients express their emotions about their health problems such as

“...I was really shocked and depressed at the beginning ... but later on I thought...this must be in God’s plan ...So I said Alhamdulillah Rablahllaminah [thanks to God” [PtIRAM24].

This quote presents the emotions that the patient went through after he was diagnosed with diabetes as well as his strong feelings and beliefs in God’s way of doing things.

3. Quotes that describe views about how other people think or what they believe and experiences on the issue in question (Corden, 2007). For example, in the current study key national health officials and patients in FGDs reported related opinions on the ways people interpret diabetes signs and symptoms.

...before they know what they are suffering from many tend to look at the signs and symptoms and try to associate these with many other diseases particularly HIV/AIDS and/or TB [PtFGRAF30]

...a lot of people are ill informed about diabetes... we have not done enough in educating the public about diabetes ... that is why they associate it with HIV/AIDS [GoKI58]

4. Quotes that demonstrated the range of sources of information used by participants.

For instance,

“I first learned about diabetes on TV, radio and newspapers... [PtIRAM05]” or “I got to know about diabetes when I was taking care of my uncle [CmFGM06]”

5. Quotes that illustrate the patient’s understanding and interpretation of an issue, concept or observation. For example,

“diabetes is a sugar disease caused by what we eat and/or from your parents...one cannot prevent oneself from diabetes. How can you prevent a disease which is caused by what you eat and passed on genetically?” [PtIRAM125].

This quote presents patients’ understanding and interpretation of the causes and preventability of diabetes.

6. Quotes that show how patients understand and experience the world and create meaning (Corden, 2007). For example, in the current study patients reported experience of their relatives having diabetes and felt that they deserve to have diabetes if it is God’s will.

... my father, mother and my sister and I have all been unfortunate! This disease has been part and parcel of our family. So, I said to myself “Oh God my father, my mother, my sister and now me? Why?” But again, I said to myself...”it’s in God’s good plans!”[PtIRAF28]

7. Other quotes were selected to show the type of language respondents’ use when communicating or talking about certain issues. In the current study for example, health care workers were trying to explain the possible causes of type 2 diabetes in relation to eating certain types of foods such as processed foods.

...people who are eating foods that have been industrially processed such as canned food products including beans, meat, fish, oils etc. are at risk of contracting this disease. Foods that lack the natural products like the oils that we get from cotton, sunflower, groundnuts... are likely to affect the pancreas resulting in the failure to produce enough insulin to process the body sugars [HcwTN13]

3.11 Ethical issues

A number of ethical considerations had been considered while undertaking the present study. First, this research was carried out in accordance with the Ethical Guidelines of the University of Otago and Muhimbili University of Health and Allied Sciences. Secondly, during the data collection process I tried to uphold a number of professional and social practices which are part of Tanzanian culture. For example, I ensured that I obtained consent from each individual or group participating in the study before the interview. Culturally I had to show a lot of respect towards the patients and their caregivers while at their homes. This included adhering to all basic expected behaviours while in the privacy of the patients' homes including the manner in which I knocked on the door, taking a seat when offered one and sharing in long unrelated conversation while sipping a glass of water or tea before starting the interviews. Finally, all participants' names were not used and/or mentioned throughout the present research. Respondents were identified by a number and a code to keep their anonymity (Table 3.5). Similarly, the names of all the key national health officials who participated in the current study do not feature anywhere in the data for ethical reasons.

3.12 Reporting of Study Findings

3.12.1 Background Characteristics

Table 3.6 presents the socio-demographic characteristics of the people with diabetes involved in this study. As seen in the Table, 15 (50%) of the people with diabetes involved in this study were between ages 50 and 65. There was an equal number of males, i.e. 10 (50%), and females among regular attendees while the number of males was higher, i.e. 8 (80%), than that of the females among infrequent attendees. With only two people with diabetes reporting having no formal education, about 57% (17) had primary level education and the rest had secondary or university education.

Table 3.6: Socio-Demographic Characteristics of People with Diabetes			
Variables	Regular Attendees	Infrequent Attendees	Total
Age			
35-50	5	3	8
51-65	12	3	15
> 65	3	4	7
Sex			
Male	10	8	18
Female	10	2	12
Marital Status			
Single	0	2	2
Married	15	4	19
Widowed	0	2	2
Separated	2	1	3
Divorced	3	1	4
Education			
None	1	1	2
Primary	13	4	17
Secondary	3	4	7
University	3	1	4
Occupation			
Retired	2	2	4
Civil servants/employed	4	3	7
Small business	8	2	10
No formal employment	6	3	9

Table 3.7 presents the illness status of the people with diabetes involved in the current study. At the time of this study only 12 people with diabetes out of 30 had been living with disease for less than five years while the rest have had it for more than five years. One person with diabetes had been living with diabetes for more than 20 years.

Table 3.7: Illness Status of the People with Diabetes			
Variables	Regular Attendees	Infrequent Attendees	Total
Duration with diabetes			
< 5 years	7	5	12
5-10	5	1	6
10-20	7	4	11
> 20	1	0	1
Chronic Illnesses			
Hypertension	6	2	8
Diabetic Foot	1	1	2
Co-morbidity & complications			
Sexual dysfunction	3	1	4
Vision impairment/ Retinopathy	5	2	7
Neuropathy	8	1	9

Among people with diabetes, eight had hypertension and two had developed diabetes foot. Many of them also reported having co-morbidity complications. For example, nine of the patients had neuropathy and a few had sexual dysfunction.

Table 3.8 presents the treatment status of people with diabetes involved in the current study. The majority of them were on oral hypoglycaemic treatment, and none of the infrequent attendees were on insulin injection.

Table 3.8: Treatment Status of People with Diabetes			
Treatment	Regular Attendees	Infrequent Attendees	Total
Non-pharmaceutical	1	1	2
Oral-hypoglycaemic	16	9	25
Insulin injections	3	0	3

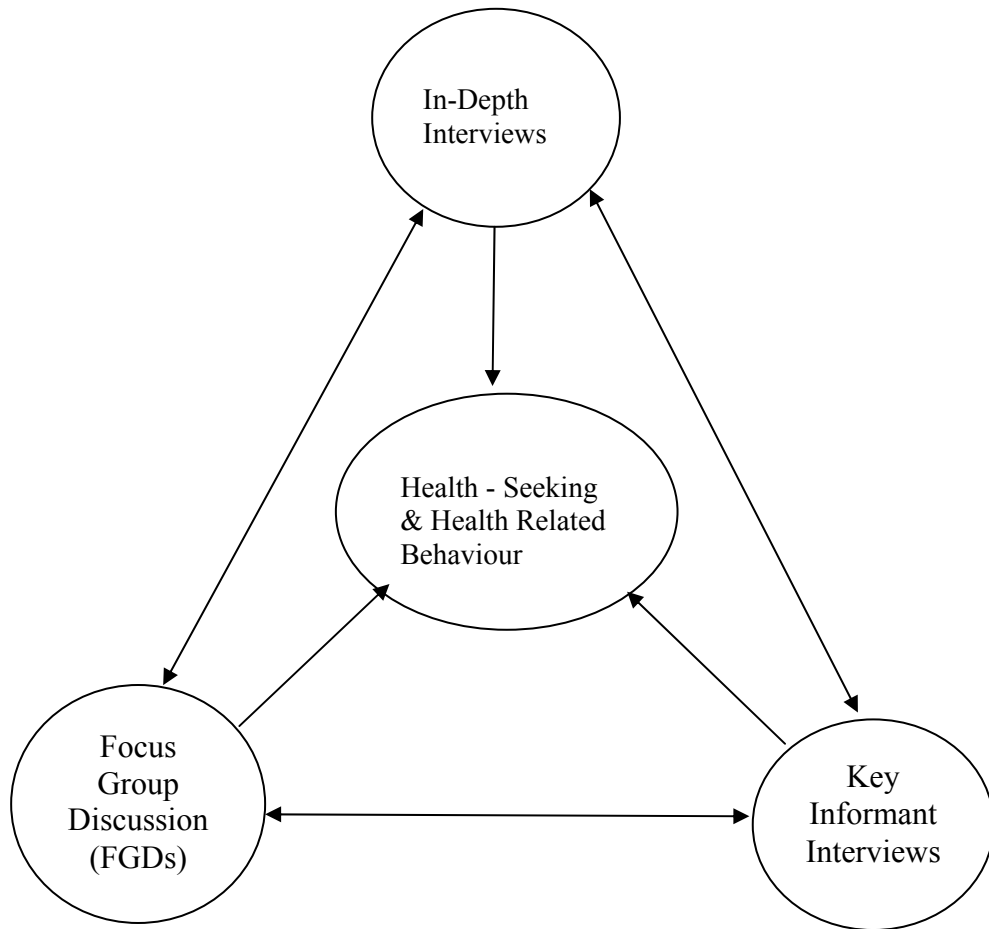
Furthermore, as shown in Table 3.8 two people with diabetes were not having any pharmaceutical treatment but were doing a special diet and exercise. Many of them,

however, were on oral hypoglycaemic treatment such as Diabinese, Metformin, and Glibeclamide tablets.

3.12.2 Presentation of Results

As described in Section 3.8 the analysis of the data generated from the current study used both descriptive and interpretive approaches (Lopez & Willis, 2004) in highlighting the factors influencing health-seeking and health related behaviour for type 2 diabetes mellitus based on the respondents' narratives and experiences. The findings are clustered under different sub-themes generated through the data analysis process and organized into three major themes presented in one chapter each.

The results presented in these chapters are drawn from the following sources: in-depth interviews with people with diabetes and their caregivers; in-depth interviews with health workers; focus group discussions with people with diabetes and selected community members; and key informant interviews with key national health officials. Triangulation of the information generated from these sources (Figure 3.10) was carried out simultaneously in the course of results presentation in each chapter. Where needed, supporting quotes from these sources were used and identified through specific codes as presented in Table 3.5.

Figure 3.10: Triangulation of Information from Various Sources

Based on the analysis of the data generated from the sources presented in Figure 3.10 the results are presented in three major chapters (i.e. Chapters Four, Five, and Six) followed by Chapter Seven which contains discussion and conclusions. Chapter Four describes the awareness and/or understanding, perceptions and knowledge about type 2 diabetes mellitus among patients, caregivers and community members. The process of presenting the current study's results in that chapter starts by highlighting the perspectives of people with diabetes followed by those of health care workers, community members, caregivers, and key national health officials. Chapter Five examines in detail the process and specific factors which influence health-seeking and health related behaviour for type 2 diabetes. It starts by presenting perspectives of people with diabetes, followed by those of health care workers, key national health officials, community members and caregivers. Chapter Six describes the challenges patients and their caregivers face in the process of care and management of this disease following diagnosis. The chapter also highlights the implications of care and management costs of diabetes, specifically focusing on the impact of these costs on the

overall health of the people with diabetes and the welfare of their families. The chapter starts by presenting perspectives of caregivers followed by people with diabetes, key national health officials, health care workers and community members. Finally, Chapter Seven presents the discussion of the research findings, focusing on the strengths and limitations of the study, the quality of the research, and the study's implications. A brief reflection on McKinlay's theoretical framework in relation to the current research is also presented. The chapter ends with tentative suggestions on priority areas for further research followed by conclusions and recommendations.

Chapter 4—Knowledge and Perceptions about Type 2 Diabetes

4.0 Introduction

This chapter explores the overall knowledge and perceptions about type 2 diabetes mellitus based on the information generated from in-depth interviews with people with diabetes, patients' caregivers, health care workers, and key national health officials. It also presents information generated through focus group discussions with diabetes patients and community members. The information is presented here under three interrelated sub-themes: knowledge and perceptions about type 2 diabetes mellitus; perceived magnitude of type 2 diabetes mellitus; and risk perception for type 2 diabetes mellitus. For purposes of identification special codes and numbers were used for each participant as presented in Table 3.5.

4.1 Knowledge and Perception about Type 2 Diabetes Mellitus

During the interviews participants were asked whether they had heard about type 2 diabetes mellitus before and their main sources of information. They were also asked about the signs and symptoms, causes, prevention, treatment, and risk perception of type 2 diabetes mellitus. Some participants were somewhat knowledgeable before diagnosis while others were not.

One of the major themes developed to explain the health-seeking and health related behaviour for type 2 diabetes mellitus was knowledge and perceptions about type 2 diabetes. Knowledge in the context of this study refers to the facts known by or experiences of the patients or people in the community about type 2 diabetes mellitus. Perception refers to intuition or the way they view diabetes and its manifestations within their social setting.

4.1.1 Awareness about Diabetes

Overall, awareness and knowledge about diabetes was limited among some patients and many caregivers including the community members as a whole. Some of the patients

were equally ignorant about diabetes before they were diagnosed with it. Prior to diagnosis most patients and a few caregivers and community members acknowledged having heard about diabetes. Few, however, had any comprehensive understanding of what type 2 diabetes mellitus was.

I used to hear from my neighbours that there was a disease called diabetes but never understood what it was like until I was diagnosed with it. But before I was diagnosed with it I had shared the signs and symptoms that I was experiencing by then with my neighbour and he said...“from what you are telling me you might be coming down with diabetes. So my advice to you is that you go down to the clinic and check it out!” Indeed when I went to the hospital the doctor ordered some tests for me and was later told that I had diabetes. [PtFGRAF01]

Many patients were unaware that they were at any risk of contracting diabetes and were surprised to be diagnosed with diabetes since they did not have any history of this disease in their families. The most rational response was to attribute its causes to spiritual powers as one of the patients put it during the focus group discussions.

I had not heard about this disease before and when they told me that I had diabetes I was really surprised! We do not even have anyone in my family who had had this disease before and this got me even more confused! So I asked the health workers...“Tell me...how this disease comes about”? So they educated me about it and it took me some time before I could comprehend the whole thing. So I said to myself “...It has all to be in God’s plan!” [PtFGRAM03]

According to the health care workers most of the patients are normally not aware of what they might be suffering from. Most of them are normally alerted by the signs and symptoms which they could not explain unless cautioned by other people who are familiar with the disease.

Many patients that we have been seeing here were not aware that they might have been suffering from this disease until the time they were diagnosed with it. Some simply came with one or two complaints which they couldn’t figure out but had never related these to anything like diabetes. For example, we had a patient here who came with quite a big wound and said: “I have had this wound for a long time and much as I have been treating it, it does not appear to respond. Some of my friends and neighbours told me that I might have diabetes and that is why I came”. [HcwRN04]

4.1.2 Sources of Information about Diabetes

Various sources of information about type 2 diabetes mellitus were identified by the few participants who had heard about diabetes before. These sources included family members, hospital, health care workers in other clinics (antenatal), relatives and

neighbours who were living with the illness, as well as the mass media. Radio, television and newspapers, for example, were reported as one of the main sources of information. According to the patients and community members, diabetes was one of the diseases frequently mentioned on radio spots paid for by the traditional healers marketing their various medications for diabetes. Other diseases include high blood pressure and low sexual desire. Other sources of information about diabetes included affected relatives and neighbours.

I first learned about this disease on TV, radio and newspapers but I had all along thought that this is a disease for Indians and Caucasians and not for Africans. [PtIRAM05]

I got to know about this disease when I was taking care of my uncle. But my neighbour also had this disease so I have been aware of it for some time now. [CmFGM06].

4.1.3 Signs and Symptoms of Type 2 Diabetes Mellitus

When asked about the signs and symptoms of diabetes patients were able to draw on their own disease presentation. Some of them, for example, were able to describe the classical signs and symptoms of the disease which include severe thirst, drinking a lot of water, body fatigue, frequent urination, dizziness, weight loss, blurred vision, excessive sweating, itching around their private areas, and low sexual desire. Others experienced abnormal vaginal discharge, skin irritation, dry throat, low saliva levels, constipation, fever, chest tightness and finger numbness. The problem of frequent urination was reported by patient caregivers and most patients during the in-depth interviews and FGDs.

... I started with frequent urination and was drinking a lot of water. The urination problem was severe. I would go to the toilet about ten times and the problem was that if I did not get there fast I would simply go in my pants! Further my body got really tired and my sexual desire got really low. This really put me off and that is when I went to see a doctor at the Muhimbili National Hospital and was diagnosed with the disease. [PtFGRAM15]

Although both male and female patients appeared to have been experiencing more or less the same signs and symptoms, the manifestations of these signs and symptoms for some were accompanied with a lot of physical and psychological discomfort. Most of

the women reported experiencing excessive itching around their genitals coupled with abnormal whitish vaginal discharge. This patient spoke about it during a FGD:

Way back in 2006 when I was in Iringa I got a severe problem of itching around the vulva and abnormal vaginal discharge. I would scratch until I got some bruises. So I went to a hospital there and they gave me some medication which did help. However, when I came to Dar es Salaam later on it started again and that is when I told my son about it and asked him to escort me to Amana hospital. There they told me to get a urine sample and they tested it only to find that my sugar levels were 31mmol/L. I was then given drugs and referred to the diabetes clinic. [PtFGRAF16]

On the other hand male patients reported experiencing low sexual desire, as revealed by one of the patients during a FGD:

Personally I have had problems with my sex life since I contracted this disease. I have simply lost the ability to meet my sexual obligations to my spouse and this has been a source of concern to me. I am really scared because it could lead to the break-up of my marriage. You know... when you cannot meet the sexual needs of your spouse it creates a lot of suspicion on her part that maybe you are having your sexual needs met elsewhere! The suspicion that you are having extra-marital relations or have a “mistress” somewhere [*nyumba ndogo*] seems obvious and this may in turn push her to look for sexual attention elsewhere. This for many of us is a source of psychological trauma. You see, you basically cannot tell your spouse every day that you are not feeling like being sexual so you sort of force yourself to do that and end up only half way because you lose your erection! [PtFGRAM17].

Other patients reported loss of vision as one of the signs of this disease, as revealed by one of them during a FGD:

...I first lost my vision...everything becomes blurred. I also have problems of blisters and tiny wounds on my legs which do not respond to treatment. But I also have a problem of frequent urination ...going to the toilet seven to eight times particularly at night. At first I thought it was schistosomiasis. So I went to the hospital for a test and that is when I was told that I had diabetes. I was really surprised and said to myself: “Is this what diabetes is all about?” [PtFGRAM18]

The community members were also able to recall some of the signs and symptoms that they noted from some of their ailing relatives as narrated here by one of the participants:

There are situations where individuals develop sores that end up as really big wounds that do not easily respond to treatment. One of my relatives had this problem before he was diagnosed with the disease and continued to nurse this wound until he died. Before he was diagnosed with this disease he had been treating this wound for months. It really got us asking ourselves “what type of a wound is this?” We even took him to see a traditional healer but the wound got worse! [CmFGM19]

Similarly, health care workers reported that a few patients who were exposed to family members, relatives, friends and neighbours who had been suffering from diabetes had some prior knowledge about the signs and symptoms.

Most of the patients who have been keenly observing these signs do say that they were suspicious that they might be affected with diabetes because the disease is common in their family or clan. Some even confidently conclude that they think they have inherited it from one of their parents! [HwTN13]

Health care workers agreed that those patients who are not knowledgeable about the signs and symptoms of diabetes often confuse the signs and symptoms of this disease with pre-existing health problems such as hypertension:

Most of the patients we see were triggered by the signs and symptoms which they could not relate to anything; that is why they came to the clinic. Others associated the symptoms they were having with other pre-existing diseases like hypertension but not diabetes. [HwRN04]

4.1.4 Perceptions of Signs and Symptoms of Type 2 Diabetes Mellitus

The perceptions of the signs and symptoms of type 2 diabetes appear to vary extensively. For example, those patients who had been around a relative or neighbour who had type 2 diabetes could immediately tell that the signs and symptoms that they were experiencing were related to diabetes. This prompted them to seek care immediately at the health care facility.

I knew it was diabetes because most of my relatives who suffered from this disease experienced some of these symptoms. [PtIRAF20]

Other patients, however, perceived the symptoms as having to do with other health problems such as malaria, flu, schistosomiasis, throat cancer, high blood pressure, kidney problems and pelvic inflammatory disease. The signs and symptoms of diabetes were also associated by some with the hot and humid weather in the city of Dar es Salaam, while others associated these symptoms with witchcraft.

...initially the symptoms did not bother me... I thought it had something to do with the hot weather in Dar es Salaam...given the nature of the exhaustion that I was feeling then. Later on I got worried about the frequency of urination. I thought I could be having some schistosomiasis. [PtIRAF21]

... the frequency of urination got worse so I knew I was suffering from something more than high blood pressure. I thought my neighbours had bewitched me because I was at that time building a house in Dar es Salaam which was near completion! [PtIRAF22]

Some patients perceived the drastic loss of weight resulting from diabetes as a possible symptom of HIV/AIDS, as revealed by one patient:

...I lost a lot of weight suddenly to the extent that got me worried that I might have contracted the AIDS virus. [PtIRAM23]

Given the limited knowledge about type 2 diabetes, other patients could not associate these symptoms with anything, as was the case with this patient:

...I was not sure where I could place all these symptoms that I was experiencing until the day I got diagnosed with the disease. [PtIRAM05]

4.1.5 Causes of Type 2 Diabetes Mellitus

When participants were prompted during the study to explain the causes of type 2 diabetes mellitus a variety of explanations were given. These included the biomedical model such as the failure of the pancreas due to a severe bout of fever or heavy dose of drugs; the types of cooking oils used; eating habits with high sugar and/or oil intake; alcohol; lack of exercise; exposure to chemicals in foods (contaminated canned foods); drug side-effects; stress (due to lack of money); overweight (due to eating too much) and heredity. High sugar intake was mentioned by many participants to be the cause of diabetes. This association may have been influenced by the Swahili term used to describe diabetes: “*ugonjwa wa kisukari*” [a sugar disease]. Interestingly, most of these responses were characterised by some degree of uncertainty. It was typical, for example, to hear a respondent begin by saying “*I don’t know*” or “*I am not sure*”, and later on mention one of these causes after extensive probing. Others described the causes that they had heard about from other sources. It was therefore common to hear a statement like “*I heard it is caused by...*” Few, however, appeared to be more confident with their responses, as was the case with this caregiver:

From what I know diabetes is caused by taking a lot of sugar while high blood pressure is caused by taking foods with too much salt and oil. Like my mother...she really used to eat a lot of stuff with high sugar levels and when it comes to her cooking she really loved to put a lot of oil into her food. [CgIRAF07]

Some patients had their own plausible explanations for the causes of diabetes but felt a bit uncertain. So they would say: *“I am not sure”* or *“I don’t know ...but”*. Many of these simply wanted to “double check” whether the explanations they had were right or wrong. As one of the patients put it:

... I do not know much about the causes for this disease and I don’t think the causes are known but I heard that diabetes can be inherited. The funny thing is that nobody in my family or clan ever had this disease. Others have been saying that it has to do with imported processed cooking oil in our foods but I am not sure how far this is true...If you remember some time ago we only used to have natural cooking oils here either from coconuts, sunflowers, animal fat etc. But of late there are all sorts of oils here whose origin we do not know! [PtIRAM08]

Other patients appeared to be confused about the causes of type 2 diabetes mellitus based on what they had been hearing from various sources as summarised by one of these patients.

...personally the causes of this disease are still confusing to me. The more I talk to people the more confused I get. You would hear that it is caused by eating foods that have too much sugar or too much fat; others would say that people who are older than 40 years or too fat are more likely to get it and the like! ...but when I look around I am seeing some children with this disease and they are not just a few. They are quite many! As you know, Muhimbili National Hospital has specifically set up a special clinic for children! So to me the causes of this disease are still a big puzzle. [PtFGRAM09]

During the focus group discussion the link between heredity and type 2 diabetes mellitus was not clear-cut for those patients who had no history of diabetes in their families. The heredity theory was drawn exclusively from direct interaction with biomedical professionals. While some patients tried to relate the causes of diabetes to heredity, others had some reservations:

I heard from the doctor that you can inherit it from your parents if one or both of your parents happened to have it. The most confusing thing to me is that I have taken the trouble of checking out if there was anybody in my family line who ever had this disease and found none! I am actually the first person in my entire family to come down with this disease. This leaves me with a lot of unanswered questions. [PtIRAF11]

Deviation from traditional African dietary patterns or “contamination” of “food culture” coupled with drug side-effects were also reported by some patients as possible causes of diabetes:

...I don’t know for sure but what I understand is that it may be caused by the type of foods that we eat nowadays....lots of chemicals... and the types of drugs we have been

taking too. As you know we are getting all sorts of drugs from different companies ...so I am sure these may be causing some toxicity in our blood system. As you know, just recently we have had more than three types of malaria drugs in the country some of which have been reported to cause a lot of side effects in patients! [PtIRAM12]

According to some health care workers the causes for type 2 diabetes were attributed to a “contaminated food model” where some respondents linked the observed rise in the prevalence of diabetes in Tanzania with the increasing use of industrially processed foods. According to these respondents, these foods tend to contain a lot of chemicals (compared to natural foods), thus exposing individuals to the risk of contracting this and other diseases:

...I think those people who are eating foods that have been industrially processed such as canned food products including beans, meat, fish, oils etc. are at risk of contracting this disease. Foods that lack the natural products like the oils that we get from cotton and sunflower seeds, groundnuts etc. are likely to affect the pancreas resulting in the failure to produce enough insulin to process the body sugars. [HcwTN13]

Other participants from the community focus group discussions tried to use a biomedical model to explain how diabetes may have resulted from pathological processes in the body:

A lot of people say that it is caused by eating too much sugar. I disagree. From my reading every organ in our body has its functions and when it fails to function it causes certain problems in our bodies. There is one organ in our stomach known as the pancreas (*kongosho*). The pancreas produces chemicals that are responsible for digesting the sugars that we take in our bodies. So when the pancreas gets damaged for one reason or another, it fails to produce the needed chemicals hence a lot of sugar is left undigested in our bodies. These high sugar levels in our bodies make us feel quite thirsty thus drinking a lot of water and urinating frequently. Incidentally the high sugar levels in the body are also observed in the urine. [CmFGM14]

Where the causes of diabetes were unclear some explanations for the observed signs and symptoms were often associated with supernatural powers as reported by one patient.

...people who don't have any idea about the causes of this disease often associate it with all sorts of things. These are the people who you would hear saying: “*Inawezekana kuna mkono wa mtu nini?*” (...*this may be a product of evil human hand or witchcraft*). They will try to associate the causes with anything positive in your life. For example, if you are doing some good business or if you are building a house you will hear them say: “*watu hawakutakii mafanikio*” (*people are jealous about your success*). Others may simply say: “*Oh...usiogope ni matakwa ya Mungu mwamini atakuponya*” (*Oh...you do not have to worry ...this is one of God's wishes so trust in him he will cure you*). [PtIRAM12]

4.1.6 Prevention and Treatment of Type 2 Diabetes

When asked whether type 2 diabetes could be prevented, most patients were of the opinion that it is not possible to prevent it. This was particularly so because of the ongoing fatalistic belief in the community that diseases befall human beings through God's wishes and plans.

...you cannot prevent yourself from getting this disease. All diseases are brought on us according to God's plans so you cannot prevent them! How can you? ... they are part of God's wishes and plans. So, nobody knows when some of these diseases may befall them! [PtIRAM24]

Some patients highlighted the fact that type 2 diabetes is passed on genetically, hence it is impossible to prevent it.

... I do not think one can prevent oneself from getting the disease. How can you prevent a disease which is passed on genetically? [PtIRAM25]

While the majority of the patients argued that prevention efforts were futile due to the underlying genetic causes and spiritual forces behind diabetes, some thought that prevention of type 2 diabetes mellitus was possible. They argued that since diabetes is caused by being overweight, it can be prevented at the individual level by adhering to proper diet and exercise:

...yes it is not treatable or curable ... but one might be able to prevent it by practicing good eating habits and doing some exercises to avoid being overweight. Personally I would like to do some light exercises like walking but I cannot do so because most of the time I feel dizzy and my sight is not very good. [PtIRAF20]

An infrequent clinic attendee similarly appeared to be less convinced about the possibilities of preventing diabetes.

It is not treatable or curable. All they do at the hospital is to control the sugar level by drugs and advising the patient to take specific drugs and diet. Patients are advised to avoid foods with lots of salt and sugar as well as heavy work and sex. The disease is not easily prevented because it has a lot to do with the food we eat. [PtIRAF27]

Lacking adequate explanations about the causes of this disease, other patients argued that the only way to prevent type 2 diabetes mellitus is to deal with it the moment you see any unusual signs and symptoms in your body:

...I do not think the disease is preventable because it hits you all of a sudden and before you know what is happening it is too late! I think all one can do is to make a habit of

going to the hospital the moment you notice any unusual signs and symptoms in your body and once diagnosed go ahead and follow medical advice. [PtIRAM23]

With regards to treatment, the participants appeared to vary in their opinions based on their own understanding and perceptions about the concept of treatment. Those who associated the concept of treatment with total cure appeared to be convinced that diabetes is not treatable or curable. This strong conviction was in part justified by their long term experience of receiving diabetes treatment without being cured. Others had seen their friends and relatives suffering from diabetes for years without a cure and some even dying from it. As a patient and a community member put it:

Personally since I started suffering from this problem and using these drugs I have not seen any sign that will convince me that this disease is treatable. Similarly, my dad and mom suffered from this disease for more than 20 years, so if there was any cure they would have been cured. For the time being we are simply thankful that there are these medications that can keep the disease under control but there is no cure for it. [PtIRAF28]

I don't think the disease can be treated. If you want to know why... just go to the diabetes clinic. Look at all those people at the clinic. These are more or less the same people you will see throughout the year. If the disease was treatable these queues would have been getting shorter and shorter every day but instead they are growing longer and longer! All the people I have known with this disease have actually died from it...how come they do not die from something else? [CmFGM29]

One patient expressed concern about the lack of evidence for anyone who had ever recovered from diabetes completely. This according to him was a basis for his scepticism. His interaction with medical professionals on this issue affirmed this view:

... the disease is not curable...I have been suffering from this disease for more than 18 years now and there are no signs that I am going to be cured from it soon! I have yet to hear of anybody who was cured from it. My son is a doctor and he has assured me that this disease is not curable. [PtIRAM05]

The few patients who were knowledgeable about the biomedical treatment and dietary requirements that go with diabetes were very confident in stating that the treatment that they were getting from the clinic was mainly meant to relieve the disease's symptoms but not cure the disease. This was well stated by one patient:

...it is not treatable ... one may feel much better and the severe symptoms may subside after using the drugs and strictly adhering to the prescribed diet... but one may not be cured completely. [PtIRAM24]

However, during in-depth interviews and focus group discussions there were patients who associated treatment with the control of signs and symptoms of type 2 diabetes mellitus as acknowledged by these patients:

My understanding of treatment when it comes to this disease is that it basically consists of using drugs to control the body sugar levels from going up. This needs to be accompanied by proper adherence to diet restrictions and doing some exercises and keeping oneself busy with small activities rather than sitting around the whole day. But you can never be cured from it! [PtFGRAF30]

From what I know now the disease can be treated in the sense of controlling it but you will never be cured although a lot of traditional healers have been claiming to have a cure for it. But I am sure you can control it because there are these drugs from the hospital and instructions on what to eat and not to eat. [PtIRAM31]

Other participants were convinced that diabetes can be treated by adhering to biomedical treatment and instructions while some patients were convinced that diabetes is not cured as revealed by one patient in in-depth interview and one of the community members during a FGD.

... I believe the disease can be treated... if you go to the doctor and follow instructions. For example, one of our fellow employees has been suffering from this disease for quite a long time but he has been going to the clinic for drugs and he has since been doing quite well... coming to work as usual. Although he still has the disease... he is still doing well. So... take your medication, go for regular tests, eat well and exercise... that to me is treatment. Or... what type of treatment are my colleagues referring to? [CmFG32]

One of the infrequent clinic attendees noted:

I think it can be treated; that is why I went to the hospital and stopped using the traditional medicines I used to take. But I do not think it can be cured or prevented because this problem is related to the foods that we eat. [PtIRAM33]

One caregiver confidently highlighted the spiritual role in the treatment and cure of diabetes:

Yes it can be treated... If I get this disease today and go to the hospital early and follow the treatment regimen I am sure God will help me out and I will be cured... Yes... it can be cured completely and you will forget about it! [CgIRAF34]

Some patients were appreciative that the current diabetes drugs despite the fact that they could not provide a complete cure for the disease, they could at least control the signs and symptoms allowing individuals to continue with their lives. As one of the patients put it:

... it is not treatable and I don't think it is even curable. You see my father suffered from this disease for quite a long time until he died from it. If it were treatable and curable he would have been cured because he spent all that time under medication. But thank God at least the drugs can relieve the symptoms if one adheres to the instructions of the doctor... with regards to prevention... I am not sure if it possible. [PtIRAF10]

4.1.7 Perceived Magnitude of Type 2 Diabetes

Overall, participants perceived the magnitude of type 2 diabetes in their communities as a problem of great public health importance. They acknowledged that the disease was now growing in magnitude, not only in terms of the number of people affected but in terms of type of people affected causing great concern amongst the population. According to FGD participants, these concerns were based on three major observations. First, the number of new people with diabetes reporting at the diabetes clinic had been observed to be increasing significantly. Second, unlike in the past when diabetes used to affect people of certain ethnicities such as Indians, Arabs and Caucasians, that was no longer the case as it was now affecting the indigenous African population in huge numbers. Finally, unlike in the past when it used to affect mainly the old, rich and overweight, it was now affecting children, the poor and people within a healthy weight range.

The concern about the increasing magnitude of diabetes was expressed by people with diabetes and key national officials during the in-depth interviews. As they said:

... it is a big problem. The number of affected people is swelling each day and almost anybody can get it. I mean children, adults, poor and rich, black and white! Many years ago I used to think that this was a disease for rich and/or wealthy people from specific ethnic groups like Indians, Arabs and Caucasians. [PtIRAM35]

...the disease is increasing rapidly and as we are speaking three out of every ten hospital admissions are now reported to be diabetes related. [CIKI36]

The observed growth of diabetes was also underscored by the health care workers who have been witnessing the increasing patient workload at the biomedical care facility.

My observation is that the number of patients is increasing each day. At the clinic for example, we are receiving three to seven new patients everyday let alone the more than 50 patients who we already have on routine care. [HcwRH38]

Some participants also acknowledged that diabetes had affected a broader population with more varied lifestyles than it used to. Unlike in the past where diabetes used to be

very rare, affecting a few rich and overweight people because of their eating habits, it was now spreading all over communities affecting people from all walks of life, as revealed by one of the patients during the FGDs.

...it is a problem... a big problem because we are seeing even young people including children with this disease. The other day I was at the clinic I saw two children who I could tell were aged five and ten attending the clinic! This gives you a picture of how serious this disease is in our communities. [PtFGRAF39]

4.1.8 Factors Thought to Cause the Growing Magnitude of Type 2 Diabetes

The increase of type 2 diabetes mellitus was acknowledged by most participants in the current study. According to the participants, the growing magnitude of type 2 diabetes in their communities was attributed to a number of factors including the changing lifestyles of the population and lack of public information about diabetes among the population. Patients in the FGDs stated that lack of information not only affects early care seeking for diagnosis and treatment of type 2 diabetes mellitus but also affects the overall patient adherence to the treatment regimen. Specifically, the health care workers and key national health officials interviewed during this study were in agreement that changes in lifestyles, particularly in the urban centres, have been contributing to the increase in type 2 diabetes mellitus.

...I would say the main reason for the increasing prevalence of diabetes in urban communities is the growing change in lifestyles. We are increasingly eating a lot of fat and oily foods as well as higher sugar levels in our diet. We are seeing people getting increasingly hooked on refined foods and doing less exercise. People are using public transport even for distances which could easily be covered on foot. [HcwDr40]

Most participants in the current study expressed concerns not only about the larger numbers of people now contracting type 2 diabetes but also about the complications and the problems of managing it for those who were already affected, as reported during the FGDs.

I think this disease is a big problem... more and more people are getting it and those who are living with it are having trouble managing it because of the high prices of the drugs and their availability at the hospital pharmacies... For example, I have had this disease for more than two years now but I have only managed to get my drugs at the clinic pharmacy once. [PtFGRA41]

Others attributed the growing magnitude of diabetes in the communities to lack of adequate public education about this disease.

...do you know why this disease is becoming such a big problem? People simply do not have enough education about it. So, people live with this disease for quite a long time and by the time they show up at the health facility it is far too late to treat them effectively. So you hear that so and so has had something amputated...the reason? Diabetes! That is why we have been calling upon the government to promote public education about this disease. [CmFGM26]

Finally, some participants agreed that lack of government action and policy guidelines on the prevention and management of type 2 diabetes mellitus at the national level was one of the major factors contributing to the growing magnitude of this disease.

...this disease is at a stage where the government should start taking national action by providing guidelines to address it like it is doing with TB, malaria and HIV/AIDS. I am saying this because I have not been hearing anything about this disease in our media except on adverts from the traditional healers. If you talk to most people here in Dar es Salaam...they will tell you that they know of one or two people who are suffering from this disease. [CmFGF42]

4.1.9 Views about Spread of Type 2 Diabetes Mellitus

Knowledge about whether type 2 diabetes can be transmitted from one person to another appeared to be limited among the participants. Some patients for example, acknowledged that they did not know if the disease could be passed from one person to another. One patient however, believed that she might have inherited it from her parents:

...don't really know but I think it can be inherited, and I think that is how I got it. [PtIRAF28]

The few female patients who had received health education during their antenatal clinic visits appeared to be a little more informed about diabetes and were confident to say that the disease cannot be passed from one person to another:

No... from the health education session we had at the antenatal clinic (ANC) we were told that it is not infectious, but you can inherit it from your relatives genetically. [PtIRAF43]

Other patients were basically uncertain, confused and worried about the conflicting information they had been getting about diabetes:

I don't really know... I heard other people saying that it can easily be transmitted from one person to another, while others are saying that it is not infectious like TB or HIV.

So I am a bit confused because when two of my friends were diagnosed with the disease and went back home to tell their husbands, their husbands divorced them out of fear that they might get it from them through sexual intercourse! I...don't know ... it is really scary! [PtIRAF10]

While the above quotes show some elements of stigma associated with diabetes, most participants were confident that this disease is not passed from one person to another as is the case with TB and HIV. People's confidence in the non-transmissibility of diabetes was also enhanced by the fact that those taking care of these patients have never been affected by it as revealed by one of the caregivers.

This disease is not transmitted from one person to another, otherwise I would have been infected by now .You see... my aunt is 79 years old and she has walking problems so I have to do everything for her including assisting her to have a shower, washing her clothes, and getting her dressed. [CgIIAF45]

4.1.10 Risk Perceptions for Contracting Diabetes

When participants in community group discussions were asked what types of people were more at risk of contracting type 2 diabetes, they were unanimous that everyone was at risk of getting this disease:

If you want the truth...apart from those who may have got this disease through inheritance, everybody is at risk of getting it... As we have been saying the disease is increasingly taking a new pattern from what we used to see...it is affecting almost everybody...young and old, men and women, black and white! It is now becoming an equal opportunity disease! [CmFGM46]

Some caregivers had this to say:

...the disease is affecting almost everybody... in the past it used to affect old people and those who were rich and fat. Nowadays we are seeing it among children, young and the old, fat and thin people... anybody can get it! [CgIRAF47]

Many participants however, acknowledged that there were certain ethnicities who were more at risk of contracting diabetes because of their comfortable lifestyles as revealed by one of the caregivers:

... in the past we used to see it among the rich Indians and Arabs because of their lifestyles... they eat well and drive luxurious vehicles with no exercise...today even the downtrodden men and women in our poor community with hard lifestyles are affected by this disease...it is a serious epidemic I tell you! Everyone is getting it. [CgIRAF48]

4.1.11 Perceived Type 2 Diabetes Complications

Patients and their caregivers appeared to be knowledgeable about the nature of complications associated with diabetes when people are not treated early. According to them, if diabetes is not treated in time one is likely to develop heart and kidney problems, blindness, sexual impotence, dehydration, hypoglycaemia, hyperglycaemia, and sores that do not respond to treatment, putting one at risk of amputation or death.

As one caregiver put it:

...the patient may run out of water in the body due to too frequent urination, constipation, loss of vision, high blood pressure and serious loss of energy in the body to a level where a person cannot walk. [CgIRAM49]

Another patient had this to say:

...one can develop high blood sugar (hyperglycaemia) which is very bad and become blind, deaf, develop kidney failure or sexual impotence. At times the complications can lead to wounds that cannot heal leading to amputation of a toe or a leg. [PtIRAF10]

Most of the patients acknowledged that they were more likely to have some of these complications if they failed to adhere to their medical regimen. Some of the patients, however, felt that these complications could happen even if appropriate treatment was taken, as revealed by one of the patients:

...I went to the health facility very early ... I was aware of the disease before I had it. So I went to Bakwata health centre where I was referred to Mwanamyamala hospital. I was very sick and the doctors at Mwanamyamala hospital referred me to Muhimbili National Hospital where I was admitted for several weeks. On discharge I was advised to attend a clinic at Mwananyamala hospital which is near to my home. But you can see that even though I went to the clinic early the disease has taken quite a serious toll on my health... right now I do not see properly and I guess after some time I might be totally blind. [PtIRAF20]

When patients' caregivers were asked whether their patients were at risk of getting any of the complications related to diabetes one of the infrequent clinic attendee's caregivers was quick to acknowledge the problem:

Yes... my patient can certainly get these complications particularly since she has not been going to the clinic and taking treatment as recommended. I am afraid that her sugar levels are going to go up one of these days and she will drop dead! My efforts to convince her to go to the clinic routinely have really not been effective. [CgIRAF50]

4.2 Summary

This chapter examines the knowledge, understanding and perceptions of people with diabetes, their caregivers and community members about type 2 diabetes mellitus. The current research found that knowledge and awareness among participants about diabetes was inadequate. Most participants were unsure about the causes of type 2 diabetes although the majority associated it with a high intake of sugar, an association derived from the Swahili name for the disease “Ugonjwa wa Kisukari” or “a sugar disease”. Biomedical causes of this disease such as heredity and failure of the pancreas were known by a few participants while some associated the disease with witchcraft and supernatural powers. The main sources of information about type 2 diabetes for most participants consisted of family members, neighbours and friends suffering from diabetes. A few patients reported having learned about this disease from health care workers and/or the mass media.

The inadequate knowledge about diabetes, and particularly the signs and symptoms that come with it were reported to cause substantial delays in the decisions to seek care. The findings also revealed a high level of uncertainty among the participants with regards to whether or not diabetes can be prevented, treated or cured. Although the majority of the patients were unsure about the possibilities of being cured of this disease, they were, however, convinced that the treatment does prevent further health complications. Most patients, for example, acknowledged that they were more vulnerable to diabetes complications if they did not adhere to their treatment regimen.

This chapter has shed some light on the overall knowledge, understanding and perceptions of participants about type 2 diabetes mellitus. The next chapter will look into the process of health-seeking and health related behaviour highlighting the decision making process for care seeking.

Chapter 5–Health-seeking Behaviour for Type 2 Diabetes

5.0 Introduction

This chapter addresses the specific factors that are likely to influence health-seeking and health related behaviour for type 2 diabetes mellitus among adult men and women in the current study. The data generated from the interviews and focus group discussions (FGDs) are organised under two related sub-themes: influences on decisions to seek care and the nature of care services sought; and initial reactions after diagnosis with diabetes.

5.1 Influences on Decisions to Seek Care

5.1.1 Nature of presenting signs and symptoms

Under this sub-theme, information was generated on the triggers, predisposing factors and barriers that influenced where people with diabetes sought care and the nature of care services sought. Most people with diabetes reported experiencing a number of signs and symptoms such as frequent urination, loss of vision, drastic weight loss, fatigue, body weakness, coughing, ongoing anxiety, polyuria, and low sexual dysfunction. Most people with diabetes reported that these signs and symptoms and their severity led them to seek care. These signs and symptoms and the manner in which they manifested themselves alerted patients and their family members and/or social networks that something was not right and that they needed to go somewhere to get some explanations.

One person with diabetes said:

... the loss of desire for sexual relations with my wife was a big turning point for me to be frank with you!. Although I was having these other problems like frequent urination and body weakness I always thought that they might have something to do with my blood pressure and alcohol. When the problem started affecting my sex life...I got really worried and that is when I ran to the hospital! [PtIRAM23]

The trigger associated with the severity of signs and symptoms of type 2 diabetes was also acknowledged by some of the community members during the FGDs. They concurred that:

...the prime push to seek care came from the signs and symptoms that the individual may be experiencing as a result of diabetes. Under these circumstances the individual had no choice but to look for answers and explanations of these symptoms. [CmFGDM14]

For some people with diabetes the decision to seek care was triggered by interpretations that they made of the signs and symptoms that they were experiencing. In some cases the patients associated these signs and symptoms with other pre-existing health conditions as revealed by one patient:

...when I started experiencing these symptoms I thought they had to do with my high blood pressure so I went to my high blood pressure clinic as usual and described these symptoms to the doctor. The doctor advised me to do a blood sugar test which I did and it turned out to be very high. He prescribed me some treatment and initiated a diabetic clinic card for me with a date to go back. [PtIRAM36]

The health care workers had different perspective. They viewed the trigger to seeking care occurred where the manifested signs and symptoms could not be explained within the existing community “lay health belief system”. The health care workers stated that community lay health belief systems had an explanation for almost all the common diseases that their members experienced. With this knowledge resource, whenever a person experienced some signs or symptoms of any disease, a “lay disease diagnosis” is normally made through this existing lay health belief system. Failure to make a lay disease diagnosis due to the unusual signs and symptoms that the patient may be experiencing normally triggers the decision for the patient to seek care elsewhere.

... the major influencing factors in the patient’s decisions to seek care at a biomedical care facility have a lot to do with the disturbing signs and symptoms associated with the disease. Their decisions are made even faster when they cannot explain the signs and symptoms through their existing lay health belief systems. [HcwRN39]

Some participants revealed that sometimes the decision to seek care was made by neither the patients nor the family but by total strangers depending on the nature of signs and symptoms and the manner in which they manifested themselves. For example, in cases where the signs and symptoms of type 2 diabetes may have put the person into a state of confusion and irritability, or making the patient lose consciousness and faint, the decisions to seek care are made quickly by those around the patient at the time and not necessarily by anybody who may be related to the patient.

...I fainted and lost consciousness at home... my relatives rushed me to Muhimbili National Hospital. When I arrived at the Out Patient Department (OPD) they carried out several investigations including diabetes and that is when they discovered that I have diabetes. They started me on medication and I stayed in the observation room for 24 hours before I was later discharged. [PtIRAM12]

In other cases where the signs and symptoms are less dramatic in their manifestation, a “wait and see” approach may normally be adopted as the patient and/or family and social networks try to find out what the signs and symptoms mean. Most participants acknowledged that the decision to seek care is normally delayed even when the patients and their family members are already aware that something is wrong. As observed in the current study, some patients had delayed seeking care for diabetes for up to 14 years. The explanations given by patients and other participants in the present study for such delays included ignorance and/ or lack of awareness about the signs and symptoms of diabetes; the “wait and see” culture; and the overriding socio-economic need to rely on home remedies including the use of medications from traditional healers and/or herbalists.

I had these signs and symptoms for almost 14 years because they were normally on and off. However, since I was extremely busy with my work at that time I never paid any attention to them. [PtIRAF22]

Some patients were basically in denial:

No...I did not seek care anywhere else. I was just at home trying to find out what I was coming down with. I kept praying, “I hope it is not diabetes like my cousin’s?” and this concern made me go to the clinic. Apparently when they tested me it turned out to be diabetes! [PtIRAF20]

Often, patients’ perceptions about the signs and symptoms of diabetes influence not only the decision to seek care but also the timing and nature of that care. Inadequate knowledge and understanding of the signs and symptoms of diabetes were reported to influence the perceptions that the patients had about this disease, often leading some to seek care for other diseases that they were more familiar with.

... when I started experiencing some signs and symptoms I suspected diabetes but again I thought it could be a hernia due to the cold weather that we were experiencing then. I waited for a week or so to be sure if it was a health problem needing a trip to a biomedical care facility. You see in our culture, you simply do not run to the hospital every time you notice something unusual in your body! ... actually, it was only after I told my wife what I was going through and she advised me that I could be suffering from diabetes, that is when I decided to seek care at the biomedical care facility. [PtIRAM24]

The current findings also show that patients who made the decision to seek care immediately following the onset of the signs and symptoms of type 2 diabetes appeared to have done so based on their knowledge about the signs and symptoms of diabetes from relatives, neighbours and friends who were suffering from it. Some of the patients for example, used to care for relatives with type 2 diabetes mellitus so they were more familiar with some of the signs and symptoms.

... I did suspect that I might be suffering from diabetes. My sister was diagnosed with the disease earlier and I was just as overweight as she was. I had heard also that the disease is inherited so I knew the chances of me getting it were high. When I started experiencing symptoms that I had never experienced before particularly the frequent micturation it then hit me! My sister had the same symptoms before she was diagnosed with it. This triggered me to seek care immediately at the biomedical care facility and not from traditional healers. [PtIRAM24]

Some patients reported trying home remedies including self medication. These actions were common where there was no apparent explanation for the signs and symptoms that the patients were experiencing and included the use of pain relief drugs such as paracetamol and/or herbal remedies. However, when the symptoms persisted, the patient and their relatives then sought advice from a biomedical care facility.

I first used some local herbs from some Maasai herbalists...whom my friend had introduced me to. They gave me some roots that I was told to boil and drink the juice but when I realised that I was not getting better my brother advised me to go to the hospital. [PtIIAM56]

Health care workers also noted that decisions to seek care were influenced by the patients' perceptions of the signs and symptoms.

... perceptions, coupled with the interpretations made of these signs and symptoms by the patients and their social networks are often the basis for the decision to seek care and where such care should be sought. In most cases the decision is made to seek care at the traditional healer's first and if things do not work out they would then come here. [HcwRN04]

Key health officials were of the opinion that the health sector has not done enough to educate the public about diabetes and the biomedical care services available to enable them to make effective and timely decisions to seek care.

I think a lot of people are ill informed about diabetes... we have not done enough in educating the public about diabetes and the services available at the biomedical care facility...some people only come to know about diabetes the day they are diagnosed

with it... I think if people were more aware of the disease and the kind of services available at the biomedical care facility their initial reaction at the onset of the signs and symptoms would be going to the biomedical care facility and nowhere else. [GoKI58]

The importance of public awareness and knowledge about type 2 diabetes mellitus in the decisions to seek care was highlighted by community members during the FGDs. According to the community members, the decision on where to seek care was a family affair involving the patient, other members of the family and/or social networks. These have a powerful influence on the decision making process so if they advise patients to either go to the biomedical care facility or the traditional healer the patient is likely to oblige. Hence, these people are vital not only in shaping the patient's perceptions of the signs and symptoms but the likely source of a cure for such symptoms.

I think the decision to seek care, when and where is influenced by the knowledge, understanding and the perceptions of the people staying with the patient. It takes knowledge and understanding of this disease and the signs and symptoms associated with it for them to be able to tell the patient: "Look, you look sick so let's take you to the hospital at once!" In this case the relatives may agree right away to take the patient to the health facility and follow up with the treatment according to the doctor's instructions. [CmFGM14]

5.1.2 Financial Resources

The decisions to seek care services were reported to be highly influenced by the availability of financial resources. During the focus group discussions with community members, for example, participants appeared to see this as the main underlying factor in the patient's decision to seek care.

... a patient and his family members could indeed find out that there is a problem that requires consultation with health care providers but for them to do so they need money to cover the costs for transport and medical consultations. If they do not have the resources handy the chances are that they would delay seeking care until these resources become available and this gives the disease more time to mature in the body resulting in some complications. [CmFGM32].

Equally so, people living with type 2 diabetes acknowledge financial resources as a factor influencing their decision to seek care at the health care facility.

...for me the big barrier is money. You see I have to board two buses which cost me about Tshs. 1000 (\$1) return. So to be able to do my blood test and buy drugs at the clinic I need like another Tshs. 9,000 (\$9). So when I do not have enough money I simply do not go! [PtIIAM113].

Unlike in the past, the health care delivery services in Tanzania have since 1993 introduced a “cost sharing system” whereby the patient has to pay for the services upfront. Before then, Tanzanians had been used to a free medical health care system whereby the consultations and treatment were paid for by the government. The cost-sharing programme had stopped a lot of people from using the biomedical care services, particularly the low income populations. In contrast with the modern health care facilities the traditional healers do not necessarily require cash payment upfront and many accept payments in kind. Food and cloth are common forms of payment. In some cases the patient may pay for the care services by working on the traditional healer’s field during the high labour demand season. These alternative modes of payment enable some poor families to meet the costs of their health care through the traditional healers as opposed to the biomedical care facilities where the “no cash no treatment” credo operates. One community member remarked during a FGD:

...our health care facilities nowadays require one to pay money upfront for all services. If a child for example falls sick and the parents have no money the chances are that the parents will first think of going to a traditional healer where at times they can have the child treated without having to pay anything upfront. The possibility of having to pay later for many parents provides them with some options in addressing the immediate problem. Mostly people pay traditional healers in kind, for example clothes, sugar, chickens, goats, and/or working on the healers’ farm. [CmFGM60]

The health care workers were in agreement with most of the patients and caregivers that the cost sharing initiative had posed a major challenge in the decision making process to seek care not only for diabetes but for many other diseases hence boosting the uptake of the services of traditional healers. For example clinicians’ key informant stated:

I think one of the major influencing factors in the decision to seek care for most patients has a lot to do with financial resources to meet the transport costs to the biomedical care facility. With the cost of transport comes the issue of paying for their services at the clinic. If you do not have money to meet these costs it is natural to consider going to a traditional healer who is at a walking distance from your house and whose services can be paid for at a later date. [CIKI61]

5.1.3 The ‘Wait and See’ Culture

According to many of the participants, individuals did not rush to the biomedical care facility the moment they felt unwell. The tendency was to ‘wait and see’ if the symptoms would go away on their own and if not, then the decision to see a health care

worker was made at that time. Furthermore, when confronted with unfamiliar signs and symptoms family and/or social networks are reported to advise against a rushed decision to seek care. “Maybe it is not what it looks like...maybe it is this or that...let’s wait and see. Maybe it will wear off by itself” are just some of the comments that a patient would hear from their family members and/or social networks. This kind of advice is noted to contribute to the delays in seeking care as revealed by one caregiver:

I think he took about one month or so before we decided to seek care...because we were observing these symptoms and whether they were increasing or not. Since we did not know what he was suffering from it took us some time before we decided whether or not to seek care at the biomedical care facility. We, however, realised that his symptoms were getting worse so we decided to take him to the hospital. [CgIRAF51]

The interpretation of the observed signs and symptoms of diabetes was also reported to influence the timing of care seeking and the nature of the care to be sought and where. As such, incorrect interpretation of the signs and symptoms could often lead to undue delays in care seeking behaviour.

It took about one month...at the beginning he thought the signs and symptoms would pass away. He is a night watchman and thought that these may be signs of fatigue due to lack of adequate sleep. [CgIRA53]

The intermittent nature of diabetes signs and symptoms was also reported to influence late decisions in care seeking.

...it took me about two to three years because whenever I felt tired and weary I used to say to myself...“Maybe I had a rough day... I better take one beer or two and go to bed early and will be OK tomorrow”. As it turned out I would experience the same symptoms and sometimes worse. I remember one day I could not even see properly. The strange thing is that I also ignored this symptom and hoped that it was going to go away. [PtIRAM54]

Other patients perceived the signs and symptoms that they were experiencing, particularly the frequent urination, as having to do with their water intake, hence they decided to restrict water intake.

She waited for a week trying to figure it out and got to a point where she tried not to drink water but even then her frequent urination problem would not go away. Then she started getting really thirsty so she started drinking a lot of water and her situation got worse! Finally we decided that we take her to the hospital! [CgIRAM49]

5.1.4 The Use of Traditional Healers and Herbalists

When the causes of the signs and symptoms are unclear, the main course of action apart from the adoption of the ‘wait and see’ attitude for many patients, their families and/or social networks is to seek the services of traditional healers and/or local herbalists. It is only when the signs and symptoms persist rather than going away as expected, coupled with failing to find relief from the use of medications from the traditional healers and/or herbalists that the decision to seek biomedical care services is made.

...others go to the health care facilities after they have gone to traditional healers and tried their medications with no notable improvement. By the time they do so their health condition might have started to deteriorate at times with serious complications including blurred vision, wounds that no longer respond to treatment and the like. [PtFGRAF81]

Another female patient had this to say during a FGD.

...there is also an ongoing belief that is being supported by some people in our community that if you want to treat diabetes start with local medications either from traditional healers or herbalists before going for the modern medicines (madawa ya kisasa). [PtFGRAFP30]

Beliefs in witchcraft particularly for a disease with no known causes are always rife as revealed here by one of the male patients:

Yes ...some people go to traditional healers in an effort to find out the nature of the disease they are dealing with... “Is this disease a result of human or God’s hand?” The ongoing understanding is that there is no disease that does not have a cure but one has to know its source! It is against this background that efforts of most patients and their family members are directed to traditional healers. [PtFGRAMP03]

In trying to find out what is wrong with their health and obtain relief for their health conditions many patients were reported to seeking care from the traditional healers and herbalists including faith healers as revealed by one of the health care workers:

Yes...a good number of patients go to traditional healers or herbalists while others go to faith healers including *Rev. X and Rev. Y* where they are prayed for by the congregation and the like. All these are efforts to get relief or answers to their health problems. [HcwTN85]

5.1.5 Role of Family Members and/or Social Networks

Family members and/or social networks were reported to have a substantial influence on the patient’s decisions to seek care, when such care is sought and the nature of care

services. Most participants reported that the first step in the pathway to care for a disease like diabetes whose signs and symptoms are not well known to members of the family and/or social network is through the local herbalists and/or traditional healers. The services at biomedical care facilities tends to be used as a secondary source of care, in most cases following the patient's failure to get relief from the signs and symptoms of this disease.

... my relatives advised me to go to a herbalist...you know in our culture when you are sick you have no voice on what type of care you need. The relatives normally take over and this is what happened to me. So I used the herbs from the herbalist but did not get better. That is when they decided to take me to the clinic at Muhimbili National Hospital (MNH). Back then there were very few diabetes patients, hence we used to get free drugs. I also used some drugs from the Traditional Medicine Department at Muhimbili but they did not really help me much. [PtIRAM05]

Furthermore, the family members and/or social networks in the present study play a significant role in the overall welfare of each member of the community. They are the ones who decide when to seek care for all sorts of ailments afflicting their members, based on their perceptions and understanding of the signs and symptoms of such ailments.

...as you are aware, traditional families have what we could call "joint caring". This is a lifestyle where everyone in the family takes care of each other and the moment one falls sick, he/she does not even have to tell the rest of the family that he/she is not feeling well. The family members are the ones who will start telling him/her that "you do not look well" or "you ought to go see a traditional healer and/or herbalist", or "you ought to go to the hospital". So, you see, the family and extended members have a strong influence on the individual not only in seeking care but also where to go for such care. [GoKI58]

According to the participants, before the patient seeks care at the biomedical care facility, he/she might have gone through a number of traditional healers and local herbalists based on the advice of the family and social networks all in an effort to determine the disease causation.

... before they came here, patients (through advice from relatives and friends) may have gone through a number of private clinics, some may have gone to various traditional healers, while others may have tried a number of herbs and traditional concoctions. A few have gone for special prayers through faith healers. Some have even gone to Chinese traditional healers who are increasingly becoming a part of our care delivery system here in Tanzania. All these efforts are geared towards finding out what they might be suffering from. [HcwDr40]

Caregivers and/or social networks were reported to have a positive influence on the use of biomedical care facilities particularly when they are well informed about type 2 diabetes mellitus and the role of biomedical care facilities in diabetes management. Some of the health care workers interviewed during the present study, for example, agreed that the majority of patients normally come to the clinic after being advised by other patients, friends and relatives. Some of these relatives and friends in some cases were also suffering from diabetes or were looking after someone who had diabetes so were informed about type 2 diabetes mellitus and its mode of treatment.

I was a major influence on her decision to seek care! You see she was stuck in this belief that she was bewitched and so had been frequently consulting one of these traditional healers. So I told her...”let’s try the hospital too and if it fails then we can always go back there... As a Mzanaki...I know there are no real traditional healers here in Dar es Salaam! The ones who claim to be traditional healers are simply looking for some means of survival!” I was glad that she obliged! [CgIRAM55]

5.2 Initial Reactions after Diagnosis with Diabetes

For many patients a diagnosis with type 2 diabetes mellitus can be overwhelming particularly in cases where the patient had no prior history of the disease in his/her family. Further, the management of diabetes calls for immediate adherence to a specific medical regimen which includes regular intake of medication, restricted diet patterns and clinic attendance schedules. Even more challenging, people with diabetes have to cope with the enormous costs involved in the management of the disease. Effective management of chronic diseases like type 2 diabetes mellitus calls for a positive attitude not only in living with the disease but also in adhering to the prescribed treatment regimen. Similarly, the attitude of family members, care givers and/or social networks towards diabetes is equally important in creating a supportive environment for overall patient care and management of this disease. It is in light of this background that I was keen in this study to get a better understanding of the perceptions, feelings and attitudes of the people with diabetes, their family members and/or social networks towards the disease following patient diagnosis with type 2 diabetes.

5.2.1 Shock and Disbelief

Very few people with diabetes had suspected they had type 2 diabetes mellitus before they were diagnosed with it. Many people with diabetes found themselves in deep

shock and disbelief at the news of their diagnosis. Others were very sad, worried, disappointed and depressed. Although these reactions are normal and expected, many, especially those who had some experience with diabetes from friends and relatives with the disease, added yet another concern about the new lifestyles that they would have to adopt in coping with diabetes. Most people with diabetes acknowledged that this was not a disease like any other. Diabetes puts a lot of restrictions on what one can and cannot eat or drink, which is a challenge. Even more challenging according to the people with diabetes, caregivers and community members is the fact that diabetes is a chronic disease requiring lifelong drug intake and adhering to a strict diet. One person with diabetes said:

...I felt really bad!...the first thing that hit me was the whole idea about taking medication throughout my life and following a strict diet that has never been in my routine...you know ...do not eat this or that or do not take alcohol and of all the good things “usile kiti moto” [*do not eat pork*] which is my favourite! [PtIRAM25]

Other people with diabetes reported that they were very scared, depressed and angry. The anger and depression of not being able to socialise made some people with diabetes lash out at time to their friends and relatives.

...I felt very bad and very scared because I knew my life was now coming to an end. I was really scared! I was also sad when I knew that I would no longer take any of the foods and drinks that I am used to... beer, tea with sugar, or chicken and chips etc. I got really depressed and was unusually angry with almost everybody. My relatives had quite a rough time with me. You see, they would prepare this or that food for me, only to hear me telling them that “...sorry I cannot take it!” [PtIRAM64]

While the majority of the people with diabetes were worried about the restrictions that diabetes was going to impose on their eating and drinking habits, other people with diabetes were more worried about what it was going to do to their relationships with people who really mattered in their lives, as revealed by these people with diabetes.

I got really worried. I knew I was going to be divorced from my husband because at that time our sexual relations had already been going through a rough time. I was experiencing this itching around my private areas and felt quite uncomfortable having sexual relations with my husband. The other thing that got me worried was the fact that I had to adapt to a very restricted diet in order to cope with the disease. [PtIRAF43]

... but again the worst thing about this disease is the complications that go with it such as loss of vision, risk of hypertension and low sexual dysfunction etc. You know ...in our culture having sexual dysfunction is a source of disharmony ...a person can lose his respect in the house. [PtIRAM25]

Some people with diabetes experienced a different type of shock at the news of their diagnosis, mainly because they had all along been worried about having contracted the AIDS virus:

I felt very bad, because my brother died from diabetes so I knew that it is a very bad disease. However, I did not believe it when they told me that I had diabetes. I had a strong belief that I might have contracted the AIDS virus ... you see this is not my body weight... I was very big two years ago. Everybody is asking me now: "What is wrong with you?" I just tell them "I have diabetes" and they say ... "are you sure it is only diabetes? You better have them do more tests?" [PtIRAF63].

5.2.2 Coping with Diabetes

The reactions of many patients following the news of their first diagnosis with type 2 diabetes mellitus moved from the state of shock and disbelief, anger and frustration to adoption of various mechanisms for coping with diabetes. One among many such mechanisms included sharing the information about their diagnosis with family members and/or their social network. This psychological process of sometimes referred to as "taming the octopus" [*kupaa pweza*] as others have put it, involves keeping everyone who 'matters' informed about the condition with the goal of getting the psychological support the patient needs to cope with the disease. Subsequently, this process generated a lot of sympathy and support for the patients from their social network, as revealed by one of the infrequent attendees:

...I was shocked and did not know what to do because I knew right away that I was facing the challenge of a disease that has no cure! I knew that I had to give up a lot of my lifestyle. I could not have my tea with sugar, could no longer drink coke, nor have salt in my food etc. But I did share information about my health condition with my friends. They were all sympathetic and gave me a lot of hope and support. They told me that all I needed to do is to adhere to the doctor's instructions and everything will be fine! [PtIRAF62]

While some patients reacted to the news of their diagnosis with anger and frustration for various reasons, including the costs involved in the management of type 2 diabetes mellitus, others were simply shocked at the beginning but later re-grouped and gave thanks to God.

I was really shocked at the beginning ... but later on I thought... "this must be in good God's plan"... So I said "Alhamdulillah Rablahllaminah" [*thanks to God*]. This is a disease from God and God is going to cure me from it. Let the Lord be praised. [PtIRAM24]

Others simply took the news with grace knowing that diabetes must have come from God, hence thanking God for whatever plans he/she might have in bringing this disease upon them despite the challenges associated with it, as one infrequent clinic attendee remarked.

... my father, mother and my sister and I have all been unfortunate! This disease has been part and parcel of our family. So, I said to myself "Oh God...my father, my mother, my sister and now me? Why?" But again, I said to myself... "it's all in good God's plans!" [PtIRAF28]

5.2.3 Self-disclosure about Living with Diabetes

Apart from finding out the reactions of the patients to the news about their initial diagnosis with type 2 diabetes mellitus and how they coped with it, the study also investigated the issues of self-disclosure about diabetes and the reactions that their family members and/or social networks had to the news of the diagnosis. As in the case of the patients, the news about type 2 diabetes mellitus was equally shocking to most family members. Some patients, for example, reported that their children were terrified by the news since they did not know how their mother could have got diabetes. Others went through different emotional feelings mainly because they did not know how to deal with it. However, one of the patients, who happened to be working in the health field, was able to allay the concerns and fears that her family members had about diabetes following the news of her diagnosis.

...my husband and my mother-in-law were very shocked about the news. In fact my mother-in-law cried a lot when I broke the news to her. She said, "What does this mean? Don't tell me that you are going to die soon!" I told her "No, I am not going to die soon. I have seen and taken care of several people with diabetes in my career who happened to live quite comfortably with this disease for more than 20 years". [PtIRAF10]

Contrary to expectations that some patients might hide the news of their diagnosis from their families, relatives and friends, most reported sharing the news readily with almost everyone in their household. The reasons for their doing so were varied. According to some, they were following the advice from the doctors who encouraged them to share information about their health condition with their relatives. This according to the doctor would enable the family members to come to their assistance should they develop health complications like hyperglycaemia or hypoglycaemia. Others felt that there was nothing to hide about the disease since other family members were also

suffering from it. However, the prime force for some of the patients to disclose their health status emanated from the fact that these patients expected to get the needed socio-economic support from family members and others in their social network to live positively with diabetes. They counted not only on their material and financial assistance but also on the psychological support in coping with the disease, as one of the patients remarked.

...I could not hide it...they need to know so that they can support me with the drugs and the food that I need. Through this openness they have been really supportive to me both psychologically and materially. I was really worried about how I was going to manage this disease alone, but since they all know about it they have been really supportive.
[PtIRAM08]

Some patients reported that they did not see a reason to share their health problems with everybody. Instead they kept the information within a close circle of family members and friends, as one patient put it.

Oh... no! I did not tell everybody. I only shared the news with my children since I knew I was going to need their support. Otherwise, why should I tell everybody that I run into the street about my problems when I know clearly that they are not going to help me in any way? At least I know that if my children know about it they will organise themselves in buying me the drugs and food that I need as well as the money I need for transport to and from the clinic. [PtIRAF65]

5.2.4 Stigma and Discrimination

In the current study the impact of chronic illnesses such as type 2 diabetes mellitus upon the sufferers' lives and those around them is profound. Diabetes affects sufferers' daily lives, their social relationships, their identity (the view that others hold of them) and their sense of self (their private view of themselves). Further, a positive approach towards managing type 2 diabetes mellitus hinges on the individual's attitude after realising that they have to live with diabetes and the support from family members and/or their social network throughout their lives. With this view the current study tried to find out if there was any stigma and/or discrimination experienced as a result of suffering from diabetes. Type 2 diabetes mellitus rarely carries stigma nor leads to discrimination. Based on the information gathered from the present study, many caregivers and patients agreed that their relationships with other people in the community even after they were diagnosed with type 2 diabetes mellitus remained as normal as ever.

No... this disease does not carry any stigma and my husband is still being invited to attending social functions in the community. They still hold him in high regard if you ask me! [CgIRAF47]

However, some patients felt that they would rather have nobody know about their health condition because in some situations some family members and/or members of their social network tend to exaggerate such conditions drawing the attention of other people, particularly during social gatherings, as reported by one of the patients.

...yes ...at times you would rather not have other people know about it because every time they keep reminding each other that you have diabetes. It makes me quite uncomfortable when I am at social functions and you hear the host shouting orders to the caterers like: “kumbuka chakula cha huyo bwana ana kisukari” [*remember to set aside a portion for this guy here...he is diabetic*]. [PtIRAM25]

Most patients during FGDs acknowledged that their relationships with other community members were never affected as a result of their diabetes self-disclosure. The majority reported continued good social relationships with their friends and other community members even after they were aware that they had diabetes.

...personally I do not think that people relate to diabetes patients differently. My relationship with my friends and neighbours since I contracted diabetes is still the same and has never changed! Actually since they realised that I have this disease they have been very close to me because they well know that a person with this disease can fall down at any time so they pay more attention to me! [PtFGRAM03]

Some however, agreed that if there were changes in their relationships with other members of the community this was mainly because they themselves chose to change rather than anything else, as one patient put it.

...there is a little bit of difference in my social relationship with my friends...I do not go to social gatherings as I used to. For example, I used to drink beer and now I do not drink any more so we don't meet regularly in bars and other drinking places as we used to. However, I cannot say they have been discriminating against me... no! [PtIRAM66]

Most community members interviewed during the FGDs also stated that the relationship between individual patients and their community were not affected by diabetes. Instead, they reported that once the community members know that a person is suffering from diabetes they tend to be more sympathetic and some tend to be more attentive to their needs. Some patients, however, acknowledged limiting their participation in social

gatherings not because of stigma or discrimination but due to complications associated with diabetes.

Yeah, nowadays many of my friends don't invite me to their social gatherings but that is not because they are discriminating against me. I told them that I am not into parties and family gatherings anymore because I sometimes feel dizzy, fatigued and my sight is not very good. [PtIRAF20]

Some patients reported some community members having limited social interactions with them but this had nothing to do with their knowing that they had type 2 diabetes mellitus.

...people in my community don't relate differently to me but since I lost my job about ten years ago because of this disease I don't have money so people will not visit me as frequently because I have nothing to entertain them like I used to. Sometimes I guess they are afraid to visit me because they think I will borrow money from them for my drugs and since I am not employed I may not be able to pay it back. [PtIRAM36]

Often, the nature of the stigma and/or discrimination that goes with any type of disease has a lot to do with the perceptions that people have about it and the association they make with other diseases. For this reason, patients were asked if there were diseases that people in the community associated with type 2 diabetes mellitus and the reasons for doing so. Most patients acknowledged that those people who were ill informed about diabetes were more likely to associate it with HIV/AIDS and TB based on the signs and symptoms manifested by type 2 diabetes mellitus before treatment, as one patient reported in a FGD.

...for some people the disease hit them really badly causing them to lose a lot of weight and really look worn out. It is at this juncture some may be suspecting that a person is infected with the "modern disease" (*ugonjwa wa kisasa*) or AIDS virus. Some of us also might have thought we had it too. I have a friend who is attending the clinic with me who once told me that all his friends had distanced themselves from him because they thought he had AIDS until he was diagnosed with diabetes. Even then it took a while for them to believe that it was diabetes and nothing more than that! [PtFGRAF30]

The low level of public knowledge about type 2 diabetes mellitus was also mentioned by some of the patients as the reason why they did not feel comfortable sharing information about their health even with their family members. These patients were worried that some of their family members and/or social networks might not understand it or would simply relate it to HIV/AIDS and consequently stigmatise them.

Yes... initially I did hide it and only told some of my family members that I had some fever. I was scared they would not understand me and that they would stigmatise me. So I continued eating the normal foods and took my pills in private. But one day I was very sick and my husband escorted me to the clinic and that is when he knew about it. [PtIRAF43]

However, since some of the signs and symptoms of type 2 diabetes mellitus are related to those observed among patients with TB and/ or HIV/AIDS some people tended to associate these with TB and/ or HIV/AIDS, hence relating to such patients with a guarded attitude.

...in the beginning before some of my friends knew that I was suffering from diabetes they were feeling reluctant to meet with me but after they knew that it was diabetes they were a bit more relaxed. I think they were now sure that I might have been not suffering from what they thought I was suffering from ... HIV/AIDS. Furthermore, some of them now know that diabetes is not an infectious disease. [PtIRAF63]

The problem of the signs and symptoms of diabetes being perceived as related to HIV/AIDS was acknowledged by other patients who emphasised that this was due to the way in which diabetes manifested itself.

...I think a lot of it has to do with the way the disease hits your system...like in my case the disease really hit me quite hard...I lost a lot of weight suddenly and my skin changed. So my friends would look at me and could not understand what was going on with my health! I remember one guy could not help his curiosity about my health, so he asked me: "What is happening to you? Are you sure you are not sick?... meaning are you sure you have not contracted the AIDS virus? All I could tell him is "that...well it is just diabetes and not that!" Some people who had seen me taking the insulin injection and the new diet which was now part of my life believe that I was really suffering from diabetes otherwise it would have been difficult and I understand that. [PtIRAM67]

Misinterpretation of the signs and symptoms of diabetes was also acknowledged by some patients in the FGDs and key health officials.

...before people know what a patient may be suffering from they tend to look at the signs and symptoms and try to associate these with many other diseases they know, particularly HIV/AIDS. However, once they know that you are suffering from diabetes, they tend to be more relaxed around you. [PtFGRAF30]

I think a lot of people are ill informed about diabetes... we have not done enough in educating the public about diabetes ... that is why they associate it with HIV/AIDS. [GoKI58]

5.3 Summary

This chapter examines the decision making process for health care seeking when faced with signs and symptoms of diabetes mellitus. The study has established that decisions to seek care from a biomedical facility are influenced by a number of factors including the following: the nature and severity of the signs and symptoms of diabetes; inadequate financial resources to meet the transport costs to the health care facility as well as other medical services at the clinic; and the perceptions of the patients, family members and/or social networks about the signs and symptoms of this disease and how these fit into the existing lay health belief system of disease causation. Based on the outcome of the “*lay diagnosis*” of the disease using the lay health belief system of disease causation, decisions might be made for either direct care seeking at the biomedical care facility or from traditional health practitioners. In some cases decisions might be made to take a ‘wait and see’ approach as the family and/or social networks wait for additional information to make a firm diagnosis. The ‘wait and see’ approach is also adopted in situations where family members feel that the disease will go away on its own.

Lastly, this chapter examined issues related to type 2 diabetes and stigma and/or discrimination. The finding shows that type 2 diabetes rarely carries stigma and/or discrimination. However, some presence of indirect stigma and/or discrimination was acknowledged by some respondents particularly before the patient is diagnosed with type 2 diabetes. This is more so in cases where the patient presents with signs and symptoms such as abrupt weight loss similar to some infectious diseases such as HIV/AIDS and/or TB. Given the low levels of knowledge among the population about diabetes these signs and symptoms are associated with these diseases (i.e. HIV/AIDS and TB) which normally carry some stigma in Tanzanian society.

Chapter Six will look into the overall care and management of type 2 diabetes mellitus specifically exploring the various challenges facing the patients and their families and/or social networks

Chapter 6–Care and Management for Type 2 Diabetes Mellitus

6.0 Introduction

This chapter examines the fundamental nature of care and management for type 2 diabetes mellitus. In particular it examines the existing challenges in regular clinic attendance, provision of quality care and self-care management of diabetes. The data generated from the current study for this chapter is organised under four related sub-themes as follows: challenges in care and management of type 2 diabetes mellitus; implications of care and management costs; use of alternative care services; and the role of family and/or social networks. Cutting across these sub-themes is the problem of limited financial resources which appears to pose varied challenges for individual patients, family members and/or social networks.

6.1 Challenges in Care and Management of Type 2 Diabetes Mellitus

When participants were asked about what they perceived to constitute effective care and management of type 2 diabetes mellitus, the majority of them mentioned two distinct yet related issues: regular clinic attendance for general assessment of blood sugar levels after diagnosis; and adherence to the prescribed medical regimen. However, despite the good intentions of the patients, their families and/or social networks in diabetes management, effective care and management of diabetes was often constrained by significant challenges. These are highlighted here under two major categories: personal or individual challenges consisting of those constraints which are specific to the patient's efforts to attending the clinic regularly; and health care system challenges consisting of those constraints which limit patients' access to quality care and the prescribed medical regimen.

6.1.1 Personal and/or Individual Challenges

While acknowledging the importance of regular clinic attendance for effective care and management of type 2 diabetes mellitus, most patients reported facing a variety of challenges in their efforts to attend regular clinic appointments. Although varying in magnitude from one patient to another these challenges which include a lack of

financial resources, poor health care infrastructure and inefficient transport were reported to have a significant negative influence on patients' efforts to manage regular clinic attendance.

6.1.1.1 Insufficient Financial Resources

Lack of financial resources to cover the transport costs to and from the clinic was mentioned by most participants as the prime barrier to regular clinic attendance. Most caregivers, for example, reported that raising the money to cover the costs for transport to the clinic let alone the money to pay for the medical consultation, blood sugar tests and drugs at the clinic was not easy, particularly when the patient was unemployed. When they could not afford it the patient had no option but to skip the clinic appointment:

The main challenge is money... you see, she cannot walk so there is no way you can put her on public transport. So we have to take a taxi which costs about Tshs. 20,000 (\$US20) return depending on where you live. I am not employed and the few resources that we have are needed in meeting other family needs including food. So if we do not have enough she just stays home. [CgIIAF45]

Other participants highlighted the financial challenges faced by patients and their families, especially where public transport was not the best option for the patients to get to their clinic appointments. According to the respondents some of the patients had lost their vision because of diabetes hence could not go to the clinic using public transport and always needed an escort. Further, once at the clinic, the patients need money to cover the costs of medical tests and drugs. According to the participants, all these costs, together with other related expenditures including lunch for both the patient and their escort become part and parcel of the patient's decision whether to go to the clinic or not. If the family and/or the social networks cannot find the financial resources to meet these costs the patient has no choice but to stay home.

Furthermore, according to some patients, the decision to seek care at the clinic is always made against a number of opportunity costs depending on the economic status of the family and the understanding of the importance of going for medical tests, as revealed by one patient:

The distance does affect the patient's decision to go to the clinic since the cost of transport is an opportunity cost for some other things that the family could have bought using that money. So, that is why the moment I got some relief I did not see the point of wasting my limited family resources to go to the clinic. [PtIRAM56]

6.1.1.2 Poor Health Infrastructure and Public Transport

The nature of health care infrastructure in the city of Dar es Salaam was mentioned by some participants as contributing to the infrequent clinic attendance for some of the patients. There are only three diabetes clinics in the Dar es Salaam region, located in the three districts of Ilala, Kinondoni and Mwananyamala. These three clinics serve patients from their respective districts and from the surrounding regions. By virtue of this arrangement, many patients have to travel long distances to the clinic to have their blood sugar levels tested and replenish their supply of diabetes drugs. Depending on where the patient lives, the distance to the clinic may be ten kilometres or more which could hinder routine clinic attendance.

Most patients and their caregivers reported that the distance to the clinic coupled with inadequate and poor public transport from their homes to the clinic had a negative impact on their clinic attendance. Others pointed out that the distance involved may necessitate taking several buses to the clinic. The transport cost coupled with difficulties of getting onto the buses particularly in situations where the health of the patients has been compromised by the disease was acknowledged by some participants to discourage patients from regular clinic attendance. Furthermore, patients with poor health often need escorts to the clinic and when this is not available the patient stays home or uses traditional remedies instead, as acknowledged by one of the caregivers:

... my aunt has diabetes and lives far away from the bus stop at the main road and every time she has to go to the clinic she needs to have someone to give her a ride on a bicycle to the main road to catch a bus. So if she fails to get that bicycle ride she cannot go to the clinic and has to wait until the following month. My aunt is overweight and has problems with her legs so she cannot walk to the main road. When this happens she resorts to some local treatment to keep the sugar levels under control. She prepares a concoction from "majani ya muarobaini" [*leaves from a wild tree*] and takes it once or so each day and it has been helping from what she says although I am not convinced. [CgIRAF70]

Although most patients could not give the exact distance from their homes to the clinic, they knew how many buses they needed to take to the clinic and the costs incurred for each visit to the clinic. Most patients reported walking for 20 to 30 minutes or more

from their homes to the bus stop depending on the health condition of the patient. Once at the bus stop, the patients face two major challenges. The first challenge is to get a bus. Since the buses are few and irregular they are always full hence three or more buses might pass by without making a stop. Secondly, when one does make a stop it barely has enough room hence it is “survival of the fittest” as every passenger tries to force their way onto the bus (Figure 6.1; 6.2).

Figure 6.1: ‘Survival of the fittest’-Commuters board a bus through the windows during rush hour in Dar-es-Salaam 2007



Figure 6.2 Passengers trying to force their way onto a bus that is already full with passengers in Dar-es-Salaam 2007



According to some patients, the medium sized buses like the one shown above can only seat between 25 and 29 passengers but most of them carry between 35 and 40 passengers. Most participants revealed that this type of transport is highly uncomfortable, making the trip to the clinic very daunting, particularly for the old and those in poor health. For some patients the idea of having to struggle to get on the buses was enough to make them to decide to stay at home, as reported by one caregiver:

...she really dreads getting into the public transport [*daladala city buses*] because they are so stuffed with people and nobody cares whether you are old, sick or dying. You literally have to fight to get into the bus and you simply have no energy for that! This is a serious disincentive and makes my effort to convince her to go to the clinic even more difficult. [CgIRAF73]

Once on the bus, the next challenge is time. According to the participants some of the buses at times make so many stops on the way for passengers to get in and out that it is impossible to make it to the clinic on time. It is for this reason that some patients reported taking a taxi when they could afford it. Apparently, the taxi option for many families is a drain on the family resources since the taxis are expensive. According to the Oxfam International (2006) most Tanzanians are living on \$1-\$2 or less (Tshs.

1,000-2,000) a day. Thus, the transport cost to the clinic especially when one has to use a taxi is a financial burden for both the family and/or social networks, as acknowledged by one of the patients:

It is about two bus rides costing about Tshs. 2,000 (\$2) return. If you cannot use a bus because of your health condition like me it will cost you about Tshs. 24,000 (\$24) return by taxi. I usually take a taxi because of my health condition and because the public transport is too crowded for me. This puts quite a financial burden on my family. [PtIRAF71]

The problem of health care infrastructure and the distances that some patients have to travel to the clinic were equally acknowledged by the health care workers and some key national health officials during the current study as having a substantial effect on patients' clinic attendance. One of the key national health officials was touched by the challenges that most patients were facing and went further to share some of the efforts that the government was taking to address the issue:

Yeah...I agree that the distance is a problem for some patients and that is why we are trying to decentralise our services. We are currently trying to establish another clinic at Mbagala Rangi Tatu. Even with this clinic we still know that Temeke is far too big for two clinics if we are planning to make them accessible and less costly for our patients. Another thing that we are currently exploring is to partner with private clinics. This option, however, needs to be taken cautiously because the private clinics are likely to be more expensive. I am sure that very few patients would manage the costs. So far we have one private clinic known as Kojashinashari close to our hospital but I have not had an opportunity to check their costs. [CIKI72]

Adding to the effects of the infrastructure on clinic attendance some of the health care workers and key national health officials further reported that seasonal weather variations were also the cause of the infrequent clinic attendance for some patients, as revealed here by one of the health care workers:

Clinic attendance is highly influenced by the seasons of the year. During the rainy season which is from April to June few patients come to the clinic because of the transport problems. Some roads in the city are not passable then so some patients have quite a rough time making it to the clinic. Another period is between June and August because this is during the budget season and most drugs are out of stock at this time so many patients do not see the need to come to the clinic. [HwRN39]

6.1.2 Health Care System Challenges

While most patients acknowledged the effective role of biomedical services in the care and management of diabetes, they were also willing to discuss the health care system

related challenges that they were facing in their effort to access quality care services. These included long waiting times at the clinic, lack of ‘client friendly’ care services, lack of quality care services, poor diagnostic skills and equipment, and poor availability of subsidised drugs. These challenges are discussed in detail below.

6.1.2.1 Long Waiting Time at the Clinic

Having survived the hassles of public transport from their homes to the clinic the patients find themselves faced with other challenges from the health care system in their efforts to access care services. One of these is the long time and they have to wait in long queues at the clinic before getting medical care services. The long waiting time and queues at the clinic was mentioned by most patients, caregivers and some health care workers as one of the factors contributing to poor clinic attendance. Some patients reported spending an average of two to six hours at the clinic before seeing the doctor/diabetes specialist. Normally most patients arrive at the clinic between 6 and 6.30am depending on where they are coming from but the clinic does not open for service until 9.30am. Despite their early arrival, however, the majority of them only see the doctor at around 10am. This waiting time was considered far too long particularly for some of the patients who did not have breakfast and those whose health status may already have started to deteriorate due to diabetes.

Figure 6.3: Female patients waiting to see the doctor at diabetes clinic-Ihala district, Dar es Salaam Tanzania 2007



The frustrations of long waiting times at the clinic are also compounded by the uncertain nature of public transport that most patients have to catch to get home after their care at the clinic, as observed by one of the patients:

Sijui hata niseme nini...? [I really don't know what to say ...?]. I hope you will not take this as an exaggeration because it is a reality. Ask any patient! Some patients leave home about 6am and at 1pm or 2pm they may still be at the clinic waiting to see the doctor. We are talking about six to seven hours of unproductive waiting! Now if you happen to live far away in places like Kisarawe or Bunju when will you get home? If you are still in town by 3pm you are surely going to run into the evening traffic and you will be lucky to get home before 7pm. You know quite well how uncertain and challenging our public transport system is for passengers! [PtIRAM24]

While acknowledging the fact that the health care workers' day starts with some ward rounds in the main hospital before they come to the clinic, some caregivers still felt that this care delivery system totally lacked due consideration of the patients who equally need the services of these health care workers. As one of them put it:

... the most frustrating thing for most patients is the fact that health care workers begin to offer their services at 9.30am or 10.00am while some of the patients have been at the clinic since 6.00am. To most patients this is quite irritating and discouraging especially for old patients and those whose health conditions have started to deteriorate because of diabetes. [CgIPAF73]

Similarly, some infrequent clinic attendees were not hesitant to vent their frustrations, particularly when they have noticed undue wasting of time by the health care workers, as observed by one of them:

If I remember well the last time I was at the clinic I think I might have spent not less than four or five hours of waiting. The doctors and other health care workers normally turn up at 8.00am or so but you will normally see them moving from one corner of the clinic to another...and by the time they start seeing the patients it is normally at 9.30 or 10.00am! Now by the time the doctor get to see you it is probably 1.00pm or later! This for me and many patients of my age is a big problem. I can manage one or two hours of going in and out but hanging around at the clinic for four to five hours is certainly far too much for my health or for any other patient. This was one of the reasons why I decided to stop going there! [PtIPAF62]

While some health care workers acknowledged the fact that the long waiting time at the clinic was one of the 'push factors' against the patients' utilisation of their services, they argued that this was due to the shortage of manpower at the clinic:

The delay for patients in getting their services has been one of the health care system bottlenecks that we have not been able to address effectively for some time now. Some of these delays are caused by the staff starting to see patients late due to morning

meetings or ward rounds at the main hospital. Some of these meetings which are meant to take up to an hour sometimes end up taking longer making our services to start at 9.00am or so while the patients have been at the clinic from 6.00am! This unfortunately pushes some patients away from our services. The other thing is that we have a shortage of staff...we have only one doctor here who is expected to see more than 50 patients a day! [HcwTN13]

Some health care workers were similarly defensive when discussing the problems of long delays in accessing care at the clinic, as was the case with this one:

Most patients come in as early as 6.00am mainly to beat the public transport problems and to get to the front of the queue here. Nobody told them to come that early. But ... we normally start our services at 8.30am so if they calculate the time they spend at our clinic they should start from this time. As for patients coming here before having breakfast I think these are restrictions of the past. We know that it takes time before the patients can see the doctor so we have been advising the patients to have breakfast before they come to the clinic. At most it takes from 45 minutes to one hour and up to four hours for those who came late to get their services because sometimes we have two doctors in our clinic. I normally spend the first 15-30 minutes or so giving them education about type 2 diabetes because we are getting new patients every day so we want every one of them to be on board with issues related to type 2 diabetes. [HcwRN85]

Similar observations were made on the issue of whether the patients could eat something or not before going to the diabetes clinic for their blood sugar assessment. Most patients reported starving before taking their blood sugar test at the clinic:

It is really bad and frustrating keeping in mind that when we go for our clinic appointment we cannot eat anything until we have our blood taken for the sugar test! Well ...if it were to end up there it could be manageable but you have to queue up again to see the doctor and later on get your drugs in another section of the hospital. When you are at the clinic you hear some patients saying, "it is better to go to the private clinic where you don't have to wait for such a long time! This is a problem of poverty..." The worst thing is that some people who are still working or who have a private business come to the clinic and expect to go back to work afterwards so when they spend the whole day at the clinic it certainly costs them a lot! [PtIRAM67]

The majority of the health care workers reported that in principle they have been advising their patients to have their breakfast before they come to the clinic for their blood sugar tests. According to the health care workers if the daily blood sugar is being controlled well then having breakfast before coming to the clinic would not make any significant difference to their sugar levels, as elaborated by one of the health care workers:

A patient who has had breakfast has 5 to 6mmol/L which is normal. The problem is that some patients who have not been managing their sugar levels well come here with

the intention of pleasing the health care worker. To do so they take insulin before they come to the clinic. So when you test their sugar levels you may find it to be as low as 2mmol/L and when you ask them if they have eaten anything they say no. However, when you ask them whether they have taken insulin they say ...yes! So you sort of wonder why on earth would they take insulin before the test? Who are they trying to cheat? We have been educating patients on the importance of these routine tests and warning them against this kind of behaviour since some may be risking the problem of hypoglycaemia and possibly death! [HcwDr86]

While acknowledging that some health care workers are likely to defend some of the shortcomings of the biomedical care delivery system, the differing opinions between the health care workers and the patients on the issue of food intake before taking their blood sugar tests questions the nature and usefulness of the “health talk” sessions that are carried out at the clinic every morning. If effectively carried out, the misunderstanding on the issue of food intake by patients before their routine sugar tests should not occur.

Furthermore, the layout and/or organisation of the biomedical care services at the clinic was mentioned by some patients and their caregivers to be highly demanding on the patients in terms of accessing different services during their clinic visits. Patients have to walk long distances within the hospital compound to get one service and yet another distance to get the next service: an experience that was reported to be very tiring for some. Indeed, this challenge was acknowledged by the health care workers and national health officials involved in this study:

You see, for some patients, coming to the clinic is a chore. The scattered nature of our services here makes some of them really exhausted before they even get to see the doctor to get their medical prescription...and this is quite discouraging. To start with, they have to queue for a long time at the hospital laboratory which is far away from the clinic. Secondly, they have to come here for another queue to have their blood pressure taken. Thirdly, they have to get into another queue to see the doctors. Finally, they have to join another queue at the hospital pharmacy for their medication. This is really a long exhausting process especially for some of the patients whose health has substantially deteriorated because of this disease. [HcwTN13]

Some key national health officials not only acknowledged the unfriendly nature of the layout of the diabetes clinical services for the users but were also willing to share some tentative solutions to the problem, as revealed by one of them:

... the layout of diabetes clinic services at the hospital can be quite demanding particularly for patients whose health has been compromised by diabetes. There is a need to consider setting up various types of services for these patients under one roof. This would, for example, require each clinic to have its own laboratory and a pharmacy

stocked with adequate drugs so that patients could get their clinical services and drugs in one place. [CIKI57]

6.1.2.2 Lack of ‘Client Friendly’ Care Services

Health care workers in the current study form the first point of contact for the patients as they enter the pathway to care and management of diabetes. Often the first impression that they make on these patients has a long lasting effect on their future utilisation or non-utilisation of the care services. Although most patients and their caregivers acknowledged getting on well with the health care workers, some patients in the in-depth interviews appeared to be neutral in their overall perceptions of the health care workers and the manner in which they delivered their care services, as revealed by one of the patients:

...we cannot really say our relationship with the health care workers is bad or good! They are there doing their part as employees and we are there to get their services as patients so we respect that. [PtFGRAM76]

Some caregivers, community members and the key national health officials had quite different perceptions of the health care workers and the manner in which they provided their care services to the patients. For example, some caregivers were dissatisfied with the nature of the patient education which was being provided at the clinic by the health care workers. They felt that the health care workers were not spending enough time educating patients, particularly those who were on insulin, on how to administer the drug on their own:

I thought they were going to take the opportunity and more time to educate her on how to inject herself and probably have her do it while we were at the clinic to see if she was doing it right...but no! They basically did not have the time. So here we are three years under treatment yet she simply can't inject her insulin and we are spending more money to have this injection done for her! I just cannot understand it really! [CgIRAM49]

While acknowledging the importance of the health education sessions that the health care workers hold at the clinic every morning, some patients did not like the way such sessions were being run, as revealed by one of the patients:

...we have a programme every Thursday where the health care workers provide general education to patients about this disease. But this type of education is too general because everyone has different problems. Some of us might be interested in having a one to one talk about some personal issues that we may not be ready to discuss in public. This then makes it difficult to get the answers that one needs in relation to his or

her problem. I will give you an example, "...as you know, this disease tends to seriously affect individual sexual life and at times one may want to know how to go about dealing with this problem. In our culture it is not polite to talk about these kinds of things in public...they are very personal and private so they need to be handled that way..." [PtFGRAM82]

Figure 6.4: A Health Education Session at the Diabetes Clinic in Dar es Salaam 2007



Others patients were not happy about the manner in which these “health talks” are given. According to some, these sessions are always rushed and when a patient stops them to ask questions the responses are equally given in a rush so in some occasions the patients keep quiet.

The rushed approach that the health care workers display in their provision of “health talks” was also observed in the manner in which they delivered their services to their patients. Some community members, for example, acknowledged that the behaviour of some of the health care workers that they have had experience with was in their opinion, not “client friendly” hence more likely to put off patients rather than pulling them towards utilisation of the services, as revealed by one of the community members:

It is common to see a health care worker scolding a patient in the hearing of every patient at the clinic!... even more disappointing is when you realise that the patient in question is old enough to be his/her father or mother! So you hear things like: “Today is not your day for clinic! You just don’t decide to come here any day you want to”...and it goes on and on...before even trying to find out why the patient decided to come to the clinic that day! [CmFGM26]

The poor attitude and behaviour of some health care workers towards the patients were also acknowledged to contribute to the infrequent clinic attendance of some patients, as revealed by one of the key national health official:

We health care providers can act as a barrier against the patients who intend to access our services. We always push them away instead of drawing them towards our services. For example, when the patients come to our health care facility are we taking the time to hear them out in order to make the right diagnosis and properly guide them into the right pathway to care? We basically don't! [CIKI57]

The lack of 'client friendly' care services from the health care workers in public clinics was echoed several times during FGDs with community members. According to some participants, these health care workers lack "personalised care" handling which is important in attracting and retaining patients under their care. Sharing their own personal experiences some of the participants argued convincingly that there were great differences in the ways health care workers in private hospitals handle their patients compared with those in the public care facilities.

If you go to Dr. 'X' who runs this private hospital you will notice quite a difference in the overall patient management. The moment you approach the doctor's desk you will hear: "Karibu... karibu ukae tukusaidie vipi?" [...*please welcome and have a seat. How can I help you today?*] He will go through your history, get all the pointers that will give him some ideas about what might be bothering you and the like! This kind of handling not only invites you to go there next time but forces you also to advise your friends and relatives to go there when they have a problem. [CmFGM77]

Another member of the community eagerly shared this contrasting experience:

In the public hospitals if you are a bit late because of transport problems and find out that the health care worker has collected all the cards that allow you to see the doctor you will have a rough time convincing her to have you in for the day irrespective of your health condition. You will hear: "... umechelewa na nimeshakusanya kadi zote hivyo uje siku ingine" [...*you are late and I have collected all the cards so come another day!*]. [CmFGM78]

The lack of 'client friendly' care services among the health care workers was further supported with vivid examples of the "uncaring" nature of some health care workers, as captured during the FGDs with community members:

You see, you may be sitting there for hours waiting for services only to hear from the nurse that the doctor won't be coming for the day because he/she has some personal problems. So the patients find themselves questioning the whole nature of care services: "After two or three hours of sitting out there on those hard benches you end up being

told that the doctor won't be coming! Why didn't he/she say that earlier?" When this happens the patients obviously leave with a lot of disappointment...and some might not have further financial resources to come back another day! [CmFGM79]

6.1.2.3 Lack of Quality Care Services

Apart from the 'unfriendly' way in which some of the health care workers go about providing their services to the patients, the quality of such services also appears to be marred by lack of transparency, corruption and lack of basic equipment and drugs. Most patients, for example, felt that there was a considerable lack of transparency in the manner in which the overall care services are provided at the clinic:

...we were put off going to the public clinic because of the poor quality of services. The waiting time at the clinic is much too long and often there is no equipment to test blood sugar levels and of course no drugs. Sometimes the health care workers say the machine is broken or it is just out of order so they tell you to go across the hospital fence and have your blood sugar tested etc...I think there is a need for more transparency in the nature of services that are supposed to be available at these clinics, the costs for the tests and the drugs because these keep on changing from one facility to another. I would recommend that diabetes patients be provided with these services free of charge since most of us are unemployed or retirees. [PtIRAM66]

One of the key national health officials agreed that the issue of transparency was one of the problems affecting the quality of care services being provided to the patients by some health care workers:

...corruption, low morale, and low salaries among health care workers are common problems facing many public biomedical care facilities in the country. Unfortunately these problems can affect their working relationships with their patients. However, I think the underlying problem here is lack of "customer care". This is why the government is now focusing on training health care workers on the importance of "customer care". This training is planned to go along with close facilitative supervision to make sure that health care workers put into practice these skills in their care service delivery. Provision of incentives without this training might fall short of expectations. [CIKI72]

Along with the problem of poor customer care from the health care workers was the problem of "preferential treatment" being provided to some patients at the expense of others, a practice commonly observed in some of these health care facilities. This behaviour was said to be motivated by corruption among some health care workers and contributes negatively to patients long queues at the clinic; poor quality of care services to some patients; and the overall infrequent clinic attendance, as revealed by one of the community members during the FGDs:

In most cases to get some attention at the public care facility you ought to know someone there. You may be seated there expecting to be seen only to find the doctor leaving with one patient he/she knows to assist him/her to get services on the other side of the hospital while the whole queue of patients stands still until the doctor gets back to resume the services! [CmFGF80]

Often, in an effort to catch up with care service delivery the doctor will see these other patients in a rush, thus compromising the quality of care. Both the long queues and the poor quality care services that the patients end up getting have a significant effect on the patients' decisions whether or not to go to the clinic next time.

However, despite the negative perceptions of the quality of care services that these biomedical care facilities provide, some patients appeared to be quite sympathetic to the health care workers given their working conditions, as acknowledged by one of them:

...the fact is that health care workers are faced with more patients than they can handle. In such a situation, and taking into consideration that they are also working in the eight hour timeframe, there is no way they could see all the patients that turn up at the clinic. Even if they decided to spend unlimited time on the patients the health care providers would still not be able to see them all! [PtFGRAF96]

The problem of the huge workload for the health care workers at the clinic was also attributed to the poor quality of the care services in the health care facilities, as observed by one patient during a FGD:

The truth is that the health care workers at the clinic have been doing their best both in educating us and providing us with care services under the circumstances. The three of them are serving between 40 and 50 patients a day so there is no wonder that they rush in everything that they do...they simply have no choice! This is the reason why we are calling upon the government to give us more doctors and nurses at these clinics! [PtFGRAF81]

6.1.2.4 Poor Diagnostic Skills and Equipment

Effective care and management of diabetes or any other disease starts with making a timely and proper diagnosis and provision of adequate guidance and support to patients throughout the care and treatment pathways. For many patients and their families, the decision to seek care at a biomedical care facility is made as part of their effort to seek explanations about the signs and symptoms that the patient is experiencing. Effective diagnosis and provision of proper care, therefore, is important to relieve the patient's

symptoms associated with their medical condition and also to reinforce the patient's positive perceptions of the biomedical care services and their continued use. Although the levels of understanding and knowledge about diabetes and its management among the health care workers was not in the scope of the current study, efforts were however made to elicit information from the participants on their perceptions of the health care workers' skills in the management of this disease.

When the patients were asked how many times they visited a biomedical care facility with the same complaints (symptoms) before they were diagnosed with diabetes some patients reported being diagnosed the very day they went to the hospital while others were diagnosed after some time. As seen in Chapter Five, for some patients the visit to the clinic was prompted by signs and symptoms perceived to be associated with other pre-existing health problems like hypertension, only to be tested for diabetes, as reported by one patient:

You see, having a sugar level of 400mg/dl in your blood is no joke...if I had made the mistake of going to this or that doctor or for that matter to a traditional healer that would have been it! I would have been history by now! I was lucky...I went straight to the hospital and they were able to diagnose my problem right away! [PtIRAM83]

Some patients, however, were not that lucky. They had to make several trips to different biomedical care facilities before they were diagnosed. Delays in getting a timely diagnosis of their medical condition were attributed to three related factors: first, through the patient's failure to clearly explain the signs and symptoms to the health care workers in order for the latter to make an appropriate diagnosis; second, due to inadequate technical skills and facilities to make an appropriate diagnosis; and finally, due to the co-existence of other diseases like malaria and high blood pressure. The latter is suspected to draw the attention of health workers with a low level of skills away from the real problem of type 2 diabetes mellitus.

Some biomedical care facilities were reported to lack these diagnostic skills thus completely failing to make a timely and correct diagnosis. This led some patients to make several visits these facilities before they could get a proper diagnosis, as reported by one of patients:

I visited one of the private biomedical care facilities about three times but they kept diagnosing me with malaria. One day, however, I fainted and lost consciousness at

home; that is when my relatives rushed me to Muhimbili National Hospital.
[PtIRAM12]

Health care workers and key national health officials acknowledged that the problems of delay and/or misdiagnosis of diabetes were a result of limited staff knowledge and skills regarding diabetes and its manifestations. According to the health officials, this problem is mainly related to limited working experience with people with diabetes and the fact that some of the signs and symptoms of diabetes are sometimes similar to those of other diseases like malaria which can be quite misleading for inexperienced health care workers:

I would say the level of knowledge regarding this disease is still low among a good number of our health workers including doctors. I think the health care workers need frequent training not only on this disease but for other diseases as well. You see, the medical knowledge is changing so rapidly and the health care workers need to catch up with the new scientific developments in the field in order for them to be able to provide up to date services for their patients. [HcwDr40]

Irrespective of the reasons for the delay or misdiagnosis of diabetes, the outcome forms a negative perception of the biomedical care services among the patients, leading them to question their original decision to seek care at these facilities.

Apart from limited skills, the clinics were reported to be lacking basic equipment like glucometers. The lack of functional glucometers required the patients to get their blood glucose tested at a private facility often across the fence from the hospital at some additional cost. This experience is not only frustrating for patients but adds to the negative perceptions some of these patients might have already with regards to biomedical care facilities. When these additional costs are combined with those of transport to and from the clinic, then one starts to understand why some of these patients decide not to go to the clinic, as revealed here:

...more depressing is when you get to the clinic after all the public transport hassles and realise that there is no machine for testing your blood sugar! This forces you to have your blood sugar test done elsewhere at some cost. You see, the costs of doing these tests in town are twice as much. So, instead of paying Tshs. 1, 000 (\$1) for the test, you end up paying Tshs. 2,000 (\$2). This really discourages a lot of patients from seeking care at the clinic. [PtIRAF28]

Further, the malfunctioning of equipment like a glucometer or refrigerator could have a serious impact on the overall provision of care services at the clinic as revealed by one of the health care workers:

Like the medical supplies the equipment are equally limited. We only have one glucometer at the diabetes clinic and so when you have 30-50 patients getting blood sugar tests this can take quite some time. We sometimes also do not have a working refrigerator for storing drugs that are urgently needed at the clinic. [HcwRN39]

Participants reported that limited basic medical equipment and storage facilities for drugs at biomedical clinics not only limit the ability of the health care workers to deliver their services effectively, but also give patients a negative impression of the quality of the care services offered at these facilities. The problem of refrigeration facilities was not unique to the health care facility. Some patients, particularly those who were under insulin treatment, were also reported to lack refrigeration facility in their homes. Apparently some health care workers have come up with alternative cooling facilities using a clay pot and cold water. Many of the patients under insulin treatment are given a demonstration of how to use the clay pot at the clinic as shown in Figure 6.5. Clay pots are traditionally used in many households in Dar es Salaam as a cooling facility for drinking water.

Figure 6.5: A demonstration cooling clay pot on top of a tin with sand used to store drugs in the absence of a refrigerator 2007



6.1.2.5 Poor Availability of Affordable Drugs

Normally, diabetes drugs at the public hospital are subsidised by the government. However, except for a few months of the year these drugs are seldom available and although they are available at the private pharmacies across the fence from these hospitals, the prices are beyond the means of many patients.

Figure 6.6: A private pharmacy outside a public hospital–Kinondoni District in Dar es Salaam, Tanzania 2007



Poor availability of subsidised diabetes drugs at the biomedical facilities therefore poses yet another health care system related challenge to patients in the care and management of diabetes, as highlighted by one of the patients during a FGD:

The lack of drugs at the public hospital pharmacies is really a chronic challenge to our care and management of this disease. It is one of the reasons why some of the patients have been turning to traditional healers for local herbs and the like because they simply cannot afford to buy the medication at the private pharmacies. [PtFGRAM87]

Poor availability of diabetes drugs was equally reported by some of the key national health officials although some appeared to blame the inefficiency of hospital leadership:

Well...personally I am not sure why this has been a problem in so many hospitals! I think much of this problem emanates from some of our hospital pharmacists. For example, one should ask oneself... how often do these clinics order the drugs? How often do they check the stock before it runs out? I am sure if some close attention is paid to these details this problem may be highly minimised. But again we need to look at the availability of the drugs at the Medical Stores Department (MSD). How available are these drugs? If for example, you send in a requisition and the drugs happen to be out of stock...how fast can these be procured? I think the whole procurement system here right from the hospital to MSD is not working well. [AcKI88]

The challenge of availability of drugs was well appreciated by some of the health care workers who particularly expressed their concerns with regard to availability of insulin:

In fact the shortage of drugs affects our working efficiency, affects the control of blood sugar levels among our patients who need it, and poses a significant challenge in the management of diabetes both for the health care workers and the patients. You see it does not make sense to put the patient through the whole process and having him/her heading home without any medication simply because the drugs are not available or affordable for him/her! It is really disheartening both for the health care workers and the patients. [HcwDr89]

Poor availability of affordable diabetes drugs at the public hospital forces many of the patients to turn to the private pharmacies where the prices of similar drugs are almost double. As mentioned in the introduction to this chapter, patients' lack of financial resources is the underlying challenge in the overall care and management of diabetes. The high costs of diabetes drugs coupled with the recommended diabetes diet were reported by some patients to subject them to an everlasting dilemma of whether to prioritise their family needs over their medical needs:

I do not earn enough to be able to buy the drugs and the recommended food that I need. I find myself having to decide between buying the drugs and special food that I need or simply buying food for the family. This is quite a challenge for me! A kilogram of wheat flour is about Tshs. 6,000 (\$6) so for me to buy that for my diet means having the family eat less of what they need! I hate to see my family eating kinds of food which they would otherwise not eat simply because of my problem. So, at times I just forget about my problem to maintain the welfare of my family. [PtIRAM25]

The high cost of the recommended diabetes diet was also recognised by the health care workers and key national health officials involved in this study as a major challenge in the care and management of diabetes:

...apart from the drugs which are prohibitively expensive, some of the diets that the patients are encouraged to adopt are out of reach for many of them. For example diabetic brown bread costs about Tshs. 700 (\$0.70), while normal bread costs Tshs. 250 (\$0.25). Marmalade for diabetes patients costs around Tshs. 6,500 (\$6.50) while the

normal one costs Tshs.1,000 (\$1). These are just a few examples of the financial challenges that many of these patients are facing. [HcwTN13]

The huge variation in price between diabetes drugs sold at public hospital pharmacies and those sold by private pharmacies was also an issue of great concern among most key national health officials interviewed during the current study. Some of them acknowledged that drugs like insulin were prohibitively expensive when purchased through the private pharmacies compared with the public hospital pharmacies, as one official put it:

...these diabetes drugs are sold at anywhere between Tshs.12,000 to Tshs.16,000 (US \$12 to \$16) for a dose while the same drugs may be obtained at the government hospital pharmacy for Tshs.5,200 (US \$5.20). [CIKI57]

These prices are prohibitive for the majority of families which are extremely poor, a situation that prompted one of the key health officials to call on the government to come up with some policy guidelines for these life saving drugs. Highlighting the cost implications of diabetes drugs, one health official had this to say:

...if insulin is not available in the public hospital pharmacy you still have to buy it for Tshs.18,000 (US\$18) or more to survive. So, affordability is a major challenge here and mind you if you are using insulin twice a day for a month you may end up spending about Tshs.75,000 (US\$75) a month. This amount is almost twice the monthly minimal salary of a government employee which is Tshs.45,000 (US \$45) a month! So, even if some of these patients are still on active government employment and we know the majority of them are not, they may not be able to afford to buy the drugs. [CIKI36]

There was some consensus among most participants that what was going on with the prices of diabetes drugs in the country was a result of “artificial scarcity”, which had its roots in the Medical Stores Department (MSD). When this government institution fails to order adequate supplies of drugs the price of the limited quantities of drugs in the private market goes up, as remarked on by one of the patients:

The major problem here is lack of medicines particularly insulin. The drugs are very expensive. A vial of insulin for example, costs between Tshs.20,000 to Tshs.40,000(\$20-\$40) at the private pharmacies. The same vial is sold here at the public hospital for Tshs.7,000 (US\$7). But the problem is that these drugs are not mostly available at the public hospital pharmacy...we can go for three months without a tablet or insulin injection from the government hospital pharmacy so we are forced to go to the private pharmacies which apparently are always stocked with these drugs! [PtFGRAM90]

The problem of unavailability of subsidised diabetes drugs at the public hospital pharmacies gives private pharmacies a monopoly on the sale of these drugs. The patients, therefore, find themselves caught in this supply and demand equation and having no choice, they have to raise money to buy the drugs or risk the medical complications associated with diabetes. The poor availability of diabetes drugs at the public hospital pharmacies while these are readily available at private pharmacies was for many patients a puzzle raising a lot of questions as one of the patients put it during a FGD:

You see there is this dilemma we find ourselves in... Every time you go to the public hospital pharmacy you are told that there are no drugs but just across the hospital fence there is a chain of private pharmacies that never run out of these drugs! So you sort of ask yourself... “where do these private pharmacies get all these drugs and how come they never run out while the public hospital pharmacies have shortages almost throughout the year?” This is just one among many questions we have been asking ourselves for a long time with no answers! It is really a big puzzle that we have been living with and it is killing us slowly! [PtFGRAM91]

6.2 Implications of Care and Management Costs

The costs of managing a chronic disease like type 2 diabetes mellitus have significant implications not only for the health of the patients but also for the overall welfare of their families. The low income of many families, coupled with costs of transport to and from the clinic, medical tests and drugs as seen in section 6.1 above pose a major challenge to the patients and their families. In an effort to pay the costs related to the management of diabetes, patients and their families were reported to adopt cost cutting measures which were detrimental to their health and the welfare of their families. The observed implications of the care and management costs of diabetes are divided into two categories: implications for the patients’ treatment; and implications for family welfare.

6.2.1 Implications for the Patients’ Treatment

As already seen in section 6.1, some patients often resorted to staying home rather than attending their regular clinic appointment if they did not have enough money to pay for transport to the clinic, and to meet the costs of the medical consultation, blood sugar tests and medication. This measure obviously has a negative impact on the patient’s overall care and management of diabetes. Other measures include the purchase of fewer

drugs than prescribed or taking a low dose of the prescribed drugs, as revealed by one of the patients:

...the price of a one-month dose of my drugs ranges from Tshs.35,000 to Tshs.40,000 (\$35 to \$40). So what I do is when my sugar level is low I stop taking my tablets which include Glycinorm 80mg OD and Glitz 30mg OD. This way I don't take the full dose. I know I am not doing the right thing in managing this disease but I have no choice just because I cannot afford to do otherwise. [PtIRAF92]

The implications of care and management costs for type 2 diabetes mellitus were also noted to be severe among patients who had lost their daily income due to health conditions related to this disease, as was the case with this patient:

You see...I was forced to retire prematurely from my job due to my health condition. Now I am having a hard time coping with the financial demands of meeting my drug and diet requirements. Sometimes I simply eat whatever is available which is not good for my health! My blood sugar has been flaring up now and then because of my poor diet. Sometimes I cannot have my insulin because I have no food to eat! [PtIRAM24]

The health care workers acknowledged that it was in recognition of the implications of care and management costs for this disease that patients are now being counselled to eat the same foods as the rest of the family members.

Well, we are now counselling patients to eat a reasonable amount of the same foods eaten by the whole family. We are for example, educating them on the importance of limiting the amount of carbohydrate and sugar intake. We are also encouraging patients to take good amounts of fluids and fruit as well as doing more exercise. [HwRN108]

Other patients resorted to using the services of traditional healers as a strategy for coping with the high costs of drugs from the private pharmacies, as remarked on by one of the patients:

I have been using the herbs from local medicine men. They are less expensive compared with the drugs from the private pharmacies in town. However, I have also been trying to do my blood sugar checkups frequently and abide by my prescribed diet. In a way I consider myself lucky because I would have been relying on my relatives to buy the drugs that I need and much as I appreciate their support I also know that they would some day start getting tired of me! I have a friend who was being helped by his relatives but now he is in a great mess because the relatives run out of money and were quite straight with him: "*this time you don't go to the clinic because we basically don't have money*". [PtIRAM66]

6.2.2 Implications for Family Welfare

The overwhelming majority of the participants in the current study reported that the impact of the financial resources that the patients have to find to meet the costs of care and management of this disease goes beyond affecting the patients' clinic attendance and purchasing the needed medication and food. This financial impact also affects the overall welfare of their respective families, as noted here by one of the caregivers:

It affects us quite a lot...you know my husband is no longer working. In the past he had at least two jobs to make enough to pay for the treatment costs and feed our family. Now that he is sick he can only manage one job and the little money that he makes is not enough to meet his medical costs. We are sacrificing a lot just to make ends meet. We are, for example, forced to eat one meal a day because we cannot afford two meals a day! [CgIRAF94]

Sharing his concerns about how the cost of his medication affects the welfare of his family, one of the patients provided the following breakdown:

A patient who is on normal diabetes drugs like myself, apart from insulin, would need to spend about Tshs.6,000 to Tshs.11,000 (\$6-11) every month out of the meagre family resources to buy drugs. This would mean squeezing the family budget very tightly and buying less food, and few or none of the other basics in the family. [PtIRAM24]

When the costs of managing diabetes are placed against other equally compelling financial demands of running an extended family (which is typical of most African families), the decision on what needs to be funded and what is to be put aside brings the harsh realities of managing this disease to the surface, as described by one of the patients:

I am currently living with my grandchildren who go to school and I have to give them money for bus fares every day. But when I am low on money and have to go to the clinic, I have no other option but to make the unfortunate decision of telling them to stay home so that I can at least use the money for my bus fare to the clinic! This happens quite often...and I have no other choice! [PtIRAF69]

The financial implications of adhering to the needed care and management of diabetes mellitus was reported to be even more significant when two or three family members happened to be suffering from the same disease, as revealed by one of the patients during the focus group discussions:

You see...this problem affects us in a lot of ways especially when you have no money. In my case for example, I have this problem and my daughter also has it. We have no source of income since the breadwinner...my husband died a long time ago. Although I

currently have a small business the level of income that I get from it cannot meet both our living costs and the medication we need. Just recently, my daughter was admitted to the hospital because she has developed a problem with her arm and we were given instructions to go and have an X-ray done. All these cost a lot of money which we don't have. Sometimes I just do not know how we have been managing! [PtFGRAF95]

6.3 Use of Alternative Care Services

Having established the fact that patients and their families and/or social networks consulted extensively with traditional healers and/or herbalists before they finally sought care at biomedical care facilities I was interested to find out the extent to which patients continued to use these alternative care services even after they were diagnosed with diabetes. The data show that after initiating treatment at the diabetes clinic some patients did indeed use alternative care services in the management of this disease. Most participants were in agreement that patients' use of alternatives services before and after diagnosis was consistent with African tradition, as summarised by one of the community members during a FGD:

Take it from us...the use of traditional healers is part and parcel of our African health care system. If someone tells you that he/she hasn't consulted a traditional healer and/or herbalist for one health problem or the other he/she will be lying! The question is what services one seeks from these healers. Health seeking for any type of ailment in our culture is a family affair. So whenever one falls sick it has been a tradition for family members to suggest where an individual should go for care depending on the nature of the problem. [CmFGF97]

While acknowledging the effective role of biomedical care facilities in the care and management of diabetes, participants reported that use of alternative care services particularly those provided by traditional healers was equally attractive for a number of reasons. First, as mentioned in Chapter 4, family members and/or social networks are not only involved in the process of the patient's decision making to seek care but continue to play a significant role in the ensuing care and management of diabetes. Family members have significant influence on the type of services to be sought by the patient, where and when. As noted in the current study, some of the patients reported using alternative care services or traditional medicines through the advice of family members and/or social networks, as revealed by one of the caregivers:

After initiating treatment at the clinic he was advised by one of his friends to try some other medications. He took him to this traditional healer who gave him some traditional medicine...a bottle of a concoction which he was supposed to take in the morning and at night. He paid Tshs.20,000 (\$20). At first it was helpful but later on he realised that

he was not getting any better and the symptoms were back soon. This is when he decided to go back to the biomedical care facility and since then he has not gone anywhere else! [CgIRAF98]

When confronted with particular signs and symptoms of a disease most traditional African cultures including the ones in Tanzania use their existing “traditional health belief model” to determine the causes behind such a disease. The traditional health belief model is a preliminary tool used by different cultures to explain the various causes of a disease through elimination. When the family members and social networks fail to explain the signs and symptoms manifested by a particular disease through this model, further consultation is sought through the traditional healers, as revealed here by one of the patients during a FGD:

...people go to traditional healers in an effort to establish whether the disease is caused by “human or supernatural” forces at the same time making sure that they have sought care through all possible avenues (“*hakuna tiba asiyo ijaribu*”) in their quest for a cure. [PtFGRAF99]

Based on the results of these consultations the family members and/or social networks find themselves in a better position to guide the patients in the “pathway to care” which the latter normally adheres to even when it is not necessarily the best, as one patient reported during a group discussion:

...after using the drugs from the clinic for a while I was advised by my relatives to use some flowers from a plant known as the Star of Jerusalem. I have been boiling these flowers and drinking the juice... I asked them if there could be some side effects if I was to have this in combination with the clinic drugs that I was already taking but they assured me that there was no problem. However, I refused to combine the two; instead I decided to put aside the drugs from the clinic and concentrated on using the local medication...for one week. I then started experiencing the same signs and symptoms that I had before...frequent urination etc. That is when I immediately decided to go back to the drugs from the clinic and I have since stayed on my diabetes drugs prescription. [PtFGRAF100]

Figure 6.7: A Plant of ‘Star of Jerusalem’ flowers used for diabetes treatment



The second major factor reported to influence the use of alternative care services was the search for a cure. In an effort to get the ultimate cure for diabetes some patients were reported to combine the drugs that they were getting from the health facilities with those from traditional healers, sometimes with negative outcomes, as revealed by one caregiver:

Yes...she continued to use the drugs that she got from the traditional healer with those from the clinic. She really fell ill and was admitted to the hospital and the doctor wanted to know whether she was taking the drugs or not so we had to tell him the truth that she was combining the drugs with those from the traditional healers. The doctor advised her to drop the medication from the traditional healers and since then she has been on the drugs from the health care facility. [CgIRAF101]

Once diagnosed with diabetes the search for a cure is a continuous process for most patients, their family members and/or social networks. The patient who by this time has accepted the “sick role” has no choice but to cooperate, as reported by one patient:

...my relatives gave me two types of herbs “Magome ya mti wa Mzambarau na shubiri” (barks of a wild fruit tree and some bitter herb). I had to boil these and drink the liquid. I did not want to take this concoction with the clinic drugs so I stopped taking the drugs from the clinic. After two weeks I realised that these herbs were not giving me any

relief so I stopped using them and went back to my clinic drugs. I am feeling much better now. [PtIRAF20]

Reacting to the reported use of alternative services, most health care workers felt that maybe this difference is what some patients need to experience in order to better appreciate the effectiveness of the drugs. According to the health care workers, for most patients and their families, once diagnosed with diabetes all efforts are geared at getting that “magic bullet” [*dawa musharab*] which will cure the disease once and for all. However, it does not take long for them to realise that indeed, there is no magic bullet for diabetes or any other chronic disease and the drugs provided at the biomedical care facilities constitute the best relief that there is and that is why these patients eventually go back to the facility. This realisation often comes after using a variety of treatments elsewhere, particularly from traditional healers, as acknowledged by one patient:

...I went to the traditional healer because my friends and my father convinced me that this traditional healer had effective drugs for diabetes... I liked the treatment there because the medicines were quite cheap, no queues. For Tshs.20,000 (\$20) I was given one bottle of a herbal concoction that lasted me for a week before I went back for more. After finishing two bottles of this stuff I did not get any relief and my sugar levels were shooting up. I went back to the traditional healer and shared my concern about my sugar levels. He gave me another type of drug in a powder form. He (the traditional healer) said to me “take one spoonful of this powder with a bottle of Coke five times a day before you go for your prayer at the mosque”. I did that but the situation got worse. I was experiencing tremors, sweating and dizziness. It was at this stage that I decided to go back to the Amana clinic and explained all this to the doctor. The doctor said: “*I think you better continue with the drugs you got from the clinic. Remember drinking a Coke or Fanta or anything sweet adds more sugar into your system*”. I went back to my drugs from the clinic and since then my blood sugar went down from 9mmol/L to 5mmo/L. [PtIRAM67]

The onset of type 2 diabetes is very gradual and so is the process of recovering from the signs and symptoms of this disease. However, most patients do not understand this and assume that the recovery process will begin soon after initiation of treatment, as revealed by one of the patients:

You see...after the initiation of treatment at the diabetes clinic it took a while before I started getting any relief. I consulted my friends and they advised me to go to one herbalist they knew who instructed me to boil the leaves of the aloe vera plant with pink or white flowers from another plant known as Star of Jerusalem and drink the concoction. I did as instructed and got some relief. So nowadays I only go to the clinic to have my blood glucose level tested. [PtIRAM66]

Figure 6.8: Aloe Vera plant used by people with diabetes for diabetes treatment



One lesson that can be learnt from the use of these herbal medications according to the participants is that their effects vary from one symptom to another and from one individual to another. Unfortunately, it is the short term relief that one individual may have experienced from the use of the herbs that many patients and their caregivers tend to go by. One of the caregivers, for example, reported some improvement in the signs and symptoms of diabetes following her patient's use of traditional medication compared with the drugs that he was getting from the clinic:

He did not go anywhere but right after he was diagnosed one of the health care workers advised him to use some medicine from the Traditional Medicine Department at Muhimbili University College of Health and Allied Sciences (MUHAS) where some of these local medications were being studied. The basis of this advice was that his sugar level at that time was not that high so the idea was to try these herbs and if his condition did not improve he could simply go back to the clinic. He paid Tshs.8,000 (\$8) for a bottle of a concoction of various herbs which he was supposed to take twice a day—in the morning and evening. After starting on this medication his condition really improved. [CgIRAF102]

The use of alternative care services, particularly those from traditional healers, stems from deep rooted beliefs in society about these traditional services. Some patients acknowledged that this belief was strongly held in their community and that if one

wants to treat diabetes effectively, the approach was to start with local medications either from traditional healers or herbalists before going for the services at the biomedical care facilities.

The third factor influencing the use of alternative care services emanates from the human drive for “self preservation”. By nature, human beings will go to great lengths to protect themselves against physical or psychological harm. This behaviour often gives the individual some gratification...that they “did something about it” rather than sitting and waiting passively. One needs to be seen to do something about it– i.e. looking for a cure.

It makes one feel responsible for his/her health...it feels good to say: “I have sought all sorts of care for this disease including treatment from traditional healers and modern care facilities and the like...but this disease does not seem to respond!” This is an assurance to oneself that he/she has not given up without trying and it is also an assurance that he/she is responsible for dealing with his/her own problems.
[PtFGRAF103]

Along with self preservation efforts some patients also sought supernatural cures and/or faith healing. Currently in Tanzania there is a growing trend of faith healers from different religious denominations claiming to cure all sorts of diseases including diabetes and HIV/AIDS. In light of this there has been an increasing tendency for patients with chronic diseases like diabetes to combine modern and traditional care services with spiritual healing services, as acknowledged here by a patient:

...I did not seek care anywhere other than at the clinic. I do, however, go for “special prayers” because I believe that even though I am taking these drugs from biomedical care facilities some form of supernatural interventions through the Holy Spirit and Jesus Christ would be needed for these to be effective. Medication alone is not enough. Prayers have their special magic you know. [PtIRAF10]

Self preservation through the use of a diversity of curative services was also noted by the health care workers, as underscored by one of them:

Yes...a good number of patients go to traditional healers, others use biomedical clinic medications while others go to faith healers...where they are prayed for by the congregation and the like. All these are efforts in trying to get relief, a cure or some answers to their health problems. [HcwRN39]

The fourth factor influencing the patients in the use of alternative care services was the aggressive advertisements made by traditional healers. The Tanzanian media, especially radio, has over the years been extensively used in advertising the various health cures that these traditional healers have for communicable and non communicable diseases ranging from hypertension, TB, diabetes, and HIV/AIDS to impotence. According to patients in the focus group discussions, these aggressive advertisements have been giving a lot of patients the option for diabetes care services as opposed to those provided by biomedical care facilities:

As you know...the traditional healers have been assuring people that they can cure all sorts of diseases including TB, HIV/AIDS and diabetes. So when one gets this information he/she jumps with joy that his/her problem has got a cure. This kind of assurance is never provided at the biomedical health facility. [PtFGRAF104]

The hope for a cure for diabetes was for many patients an opportunity that many patients should take, as acknowledged by one of the patients:

...you see, when you are faced with a disease whose cure is unknown you find yourself in a very gullible position. You will take seriously any suggestion that you get from almost anybody which might offer some hope for a cure. So when you hear these traditional healers advertising their powers to cure all sort of diseases including diabetes, HIV/AIDS and the like...you basically feel that here is an opportunity for me to be cured. That is why a lot of patients including those with diabetes are seeking the services of these healers. [PtIRAM23]

Some patients were reported to convince each other about seeking care from the traditional healers because they heard this healer had “the cure drug”:

I heard people saying, “*we are going to traditional healers just to try both medications because you cannot rely on only one type of medication if you want to be cured.*” I must say I started believing in them. You see the traditional healers like Dr. ‘X’ have been assuring the general public through their radio ads that they can cure many diseases including diabetes. This is what got me to go there and try...I had nothing to lose! [PtIRAF28]

The health care workers on the other hand agreed that traditional healers had a very big influence, particularly of late, through their radio and TV advertisements on the nature of the treatment they provided. Some, for example, have confidently been informing the public that they cure diabetes, while at the clinic patients were told that there is no cure for diabetes. The treatment that they were getting at the clinic only controlled their sugar levels and did not cure the disease. This information was enough to convince even

those patients who were keen on using care services from biomedical health facilities to give traditional healers a try.

...they have quite a strong influence! You see, the traditional healers, as opposed to the Ministry of Health, for example, have been running quite a strong advertising campaign on the various services that they have been providing including those which guarantee effective cures for diabetes and other diseases like HIV/AIDS. With these kinds of ads, where do you think the patients will go? Obviously to these healers! [HcwTN13]

The traditional healers have been growing ever bolder in their advertisements particularly given the lack of a strong reaction from the government to the false in claims to cure diseases like diabetes and HIV/AIDS. The convincing nature of these advertisements to a group of desperate patients trying to get a cure for a chronic disease like diabetes makes it very difficult for health care workers and health education specialists to convince the general public that diabetes has no cure. This is even difficult when the patients are told that the available drugs are only meant to control the blood sugar levels and not cure the disease, as remarked by one patient during the group discussions:

You see, another problem is that a lot of people have little faith in the so called “dawa za kizungu”[*modern medicine*] This is bearing in mind that before the arrival of the “modern medicines” all sorts of ailments used to be treated through the traditional healers or medicine men/women. “So why not go back to this method since the modern medicines cannot cure diabetes?” [PtFGRAF30]

The fifth factor influencing the use of alternative health care services was lack of adequate knowledge about type 2 diabetes mellitus. Most health care workers recognised that the patients’ lack of information about diabetes and the importance of clinic-based treatment as opposed to care services from traditional healers tend to give the latter an upper hand in influencing patients’ health care seeking behaviour.

I think patients seek care services from the traditional healers for various reasons. To start with, they go there because they have these signs and symptoms that they have been experiencing and have no clue what these are all about! They lack information. So...when they come to us...what do we do? We give them all this long talk about the disease not having a cure and that they have to undergo treatment throughout their lives! We assure them that if they come to the clinic for frequent blood sugar tests and adhere to their medical prescription they will be able to live comfortably with this disease but not be cured of it!. So...some believe in what we tell them; others don’t and we understand. On the other hand, those who go to the traditional healers are assured of a cure although there is none! It is only after using the services of these healers without any success that they decide to come to us. [HcwDr105]

The lack of adequate information and knowledge about type 2 diabetes also appeared to affect the uptake of biomedical drugs for type 2 diabetes coupled with other religious beliefs, as revealed by one patient during the FGDs:

...my neighbour for example, is a strict Muslim from Pemba...he has completely refused to use insulin injections because he believes that the insulin is made from extractions from pigs...so he has been insisting on having tablets instead. He has also been taking these tablets with other local medications that he has been buying from traditional medicine men in the island. The result of this management approach is that his sugar levels have been acting up simply because the tablets are not as effective in controlling the sugar levels as insulin injections. [PtFGRAF106]

The final factor influencing the use of alternative care services was the high cost of care and poor management of diabetes through the biomedical care facilities. The unfriendly nature of care services from health care providers as seen in section 6.1 in most of the biomedical health care facilities, coupled with related costs and poor accessibility to drugs as seen in section 6.2, are a strong influence on many patients and their families as well as social networks to seek alternative care services, as supported by one of the health care workers:

Some patients continue to use both types of services even after they have been diagnosed with this disease. Part of this behaviour can be attributed to the unfriendly nature of our services—long waiting times at the clinic, the lack of drugs, and related costs. Further, we are dealing with some patients who have been convinced through their family members and friends that traditional healers are the answer to their problem. These patients will continue seeking and utilising care services from these healers despite our efforts to convince them that the hospital services are the best source of care for them. [HcwRN39]

It is interesting however, to note that despite the tendency of some patients and their family members and/or social networks to increasingly use alternative care services even after the diagnosis with diabetes, some remained committed to the care services at the biomedical care facilities. Two of the factors influencing their decision to stick with biomedical care services were health improvement following the initiation of biomedical treatment, and lack of confidence in the quality of the services provided by traditional healers. With regard to confidence in the quality of biomedical care services one of the caregivers had the following to say:

No...he did not seek care elsewhere after diagnosis apart from the diabetes clinic. You see, after the first dose his health improved so significantly that we were all surprised and this strengthened our belief in the effectiveness of the biomedical care services in the care and management of this disease. [CgIRAF106]

Some caregivers acknowledged that they were quite conversant with the health complications that patients with similar problems were having following their use of alternative care services from traditional healers and this convinced them that these healers were trying to make a living off the health problems of these patients. Other patients and caregivers reported having used some of the services of traditional healers with no significant improvement, as revealed by one of the patients:

I don't believe in them (traditional healers) and I have no confidence in their treatment. But I have used a number of local herbs including...“Magamba ya Mzambarau” (leaves of the fruit tree), “Majani ya Muarobaini” (backs of a wild tree) and ginger. I have also taken some concoctions from various trees whose names I cannot even recall with no improvement so I went back to my clinic services. [PtIRAM23]

The second factor which made some patients continue with the biomedical care services was lack of confidence in the quality of services provided by traditional healers. Most patients and their caregivers acknowledged that the quality of services provided by the traditional healers appeared to be lacking in many ways, as revealed by one of the caregivers:

I don't believe in traditional healers' services so I have never bothered taking my mother there. You know...the drugs that these healers provide have no specific standards. You can never tell whether you are taking 5mls or 10mls: they just tell a patient “*take this bottle of concoction and use it...when it is finished come back for more*”. So one might even finish the bottle over two days and go back! Without specific measurements it is very easy for a patient to overdose which could have serious health consequences! [CgIRAF107]

6.3.1 Impact of Alternative Care Services Utilisation

Having seen the trends in the utilisation of services of traditional healers before and after diagnosis with diabetes, the study also explored the impact of such service utilisation on the overall care and management of diabetes. As seen earlier, most patients who start their quest for care through traditional healers only turn to the biomedical care facility when they do not get relief from their health problems. However, depending on when they go to the biomedical care facilities their health may have already started to deteriorate significantly hence, the efforts to reverse the situation might not have a positive outcome, as revealed by one health care worker:

...our goal here at the clinic is to treat the patients and ensure that they do not develop the serious complications related to diabetes. But...once they start with the traditional healers they waste so much time there that when they come to us their health situation

has badly deteriorated and so our efforts to help them do not produce the desired outcome. It is because of such delays that the majority end up with serious complications that we cannot manage effectively leading to some losing their sight while others end up having amputations. [HcwRN108]

Apart from causing undue delays in seeking care at the biomedical care facility the use of alternative health care services, particularly those involving traditional healers and/or herbalists, was reported to create other health problems including intoxication from the various concoctions provided by these healers, as revealed by one health care worker:

The type of treatment used by traditional healers varies from one healer to another... some are using roots, others are using herbs while a few are using white and pink flowers. Still others are reported to use garlic. Irrespective of the medication, these healers may basically be giving these patients a combination of herbs which may relieve the pain that they might be going through at the time but it does not control the sugar levels. Some patients do end up with even more problems after going through this type of treatment. I have had two sad cases of this nature...one was in fact a health care worker here at the hospital who went to these traditional healers. He already knew he had diabetes but went there and the traditional healer gave him some medicine only to make his situation worse and he died! The other patient was at risk of liver failure due to intoxication resulting from a variety of concoctions that he was given by some of these healers. [HcwDr40]

Another impact of health care seeking from traditional healers according to the health care workers was the patients' mixing of the traditional medication with the drugs that they were getting from the biomedical health facility following the advice of friends and relatives. At times some of these patients stopped going to the clinic, resulting in some major health complications, as described by one of the health care workers:

...the worst scenario is where the patients combine the medication from our clinic and the drugs they get from these healers. We had a patient here who came in with a fasting blood sugar level of 23mmol/L and after treating him the sugar levels went down to 10mmol/L. However, once his health improved he never came back. Back home the family members and friends discouraged him from coming back telling him that this was a total waste of time and money and that there was this traditional healer who could cure diabetes! So he went there and started using the medication from this healer only to realise later that he was already developing some complications including a sore on his leg. He came back to the clinic and we tried as much as possible to assist him but it was too late: we had to amputate his leg to save his life. [HcwTN13]

However, some health care workers described some positive experiences from the use of alternative care services. They were of the opinion that they would not discourage the patients' use of these services including those from the traditional healers:

...I do not discourage them from going to traditional healers either. I tell them that if they feel that the medication they are getting from the traditional healers is helping

them...well and good. I tell them, BUT do not fail to come to the clinic to check your blood sugar levels. And indeed almost all come back to check their sugar levels. I think it is a good principle to let them make up their mind on the kind of services they want to use. But I do make sure that I tell them the truth...that there is no other cure that is known to treat diabetes. The treatment which we provide here is the most effective in controlling the sugar levels...and indeed some have come to believe so. I believe that if you tell them not to go to these healers they are going to go there all the same. So let them learn from their own experiences. Over time we have seen that this approach works better because those who understand and appreciate our advice and care do not seek care anywhere else once they come here. [HcwDr40]

6.4 Role of Family Members and/or Social Networks

Family members and social networks in the current study featured consistently, not only in influencing patients' decisions to seek care, but also in the care and management of diabetes. Long after the patient had been diagnosed with diabetes, family members and/or social networks continued to play a significant role in influencing the nature of care and management sought as seen in section 6.2 and also in providing social support. Social support in the care and management of type 2 diabetes mellitus in the current study was perceived to take place in two different forms. The first one is emotional support which includes expressions of affection, acceptance, and approval. The second one is instrumental support which includes assistance with self-management, financial support for medication and/or diabetes-related needs. The significant instrumental support observed in the current study included material and financial support, while emotional support included psychological support that the patient needed in coping with diabetes. Most patients reported getting instrumental and emotional support from family members and/or their social network, as revealed by one of the patients:

...to be honest, I get almost all my support from my husband and my children. My husband and my son buy all the drugs I need if they have money; otherwise I just make do with the little they can afford while they are looking for some more. My son also escorts me to the clinic, while my daughter cooks and does my washing. [PtIRAF109]

Family members and/or social networks continue to play an active role in influencing the care of the patient after initiating treatment at the biomedical care facility. The strong influence that family members and/or social networks have over the management of the patient's condition was positive or negative depending on the knowledge that these members had about type 2 diabetes mellitus and their overall perceptions about the role of biomedical care facilities in managing diabetes. In some situations, for example, the influence of family members and/or social networks was reported to

contribute towards poor adherence to the treatment regimen for some of the patients, as was the situation with one infrequent attendee:

...a friend of mine visited me and said to me “Hey!...look, you will die from this disease if you are not careful. You cannot totally rely on the hospital drugs. You have to try other remedies. She brought me some roots of a certain tree and instructed me to boil these with water and take the concoction. So for some time I was using both the hospital drugs and this concoction but later on my brother advised me to stop one drug otherwise I will not know which one was effective for my problem. So I decided to stop using the hospital drugs only to realise later on that my situation was getting worse. I then went back to the hospital drugs, stopping the use of herbal medications completely. [PtIRAF62]

In the African tradition, the responsibilities of taking care of a sick person are normally shouldered by family members and only in rare situations is that responsibility taken up by people who were not blood relatives. However, as communities become more urbanised, social networks are increasingly shouldering part of these responsibilities. Apart from spouses, children and other blood relatives, only a few patients were looked after by friends or total strangers.

Despite the social support received from family members and/or social networks, some patients acknowledged experiencing some uncertainties with regard to financial resources to meet the costs of their medical care (Section 6.2). Even where these resources were forthcoming, they were far from adequate given the high cost of medications, as reported by one of the patients during the group discussion:

...as they say “...*Nguo ya kuazima haisitiri mwili*” [“... *a borrowed cloth can never cover the body adequately*”]. This means that any kind of support that you get from other people can never meet all your needs and expectations because it depends on whether the individual has it or not and if he/she happens to have it the issue is whether the resources will be made available at the right time and amount to meet your needs”. [PtFGRAM110]

Most patients also, reported being uncomfortable with the type of emotional support that they were getting from family members and/or social networks. This experience for some patients was highly visible during social gatherings, as reported by one patient during a FGD:

Personally I feel very bad when I visit friends...you will hear the family drawing attention to it: “*Mzee ameshafika kwa hiyo mkumbuke chakula na kinywaji chake kinajulikana*” (“*our old man has arrived so remember the type of food he needs and the drinks he takes*)... although they feel good attending to me and making sure that I am

comfortable throughout...I really feel quite uncomfortable because I know it takes them away from having fun! [PtFGRAM111]

Given the chronic nature of type 2 diabetes mellitus and the demands it places upon the whole family, some family members reported that they were overburdened. This was mostly the case where there were competing demands on the financial resources for household needs in addition to the costs associated with the care and management of diabetes. These overriding demands at the household level at times caused substantial stress for family members, sometimes leading to the inadequate provision of emotional support to the patient, as acknowledged by one of the patients:

My wife is currently in Arusha and we have separated for some years now since I had this disease. She could not understand that when we literally had no money in the house I still needed to take the little that was available to cover my medical expenses for a disease that is not curable. She got to a point where she could not take this any longer so she decided to leave! [PtIRAM24]

Other patients felt that they were not being supported and this feeling made them highly frustrated, bitter and critical of their family members:

I don't get any support from anyone else except my children...my relatives are very selfish. They never care about my health particularly now that they know I am no longer working! You see when I was working I used to have a lot of friends but since then some have withdrawn from me. Part of this is because I no longer go to bars and clubs anymore so we do not meet as we used to. I no longer go out to places where we used to hang out together so I can understand why they do not even come and check how I am doing! [PtIRAM24]

Diabetes and HIV/AIDS are chronic diseases which have no cure. Loss of weight is one of the symptoms of both illnesses. As described in Chapter 4, when a person loses weight drastically without an obvious reason it led many lay people, and unfortunately some health care workers who were not familiar with diabetes, to conclude that the patient might be infected with the AIDS virus. With this suspicion, until proven otherwise, some close family members and friends tend to take a cautionary stance when interacting with patients who are suffering from diabetes for fear of contracting the disease themselves. When this happens, many patients find themselves getting quite limited emotional support from their family members and/or social networks, as reported by one of the patients:

Initially before going to the biomedical care facility and starting treatment my brother was the one who was supporting me because my wife ran away from me when she realised that I was very sick. She got really frightened when I lost weight abruptly and

said to me: “Naona mwenzangu ni vizuri sasa uwaite ndugu zako uwaambie kuwa unaumwa ili tusaaidiane maana sasa yatanishinda na inatisha maana sijui unachoumwa (*I think it is about time you called your relatives to come and give me a hand in taking care of you because I think it is becoming too much for me. I am so scared because I am not even sure what you may be suffering from*). I could tell she was worried that I might be infected with the AIDS virus. So I sent someone to call my brother and my brother came and moved into my house to take care of me. Later on my wife said to me “*I am going to take a brief holiday at my relatives’ house*”. I said to her “*It is OK*”. When she came back some months later she found that I was still alive and looking even better following the treatment. My brother told her that “*Haya shemeji, mumeo alikuwa anasumbuliwa na kisukari kwa hiyo usiwe na wasiwasi wa kumhudumia (OK...sister- in-law. Your husband was suffering from diabetes so do not be scared of taking care of him)*. It was at this juncture she agreed and came back to our house. So in short for the moment she is the one who is doing the cooking for me, washing my clothes, cleaning the house and sometimes escorting me to the clinic. [PtIRAM36]

6.5 Challenges in Living with Type 2 Diabetes Mellitus

One among the many challenges of living with a chronic disease like diabetes as seen in Section 6.1 is the need for regular clinic attendance and keeping to the daily drug intake and recommended diet. As revealed in the current study, this is not only a challenge for the individual patient but also a challenge for the whole family and social network given the collective approach in which families care for their sick relatives. This section highlights the various challenges that the patients and their families face in living with type 2 diabetes mellitus. While acknowledging the challenges of living with type 2 diabetes, participants were in agreement that once the individual accepts their health condition and sticks to the prescribed medication and diet the disease is manageable, as revealed by one of the patients:

Since I started treatment I have made significant improvements despite my own challenges...I have managed to bring my sugar levels down from 21.3mmol/L to 4mmo/L. according to the tests that I had today...I am sure the doctor is going to be happy with me and I am happy about it myself. Apart from ensuring that I take my drugs according to the prescriptions I also adhere to the diet that I have been advised to follow...no sugar, less oil, less salt, and less starch. As for fruit I have tried to avoid pineapples, mangoes, pawpaws and bananas. My main vegetable is cucumber with a pinch of salt. I am quite happy with myself Alhamdulillah Rablalaminah [*Thanks be to God!*]. [PtFGRAF52]

Other patients, however, were having difficulty coming to terms with diabetes and the nature of the adjustments that the individual has to make in order to manage it, as revealed by one of the patients during a FGD:

...my mother-in-law died from this disease because she did could not adhere to her diet and prescriptions and was very argumentative...she would take everything that she was

told not to eat or drink, saying: “You see, I just cannot stop eating what my heart wants because I know very well that this disease has come upon me not because of the stuff that I eat or drink but through some evil people out there” - *meaning witchcraft*. This got her into a lot of complications including total blindness and later on she died from it! [PtFGRAF30]

Some caregivers reported that their patients were cheating on their diets and eating and drinking whatever they felt like, as revealed by one of the care givers:

He is simply stubborn! He will eat whatever he likes so my efforts to advise him on sticking to his diet to date have not been successful! Once he says no...that is the end of the debate! [CgIRAF98]

Others patients reported facing the challenge of not having someone who could prepare food for them. This was particularly so in cases where individuals were living alone without partners.

...I have no one to support me here with the cooking the diet that I have been advised to eat. My wife is in the countryside attending to our family properties. So all I have been doing is eating food from the vendors (*mamantilie*) whose food is prepared for the masses. It is hard to have them prepare something special for me...they just don't have the time and it is not worth their business! [PtIRAM25]

Apart from diet, some patients were facing other challenges in coping with the administration of diabetes medication such as insulin.

...my sight is not good so I cannot draw the correct dose for my injection...the other thing is that I always need an escort to the clinic since I cannot go to the clinic alone. There was a time when I missed my clinic appointment because my daughter Amina was away. [PtIRAF20]

6.6 Exploration of Infrequent Clinic Attendees

Examining the socio-demographic characteristics of regular and infrequent attendees as shown in Table 3.6, nearly half of infrequent attendees (4/10) were over 65 years old compared to less than a quarter (3/20) of the regular attendees. One patient among the regular attendees has had diabetes for more than twenty years while none of that duration were reported among infrequent attendees as shown in Table 3.7. Otherwise there are no obvious differences in their demographic characteristics.

While all patients and their caregivers reported a number of challenges (i.e. public transport to and from the clinic, the costs of transport and medical assessment, costs of

drugs and non-availability of drugs at the hospital pharmacy, the long queues at the clinic and poor attitudes of some of the health care workers in the course of care service delivery etc.) related to clinic care and management of diabetes as described in sections 6.1.1 and 6.1.2, I was curious to find out why some patients still managed to attend the clinic regularly while others did not. In doing so, I examined 10 infrequent attendees to find out the specific reasons that might have led to the observed behaviour. Three specific reasons were apparent: relief or total absence of symptoms following medication, overriding work demands, and overriding family health priorities.

Firstly, although following the diagnosis of this disease most patients were educated and counselled on the importance of adhering to their prescribed medical regimen and attending regular scheduled clinic visits for general medical observations and assessment, some of the patients did not do so. Part of this behaviour can be explained by the fact that some of these patients were not motivated to continue going to the clinic once the signs and symptoms of this disease had subsided following the initiation of treatment.

I used the drugs and later on went back to check the blood sugar and noticed that it was normal. So I took some more drugs and continue using these and checking my blood sugar at some nearby private hospital. My sugar level has since been normal and I resumed my trips to Zanzibar and Mwanza. So in a way I thought that I did not have to spend more money on my treatment since my health was not that bad and some of the local herbs that I have been using have been helpful. However, in the past two weeks or so I have started getting the same symptoms I had then such as frequent urination, perspiration and body fatigue. I think I am going to go back to the clinic and have this checked (PtIIAM114).

Associated with this behaviour was lack of understanding and appreciation of the importance of a regular intake of prescribed drugs and attendance at scheduled clinic visits for general medical observations and assessment. Other patients associated the disappearance of signs and symptoms of this disease with “spiritual” healing, hence the lack of perceived need for clinic attendance.

...my sugar level went down to normal so I knew Jesus had cured me so all I have been doing since is simply going to a nearby health facility once in a while to check my sugar levels and continue with the medication as needed (PtIIAM115)

Secondly, the infrequent attendance at scheduled clinic appointments can be explained by the overriding nature of work demands.

I used to travel a lot because I am a sailor and I stay on the ship most of the time travelling to Zanzibar, Tanga, Mtwara and sometimes Mombasa so I simply could not keep my clinic appointments. But of course some time if I am not very sick I just check my blood sugar at the private clinic because the long queues at the public clinic are just a turn off for me. I simply do not have that much time to spend at the clinic (PtIIAM114).

Finally, overriding family health priorities can be used to explain the observed behaviour among the regular and infrequent clinic attendees as shared by one of the patient here.

I was having a lot of family demands...we had a child whose health was not good because he was always falling sick so all my income was being spent on his care. So in a way I thought that I did not have to spend more money on my treatment since my diabetes was not that bad and the local herbs that I was using were helpful (PtIIAM116).

6.7 Summary

This chapter describes the nature of care and management services for type 2 diabetes mellitus following the patient's decision to seek care at the biomedical health care facility. While acknowledging the importance of regular clinic attendance and adherence to prescribed medication as the strategy for care and management of diabetes, the majority of the patients and their families as well as social networks reported facing a number of challenges. These were divided into two major categories: challenges that were directly related to the individual's efforts to seek care; and those related to the nature of the health care system. Along these challenges is the problem of limited financial resources which appears to impact on the care effort both by the individual patient and family members and/or social networks.

Section one of this chapter focused on the challenges that patients face in their overall efforts in the care and management of type 2 diabetes mellitus. Patients reported facing a variety of personal challenges in their efforts to adhere to their recommended care and management programme. These included lack of financial resources to meet the costs of public transport to the clinic, and pay for the medical consultation fees, blood sugar tests and their medication. Associated with clinic attendance difficulties is the problem of inadequate public transport, poor accessibility to the clinic due to distance, long waiting times at the clinic due to long queues at the clinic for the various services, and a

lack of 'client friendly' care services often associated with poor attitudes among some health care workers in the course of their service delivery. The challenge of accessing quality care services was also associated with inadequate skills among the health care workers in the diagnosis and management of diabetes coupled with limited basic equipment for effective service delivery. Topping this list of challenges was poor availability of affordable diabetes drugs particularly insulin whose prices are prohibitively high when purchased through the private pharmacies.

These challenges, especially those related to financial resources, were noted to have significant implications for the patients' welfare and that of their families, often leading patients to seek alternative care services from traditional health practitioners. The impact of alternative care service utilisation was also examined, looking at its implications both in delays in care seeking and its compromising the quality and effectiveness of the biomedical care and management programme. The supportive role of the family and/or social network in a patient's adherence to a diabetes care and management programme was examined.

Chapter Seven will discuss the principal findings of the current research, strengths and limitations, implications of the findings, priority areas for further research followed by conclusions and recommendations.

Chapter 7–Discussion and Conclusions

7.0 Introduction

This study sought to answer the following question: What are the key factors influencing health seeking and health related behaviour and care management for type 2 diabetes mellitus? This study was prompted by limited information in the existing literature on health-seeking and health related behaviour for type 2 diabetes mellitus among adult men and women in sub-Saharan Africa including Tanzania. Lacking also in Tanzania are qualitative studies on patients' health seeking and health related behaviours for type 2 diabetes in particular.

The study employed McKinlay's (1972) theoretical framework (Chapters Two and Three) in exploring factors influencing health-seeking and health related behaviour to care and management of type 2 diabetes in Tanzania. The framework highlights six major factors perceived to influence health care seeking behaviour. These include: financial costs of medical care, geographical location (proximity), socio-demographic factors, social-psychological, socio-cultural factors and organisational or health delivery system factors.

Using qualitative research methods, data were collected from regular and non-regular clinic attendees, patients' caregivers, health care workers, selected community members and key national health officials. This chapter discusses the major findings of the study and their implications for policy and research as well as future organisation of diabetes care and management services, including the development and implementation of public health interventions against diabetes in Tanzania. The chapter is divided into six major sections: a summary of the findings, discussion of the key findings, strengths and limitations of the study, study implications (i.e. policy, primary health care, advocacy and community mobilization and research), priority areas for future research, followed by conclusions and recommendations.

7.1 Section One: A Summary of the Study Findings

The current findings have been presented in three chapters (Chapters Four, Five, and Six) organised under specific themes addressing the main objectives and research questions of the study.

Chapter Four described the awareness and/or understanding, perceptions and knowledge about type 2 diabetes mellitus among patients, caregivers and community members. The findings suggest limited awareness and knowledge levels among the participants. Few patients and/or their caregivers had any comprehensive understanding of type 2 diabetes mellitus prior to diagnosis. Knowledge was generally better among patients after diagnosis. However, many of the patients were still unsure about the causes of type 2 diabetes even after living with this disease for more than a year. Some of these patients and their caregivers were not sure whether or not diabetes could be prevented, treated and/or cured. Most respondents associated the causes of type 2 diabetes with high sugar intake in line with the Kiswahili term for diabetes “*ugonjwa wa kisukari*” (a *sugar disease*).

The signs and symptoms of diabetes prior to diagnosis were attributed by many patients to existing health problems such as malaria, flu, schistosomiasis, throat cancer, high blood pressure, kidney problems and pelvic inflammatory disease. Other patients attributed the signs and symptoms to the hot and humid weather in the city of Dar es Salaam, while some were convinced that they had been bewitched. In many African countries, including Tanzania, diseases where the causes are not obvious are often associated with evil spirits and/or supernatural powers including witchcraft (Kofi & Anarfi, 1997). The limited knowledge about diabetes was also associated with low perceptions of risks for contracting this disease among the majority of patients, which could result in delays in seeking care.

Chapter Five examined in detail the process and specific factors which influence health seeking and health related behaviour for type 2 diabetes. The findings indicate that the severity of diabetes signs and symptoms, and knowledge and perceptions of these symptoms were key triggers for the decision of the patients to seek care at a biomedical care facility and/or elsewhere. The findings also show that financial resources and the family and/or social networks play an important role in influencing patients' decisions

whether and where to seek care. The findings suggest the existence of a system of lay diagnosis, referral and attribution of causation. When people fail to get appropriate explanations of the causes of the disease through the lay disease diagnosis system the condition may be attributed to witchcraft or other supernatural forces.

Issues related to type 2 diabetes and stigma and/or discrimination were also examined in this chapter. The findings show that type 2 diabetes rarely carries stigma and/or discrimination. However, the presence of indirect stigma and/or discrimination was acknowledged by some respondents particularly before the patient is diagnosed with type 2 diabetes. This is more so in cases where the patient presents with signs and symptoms such as abrupt weight loss similar to some infectious diseases such as HIV/AIDS and/or TB. Given the low levels of knowledge among the population about diabetes these signs and symptoms are associated with these diseases (i.e. HIV/AIDS and TB) which normally carry some stigma in Tanzanian society.

Chapter Six described the nature of the challenges patients and their caregivers face in their diabetes care and management efforts following diagnosis and initiation of biomedical clinic treatment. Although varying in nature, most patients reported facing major challenges in attending a clinic regularly because of limited financial resources, long travel distances and inadequate and poor public transport infrastructure coupled with high costs for transport. Patients also reported facing major challenges in adhering to their medical regimen due to the high costs of drugs and limited availability of affordable drugs at public health facilities. Other challenges associated with care and management of diabetes were reported to emanate from the nature of the health care system. For example, the care services provided by some health care workers were reported not to be ‘user friendly’ and/or patient centered, hence putting off some patients from using the clinic services. The overall poor organisation of the clinics’ services, coupled with long waiting times and queues at the clinics were also reported to negatively influence patients’ using of biomedical clinic services. A combination of these challenges resulted in some patients seeking alternative care from herbalists and/or traditional or faith healers whose services were likely to be considered accessible, ‘user friendly’ and affordable.

The chapter also highlighted the implications of the care and management costs of diabetes, focusing on the impact of these costs on the overall health of some patients and the welfare of their families. It is worth noting the observed tendency of the patients to take fewer drugs than prescribed in their treatment regimen due to lack of money to buy the full dose, as well as irregular intake of drugs contrary to their prescriptions. The roles of the family and/or social networks in influencing the care and management of this disease, including the provision of instrumental and/or emotional support (social support), were highlighted.

7.2 Section Two: Discussion of the Principal Findings

This section discusses the principal findings of the current study, highlighting their implications for policy, research and the management and control of diabetes. The discussions of the study findings are organised into three interrelated themes: knowledge and perceptions about type 2 diabetes mellitus; health-seeking behaviour for type 2 diabetes; and care and management for type 2 diabetes mellitus.

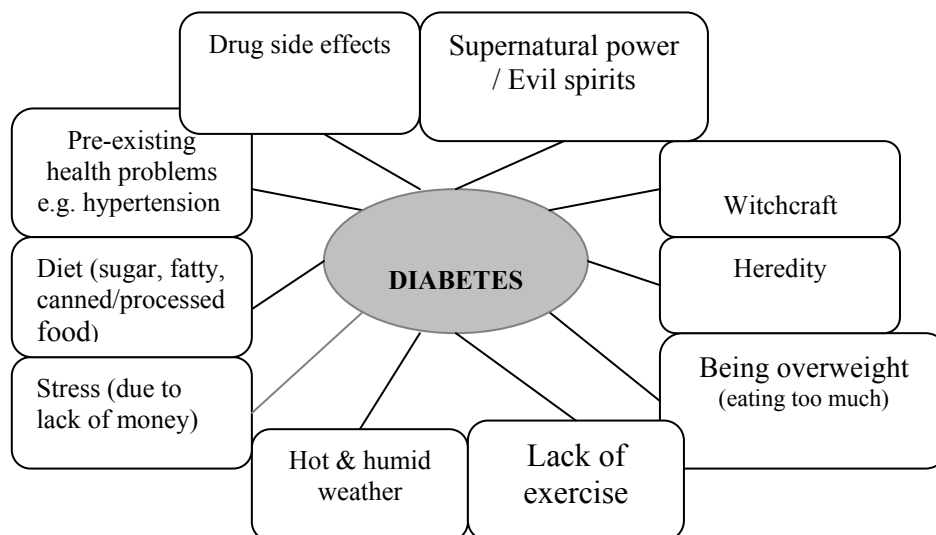
7.2.1 Knowledge and Perceptions about Type 2 Diabetes Mellitus

The current study suggests that awareness and knowledge about type 2 diabetes mellitus were limited among the participants. The causes of type 2 diabetes were unclear to many, even among the patients who had already lived with this disease for more than a year. It was typical, for example, to hear a respondent begin by saying “*I don’t know*” or “*I am not sure*”, and later on mention some possible causes only after extensive prompting. It was also common to hear a statement like “*I heard it is caused by...*”. As observed in a study in Canada, the use of phrases such as “*I guess*” and “*I figure*” by a respondent suggests uncertainty and knowledge gaps regarding causes of diabetes and self-care management (Hernandez, 1999). Similar observations were made in another study by Carbone et al. (2007) among Latino diabetes patients. Inadequate public awareness and knowledge about diabetes symptoms may explain the lack of early care seeking and diagnosis (Al Shafae et al., 2008) for diabetes. The limited awareness and knowledge about diabetes found in this study pose a major concern for health promotion.

Most respondents associated the causes of type 2 diabetes with high sugar intake in line with the Kiswahil term for diabetes “*ugonjwa wa kisukari*” (*sugar disease*). Excessive intake of sugar such as in alcohol, tea/coffee and soft drinks was seen as a cause of diabetes by many participants in the present study. This finding is consistent with observations made in North Province in South Africa, where diabetes was identified as “*bolwetsi bja swikiri*” (*disease of sugar*) (Peltzer, 2001). In Ghana the Twi term “*esikyere yare*” (*sugar disease*) (Aikins, 2003) referred to a simplified definition of diabetes which was used by public health educators to reach illiterate communities. Excessive sugar intake was also attributed to the development of diabetes by participants in studies in the USA (Johnson. Sega, 2007) and Cameroon (Kiawi et al., 2006).

Multiple factors were reported in the current study to be associated with type 2 diabetes. These included heredity, lack of exercise, being overweight, stress, drug side-effects, weather, pre-existing diseases, excessive sugar intake, fatty foods and particularly canned and/or processed foods. Others reported diabetes to be caused by supernatural powers or evil spirits as well as witchcraft, as summarised in Figure 7.1. Similarly, the below Figure 7.1 would make an ideal model for disease prevention in Tanzania.

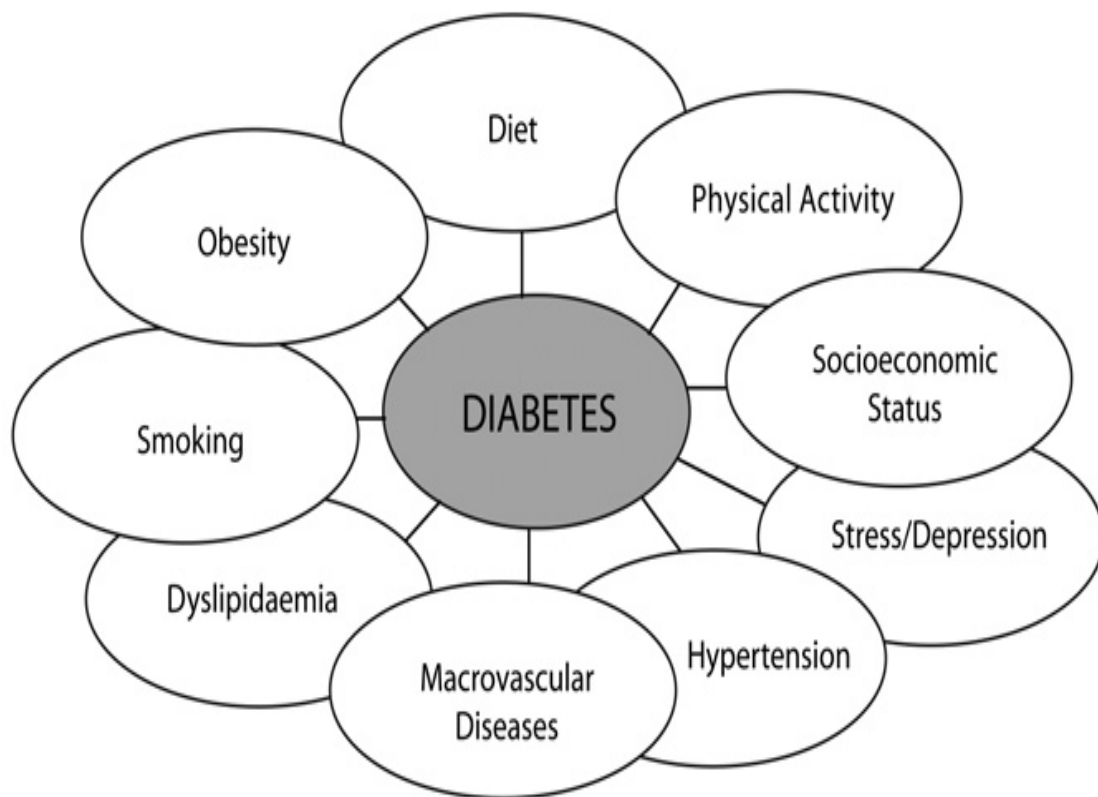
Figure 7.1: Factors associated with type 2 diabetes mellitus in the current study



Other authors have explored different beliefs about causation of diabetes. For example Colagiuri et al. (2006) in their review identified a range of factors (Figure 7.2). It is

interesting to note that the two figures show some overlap in the beliefs about diabetes causation, but they also show some differences. For example, both figures show some factors which fit the biomedical model such as heredity, obesity, diet, hypertension and poor physical activities. They both show factors which fit an environmental model such as socio-economic factors. They also show factors which fit the psychological model such as stress. The factors unique to the current study are part of the environmental model: hot humid weather and supernatural powers including witchcraft.

Figure 7.2: Factors associated with type 2 diabetes mellitus



Source: Colagiuri, Colagiuri, Yach, & Pramming (2006)

Limited knowledge and misinterpretations of the presenting signs and symptoms of diabetes as reported in Chapter Four proved to influence the nature of care sought, the sources of care and the timing of care seeking. When the signs and symptoms do not fit into the existing traditional health beliefs, the disease is easily associated with ‘supernatural powers’ or ‘witchcraft’ for lack of an adequate socially acceptable explanation. Chronic diseases like diabetes may therefore be classified as “out of order” or artificial illness, a term encompassing those types of ailments not coming from God

(Chapter Two) (Muela, 1999). The attribution of the causes of diabetes to supernatural powers or evil spirits and witchcraft, as observed in the current study, was among the major causes for delays in health-seeking behaviour for diagnosis and treatment and/or decisions to seek traditional healers' services rather than biomedical services.

7.2.2 Health-seeking Behaviour for Type 2 Diabetes

This section highlights and discusses the findings on the initial triggers that led patients to seek care for type 2 diabetes mellitus and the nature of and place where such care services were sought. According to the current findings some patients did not immediately seek care when they first experienced unusual signs and symptoms in their body. The findings show that some patients who had prior knowledge about diabetes through relatives, neighbours and friends who were suffering from it appeared to have decided to seek care immediately following the onset of the signs and symptoms of this disease. These findings are consistent with observations made by Kapur (2001) in India where patients who were aware of diabetes or those with family members with diabetes were reported to have sought care for this disease at the clinic earlier. Moreover, other studies mentioned in Chapter Two reported that delays in diagnosis due to late health care seeking have been attributed to patients' poor knowledge about diabetes and associated misconceptions of the presenting signs and symptoms (McLarty, Pollitt, Swai, & Alberti, 1997).

This study also found that knowledge about the signs and symptoms of diabetes by itself might not be enough to trigger action to seek care. Instead, as McKinlay's (1972) theoretical framework (Chapter Three) argues, the decision to seek care is influenced by other socio-cultural "prescriptions". Indeed, as Nido and Turner (1988) observed in their study in the USA, existing cultural and social factors have a major influence not only on the differences in lay perceptions of disease symptoms but also on the meaning and significance that patients assign to such symptoms and hence, the subsequent action. According to Nido and Turner the perceived significance of symptoms is an important factor in the decision to seek medical care as well as in complying with medical advice provided by the health care workers. Nido and Turner's observations are also reflected in the current research findings. The signs and symptoms of disease were

assessed using traditional lay belief systems on disease causation after which the decision was made on the nature of care to be sought and the sources of such care.

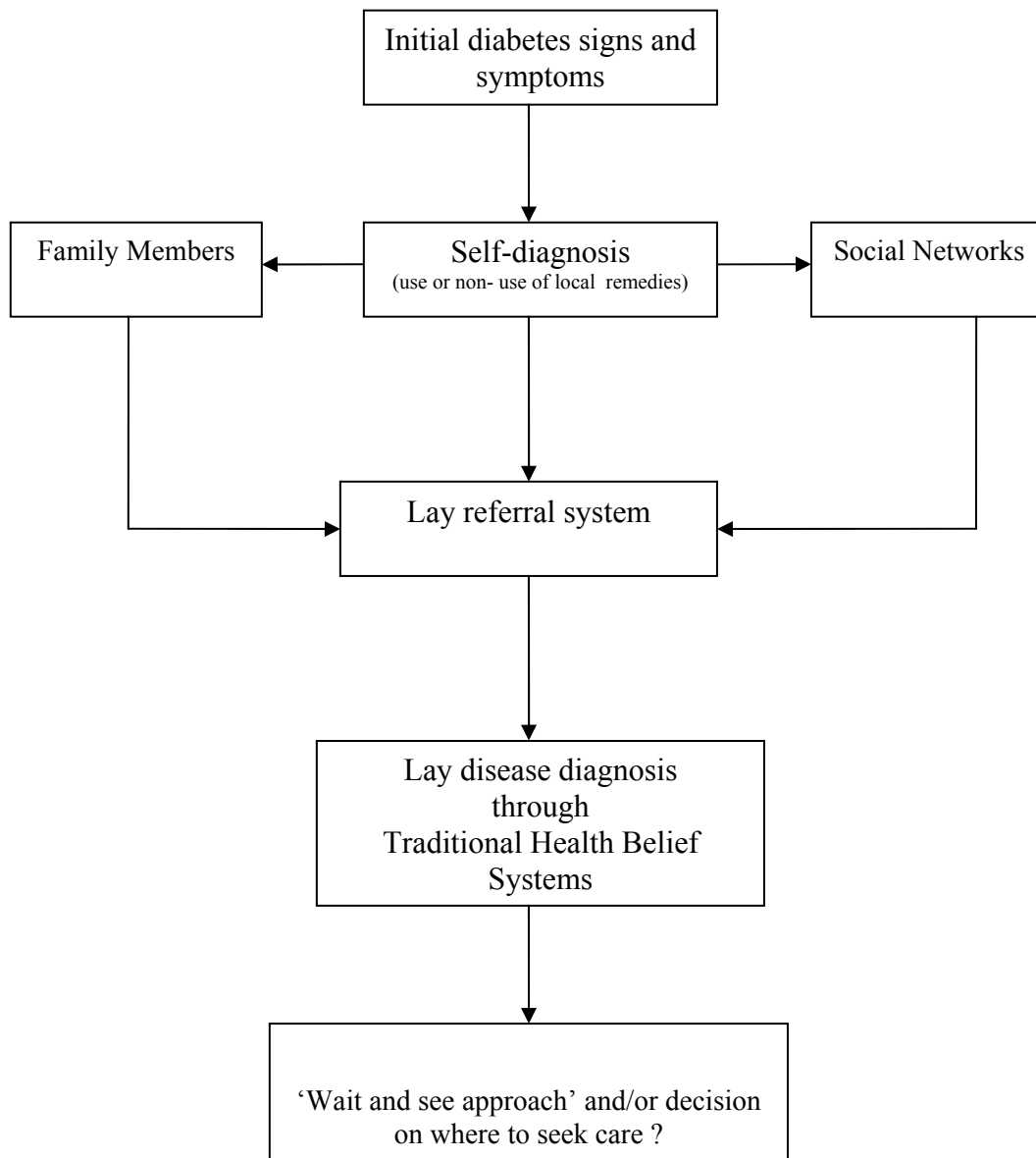
In the same vein, Nyamongo (2002) in Kenya argues that cultural and social factors have great influence not only on the differences in lay perceptions of disease symptoms but also on the meaning and significance that patients assign to such symptoms and their subsequent actions. His observations were supported by other findings in the USA where Freund and McGuire (1995) affirmed that people do not respond to the biophysical aspects of symptoms, but rather to the meaning of those symptoms which are normally derived from the socio-cultural context.

The above arguments are in line with those made in Good's (1987) theoretical framework based in his observations in Africa (Chapter Two), and they are consistent with the findings of the current study which show that although the decisions to seek care are mainly a family-based affair, they are sometimes influenced by wider social networks and the broader social-cultural framework. The models presented in Figures 7.3 and 7.4 try to capture the interactions of the different factors that influence the patients' decisions to seek care, when such care is to be sought and the nature and source of such care. The model in Figure 7.3 describes pathways to health-seeking behaviour, highlighting the various factors that come into play in the decisions to seek care following the onset of the signs and symptoms of diabetes. The model in Figure 7.4 similarly looks at the key determinants of the source of care services following the decisions to seek care. While the two models appear to be discrete, in reality they are overlapping and continuous.

As shown in the model in Figure 7.3, the first stage in the pathways to care starts with the onset of signs and symptoms of the disease. In the absence of previous familiarity and knowledge about the signs and symptoms, these are often met with a period of uncertainty as the patient tries to figure out what she/he might be suffering from. This period may involve the use or non-use of local remedies by the patient to address the symptoms (stage two). In the event that these symptoms persist, a feeling of concern sets in and this is when family members and/or social networks are consulted. As observed by Freidson (1970) in his studies in the USA, when individuals are faced with unfamiliar signs and symptoms in their bodies they tend to look for interpretations of

these signs and symptoms and some use un-prescribed drugs. When these symptoms do not go away they consult their families and/or social networks or what he referred to as the 'lay referral system'.

Figure 7.3: Pathways to health-seeking behaviour



In the current study some patients reported consulting neighbours and/or people with diabetes to confirm the observed signs and symptoms and evaluate their health status (stage three). Following the consultations with the family and social networks these signs and symptoms may be given a 'lay disease diagnosis' using their culturally existing 'traditional health belief systems'. Under normal circumstances, through

‘traditional health belief systems’, family members and/or social networks could make a ‘lay disease diagnosis’ based on the observed signs and symptoms and decide on the course of care and treatment (stage four).

Based on the outcomes of the ‘lay disease diagnosis’ the patient moves to stage five consisting of the actual decision to seek care and treatment. Often the outcome of the ‘lay disease diagnosis’ at stage four could lead to three care seeking and treatment options: using the traditional care system or the biomedical care system, or further observation which may take the ‘wait and see’ approach. Normally this approach would be taken when the ‘lay diagnosis’ fails to come up with tentative explanations for the observed signs and symptoms that warrant care seeking from either the traditional care system or the biomedical health care system. The wait and see approach is normally adopted in the hope that the signs and symptoms may disappear on their own or further evidence might emerge in due course about what the patient may be suffering from. This observation is consistent with the ‘wait and observe progress’ approach noted in the Kenyan study (Nyamongo, 2002). At that stage the decision would then be made with more certainty on the nature of care to be sought and source of such care (i.e. modern versus traditional health care systems).

The nature of the care services to be sought and their source (modern versus traditional health care systems) following the decision to seek care is determined by a number of factors as presented in the model in Figure 7.4. The findings of the current study suggest that decisions as to where care services are sought often become a contest between the traditional and the biomedical care services, with biomedical care services often not being the first treatment choice due to their inaccessibility, high cost and payment policies and perceived unsatisfactory care delivery arising from the poor attitude of some service providers. Normally the decision on the initial source of care is based on the knowledge, perceptions and beliefs held by patients and their families and/or social networks regarding the nature of care services provided (Figure 7.4). As observed in this study, some patients and/or caregivers perceived the treatment from traditional and faith healers and/or herbalists to be more convenient, more friendly and promising than that provided through biomedical care facilities. For many patients and their families, the proximity of the services and the unlimited availability of drugs and of the traditional practitioners for consultations—unlike the biomedical services—was a major

influence towards the using of their services. The services of traditional practitioners were also reported to be cheap and the mode of payment was flexible for most patients. The unfriendly attitudes of some health care providers towards the patients was also reported to negatively influence the decisions of patients, their caregivers and/or social networks in seeking care at biomedical facilities. These observations are in line with Kroeger's (1983) findings on the accessibility and acceptability of health services to patients, their families and social networks. Specifically, it influences patients and/or their social networks' opinions and attitudes towards the selection of either traditional and/or biomedical healers.

Similarly, patients with previous experience with diabetes signs and symptoms (i.e. those whose relatives and friends have had diabetes) were more likely to seek care at a biomedical health service compared with those without such experience. Other patients with conditions such as hypertension appeared to have sought medical care at the biomedical facilities earlier due to having interpreted the signs and symptoms that they were experiencing as having to do with their hypertension.

...some patients associated the symptoms they were having with other pre-existing diseases like hypertension but not diabetes. [HwRN04]

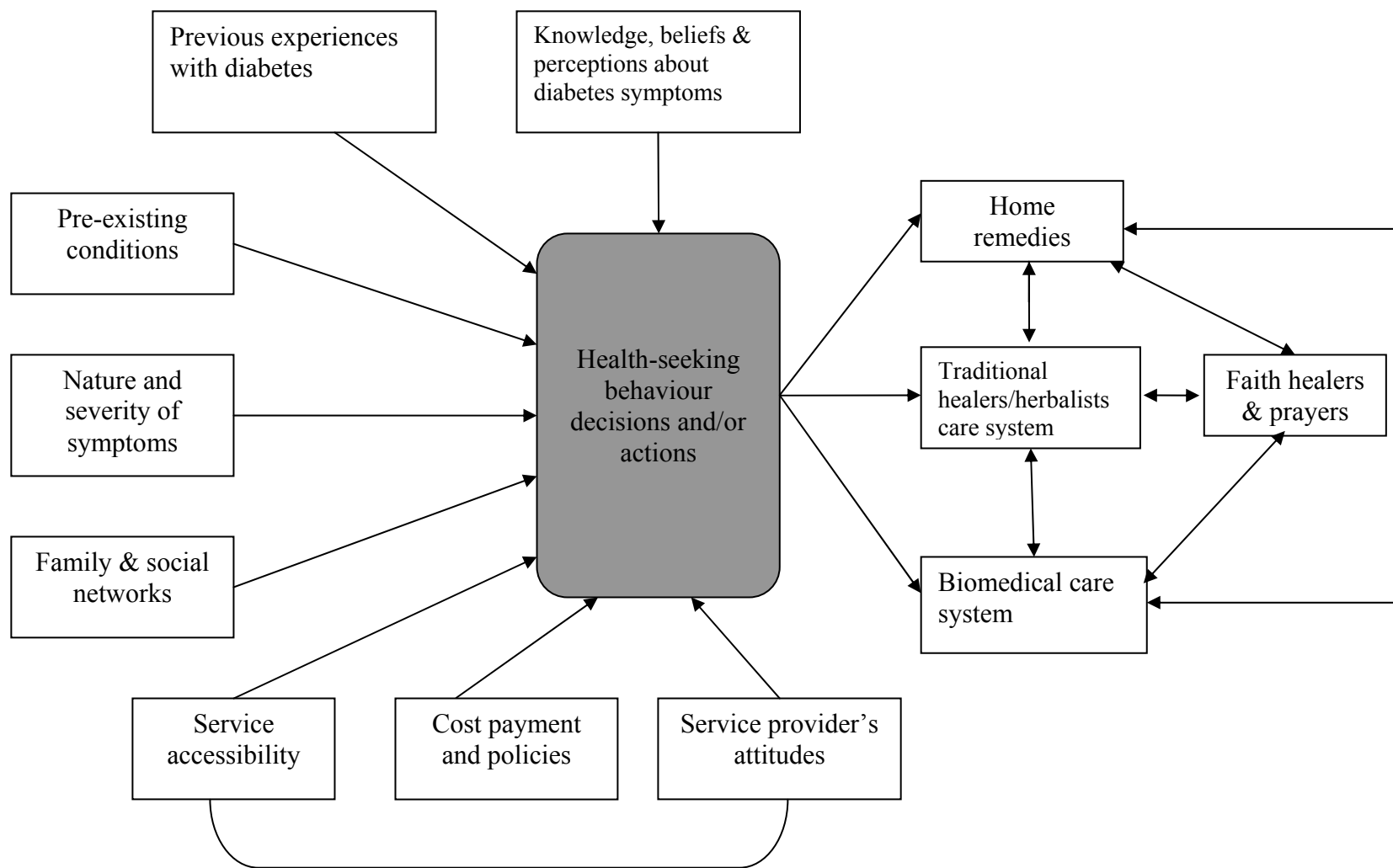
Other patients sought care at the biomedical facility due to their long-term experience, belief and confidence in the effectiveness of biomedical care and treatment of other diseases. The nature of the signs and symptoms and the severity with which they manifested themselves triggered some patients to seek care at a biomedical facility. According to some patients in this study, it was the high frequency of their urination and loss of sexual desire that triggered them to seek care at a biomedical facility.

The current study also noted that the decisions to seek care at biomedical care facilities and continued use of such facilities for care and treatment of diabetes appear to be highly influenced by the availability of financial resources. Even when the 'lay disease diagnosis' process presented in Figure 7.3 prescribes the need to seek care from the biomedical care system, the decision to do so often hinges on the availability of financial resources. These findings are congruent with Kroeger's (1983) and McKinlay's model which includes cost in relation to health care services. The findings are also supported by Mbanya and Sobngwi's (1997) study in Cameroon. Based on their

findings, Mbanya and Sobngwi argued that the lack of financial resources was a major constraint in accessing health care for diabetes care services. They further noted that this problem was not only observable in Cameroon but also in most sub-Saharan African countries (Chapter Two). Similarly, a study conducted in Tanzania by McLarty et al. (1997) affirmed that cost may deter patients from seeking care and treatment for diabetes.

The model in Figure 7.4 also shows that patients tend to move from one type of care system to another (e.g. from traditional to biomedical care services and/or faith and prayers healers) in their effort to find a better explanation of their condition. This was more likely to happen for those patients who found out about diabetes for the first time when they were diagnosed with it and especially those who did not have any history of diabetes in their families. For some, the disbelief of being affected with diabetes often led them to associate the disease with witchcraft and other supernatural powers.

Figure 7.4: Determinants of health-seeking behaviour



Biomedical and traditional services

The challenges of accessing care for diabetes and continuing with it through the cost sharing system have been exacerbated by the lack of access to health care insurance for most patients in Tanzania (Mamdani & Bangser, 2004). Lack of access to health care insurance was also reported to pose similar major challenges for people with diabetes in accessing quality care in Cameroon (Paschal, Unwin, & Phillimore, 2008). However, Shaikh and Hatcher (2005) in Pakistan have noted that the mode of payment, whether through insurance, self-payment and/or government assistance, is also likely to affect health care seeking behaviours for some patients.

The present findings revealed that most patients cannot afford biomedical services particularly with the current system of cost sharing and the absence of health insurance. Other studies (Chapter Two) also reported that less developed countries, including Tanzania, cannot afford comprehensive biomedical care systems and have few if any health insurance programmes, thus, healthcare depends upon clinics and private practitioners (Simpson, 2003)

7.2.2.1 Stigma and Discrimination

Stigma and discrimination have often been used interchangeably in the literature, although discrimination is often taken as a behavioural manifestation of stigma. In an earlier study in Tanzania, Simpson (2003) for example noted that there was discrimination against people with diabetes when it comes to employment, insurance, social life, marriage and adoption. Nevertheless, it was not clear from her study the nature of the stigma that she was referring to. For example, was this discrimination “directly” or “indirectly” associated with diabetes? The concept of stigma has been defined in many forms following Goffman’s (1963) classic work. Goffman defined stigma as “*an attribute that is significantly discrediting*” and which serves to reduce the status of the person who possesses it, in the eyes of society. He then went on to identify three kinds of stigma: the first was called stigma derived from physical deformities; the second was the stigma associated with perceived “blemishes of individual character” (i.e. due to mental disorder or homosexuality); and the third was designated “the tribal stigma of race, nation and religion”. This third type of stigma is perceived to be “transmitted through lineages” and possessed equally in all members of a family, and

implies that the group membership and group identity could (in themselves) be sources of stigma (Wailoo, 2002). While none of these forms of stigma were specifically noted among the patients involved in the current study, it can, however, be argued from the findings that some did experience “indirect stigma”. Some studies, for example, have shown that it is not necessary for people to actually experience stigma directly or personally (“enacted stigma”); stigma may also be perceived or presumed to be there (“felt stigma”) (Scambler & Hopkins, 1986). This latter type of stigma is psychologically more damaging and difficult to challenge in public (Bharat, 1999; UNAIDS/WHO, 2001). In the current study, indirect stigma was specifically associated with the presenting signs and symptoms of diabetes before diagnosis. For example, in cases where the patient presented with severe weight loss, a symptom typical of people suffering from TB or HIV infection, it was more likely that the patient would be stigmatized, not because they were known to have diabetes but because people perceived them to be suffering from TB or AIDS. This finding is similar to the one in Ghana where De-Graft (2006) noted that patients who were experiencing extreme weight loss because of diabetes were stigmatised mainly from the “assumptions” held by neighbours and community members that the weight loss was due to AIDS or TB. The presence of this formed /perceived “indirect stigma and/or discrimination” is likely to reflect the presence of misinformation or low levels of knowledge about diabetes among the population, which was demonstrated in the current study.

Furthermore, it can also be argued from the current findings that there were some elements of “felt stigma”. As noted in the findings presented in section 5.2.4, much as there was no evidence of a patient being stigmatized and/or discriminated against because of this disease, some were still not willing to share their medical conditions with other people including family members because of the fear of being stigmatised.

Yes... initially I did hide it and only told some of my family members that I had some fever. I was scared they would not understand me and that they would stigmatize me [PtIRAF43]

It is quite clear from the above quotation that although many patients did not actually experience stigma directly or personally (“enacted stigma”), some perceived it to be there (“felt stigma”) and this influenced their health care behaviour.

...to hide my having the disease I continued eating the normal foods and taking my pills in private. But one day I was very sick and my husband escorted me to the clinic and that is when he knew about it [PtIRAF43]

While this might be an isolated case there are reasons to believe that concerns about direct or indirect stigma are likely to have negative implications for the overall health related behaviour of people with diabetes. Similar observations have been made in relation to other diseases like TB (Nguma, 2003; Campbell et al., 2005). Campbell and colleagues, for example, argue that stigma impedes the delivery of effective social and medical care, enhances the number of HIV infections and diminishes the public health effects of anti-retroviral treatment (ART) because people living with HIV/AIDS (PLWHA) are not able to interact with their families and the communities which are supposed to make them feel part of society.

Apart from “indirect stigma” and “felt stigma” it can also be argued that the findings of the current study show some elements of “self-stigma”. In his study on stigma and HIV/AIDS in India, for example, Bharat (1999) identified two forms of stigma: courtesy stigma and self-stigma. Courtesy stigma is the stigma shared by all those associated with the stigmatized person (i.e. health care providers to HIV infected people). Self-stigma is stigma that is accepted and internalized by the person and used to legitimize others’ negative actions such that challenging it becomes difficult. Instead the person restricts their own behaviour out of a sense of vulnerability or indulges in self-blame (Bharat, 1999). The findings presented in section 5.2.4 appear to mirror Bharat’s findings. Some diabetes patients for example appear to have “restricted their own behaviour” in relating to others or participating in social functions just because of this disease.

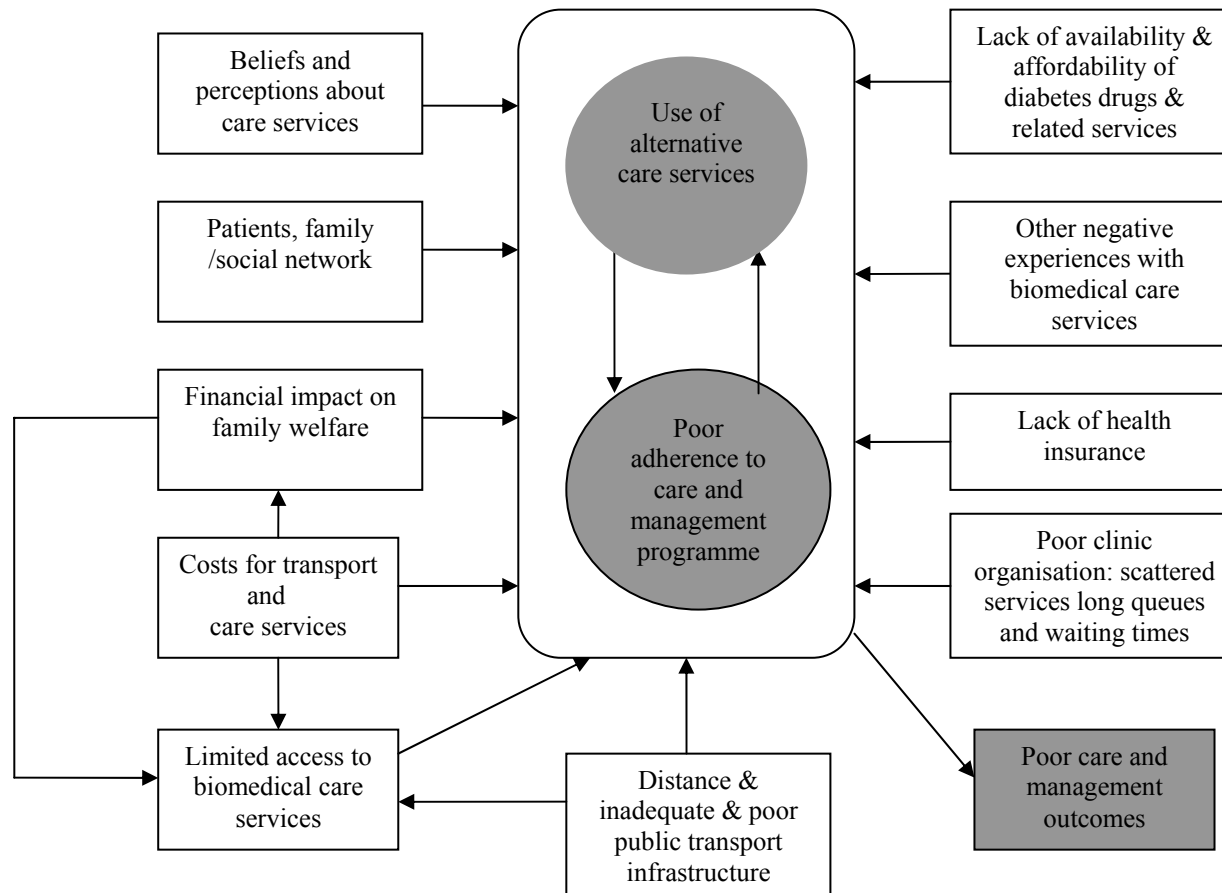
Yeah, my friends don’t invite me to their social gatherings anymore because I told them that I am not going into parties and family gatherings because I sometimes feel dizzy, fatigued and my sight is not very good. [PtIRAF20]

This patient, not only ‘self-stigmatizes’ according to Bharat’s (1999) definition, but also labels herself as a person with “an undesirable difference” (Goffman, 1963) from the members of her social group because of diabetes.

7.2.3 Care and Management of Type 2 Diabetes Mellitus

This section highlights and discusses findings on the care and management of type 2 diabetes. The concepts of care and management in the current study are defined here to include all the activities of the patients, their family members and/or social networks and the health care workers that are aimed to ensuring that type 2 diabetes is kept under control following diagnosis. An effective care and management programme for type 2 diabetes therefore, entails amongst other things adherence to regular clinic attendance and the treatment regimen. However, in their efforts to adhere to the care and management programme for diabetes, as presented earlier in Chapter Six, patients reported facing a number of challenges whose interactions with other factors negatively affect the patient's adherence to a care and management programme and consequently the overall diabetes treatment outcome. The discussions in this section highlight the interactions among these factors as summarised in the model in Figure 7.5

Figure 7.5: Challenges to patients' adherence to diabetes care and management programmes



Based on the study findings and the factors presented in the model in Figure 7.5, the challenges that patients face in their efforts to adhere to the care and management programme for diabetes can be categorised into two groups: those challenges which appear to affect individuals in their quest for care and treatment services at a biomedical facility; and those challenges related to the health care delivery system. One of the two major pillars of effective care and management programmes for type 2 diabetes is regular clinic attendance for general assessment and monitoring of blood sugar levels. At the personal or individual level the prime challenge facing most patients was the inability to regularly attend the clinic. The challenges to regular clinic attendance were associated with a variety of reasons including distance to the clinic due to inadequate and poor public transport. Equally challenging were the costs for transport and medical services at the clinic. A combination of distance, inadequate and poor public transport with lack of financial resources to meet the transport cost and care services limit patients' access to biomedical care services thus negatively affecting their adherence to care and management programmes.

The challenges of distance to the health care facility observed in this study are consistent with observations made by Shaikh and Hatcher (2005) in Pakistan and McKinlay (1972) in Scotland where proximity of health services to the target population was reported to play an important role in the utilization of biomedical services. In many sub-Saharan African countries, most diabetes clinics are usually located at central teaching hospitals in towns, making them less accessible for the majority of the urban and/or rural population (Gill, 1988; Amoah, 2002; Levitt, 2008). In Ghana, poor geographical access to biomedical services was reported to make some people with diabetes move from where they live to the nearby towns in order to cope with distance and public transport problems (Aikins, 2002). Similar observations were made in the current study in Dar es Salaam where patients resorted to moving in with relatives who were closer to a diabetes clinic for the same reason.

Respondents in the present study reported the distance to biomedical clinic to be a barrier to regular clinic attendance and proposed the decentralisation of diabetes care services to lower level health care facilities including dispensaries, to increase the proximity of these services to patients. Although McKinlay's (1972) model down-

played the influence of proximity in patients' care seeking at the biomedical facility (Chapter Three), he was, however, point out that the issue of proximity should be taken into account with other factors affecting the patient's efforts to seek care at a biomedical facility. Indeed as observed in the current study, the combined influence of a long distance to the clinic with the scarcity, inaccessibility and high cost of public transport was noted to be a major impediment to patients' adherence to regular clinic attendance.

As in the patients' decisions to seek biomedical care as opposed to that of traditional health practitioners and vice versa (Figure 7.4), the study observed that the beliefs and perceptions that the patient, their family and/or social networks have about the nature and effectiveness of services provided at the clinic had some influence on patient's adherence to care and management programmes. In other words, even where distance is an issue the family members and/or social network will do all that needs to be done in raising funds which will enable the patient to get the kind of care they believe will be effective. These observations appear to support other findings in Kenya where lay people were reported to switch from one alternative health care source to another based on the perceived effectiveness of the particular health care alternatives (Nyamongo, 2002). Moreover, Young (1981) in Mexico observed that individuals' knowledge, beliefs and perceptions of the efficacy of the treatment were instrumental in the choice of care services and adherence to the care and management programme.

As noted by Sheeran and Abraham's (1995) model (Chapter Two), the findings in the current study revealed that the perception and understanding of the family and/or social networks of the seriousness of the health condition and the implications of delayed or inadequate care and management equally influenced the decision to seek care irrespective of the distance to the clinic and related costs. It is at this juncture that the role of public education about diabetes becomes critical. In their study in the Torres Strait Islands, for example, Wong et al. (2005) noted that many patients appeared to have limited knowledge and understanding of the importance of regular clinic attendance and taking their medication regularly. Education will increase public understanding about diabetes and particularly the awareness of the patients, their families and/or social networks of the need for regular clinic attendance and adherence to care and management programmes.

Regarding care services the people with diabetes reported a number of challenges related to the health facility in the delivery of diabetes care services. As summarised in the model in Figure 7.5, a number of negative experiences with the biomedical care services were mentioned. These included scarce and expensive drugs, poor care and management skills among the health care workers, the unfriendly nature of the care services delivery, poor organisation of the clinic such as long waiting times and queues, and geographically scattered services at the clinic. Although assessing the skill levels of health care workers was not within the scope of the current study, it is worth noting from the patients' observations that some health care workers often failed to make the right diagnosis despite patients visiting the hospital several times with the same complaints. While it is difficult at this juncture to tell whether these were isolated cases in the course of the care and management of diabetes or a reflection of a general lack of technical skills among the health care workers, the observations were however, consistent with those made earlier by Ramaiya (2005) in his studies in Tanzania. In his findings, Ramaiya noted that some health care providers lacked the skills for diagnosis and management of diabetes. He further noted that many health care providers were not knowledgeable about the nature of the health education they needed to provide to their patients at the diabetes clinic. The limited levels of knowledge, coupled with the attitude of some of the health care providers towards their patients, to some extent contribute to the noted unfriendly nature of services observed in the current study.

Unlike in the care and management of acute diseases, where interactions between the health care worker and the patient may be limited, the management of chronic diseases like diabetes normally requires long-term interactions between the health care provider and the patient. As such, unfriendly client management or lack of 'personalised care' on the part of health care workers may have a long-lasting impact on the perceptions of the patients towards the care services. This is why the subject of doctor-patient relationships has attracted so much interest when dealing with the care and management of chronic diseases like diabetes. In their study in the Torres Strait Islands, Wong et al. (2005) for example, noted that doctors were changing patients' medication without providing adequate explanations of why such a change was made.

Furthermore, while the majority of the patients in the current study reported getting along with their health care workers, a few were unhappy with the approach with which care services were provided. As in other studies, the most common rationale given by health care workers for the lack of 'personalised care' of their patients and other related behaviour is lack of time and the large number of patients that they need to attend to. It is this lack of attention to the doctor-patient or health care worker-patient relationships which participants in the present study reported as deterring some patients from utilisation of biomedical health care services. Some explanations of the concerns observed here among the patients are also found in Aikin's (2002) study in Ghana where she noted that the traditional medical hierarchy has an intimidating and often alienating effect on the doctor-patient relationship. The formal structure of the current care services does not allow adequate consultation time for patients, which is vital in the development of doctor-patient rapport (Aikins, 2002).

The nature and organisation of the care services at biomedical facilities were also observed to influence clinic attendance for people with type 2 diabetes. The physically scattered nature of the services at the clinic, the brief clinic opening time; the waiting times and long queues for care services; favouritism of the health care workers towards some patients and related corruption elements, were all reported to pose significant challenges to patients in their adherence to a care and management programme. Most patients reported waiting an average of two to four hours or more before seeing a diabetes specialist which negatively affected some patients' continued use of services at the biomedical clinic. For some the long waiting time at the clinic was a factor in their decision to stop attending the biomedical clinic. These observations are consistent with those made by Wong et al. (2005) in their Torres Strait Islands study where long waiting times at the clinic contributed to subsequent missed clinic appointments. Improving the structural arrangements in the provision of the different health services provided at the clinic coupled with increasing the number and quality of health providers and equipment at the clinic were proposed as measures to attract and keep clients in the diabetes care and management programme. Similar observations were made in Aikin's (2002) study in Ghana as a strategy to address these challenges.

Adherence to prescribed medications and diet was also identified among the challenges that patients were facing in diabetes care and management. Type 2 diabetes mellitus usually requires strict adherence to dietary and treatment regimens (Pladevall et al., 2004). Medications for type 2 diabetes are prescribed by medical professionals and dispensed with the expectation of adherence to dosage, timing, use in relation to ingestion of recommended food and continuation of this behaviour over long time periods (WHO, 2003). However, diabetes regimen adherence problems are commonly reported among individuals with diabetes, making glycaemic control difficult to attain (Delamater, 2006). Findings in the current study show that the costs of prescribed diabetes diet, drugs and associated services, including transport to reach distant biomedical care facilities, the cost of laboratory tests and X-rays if needed are a major challenge to most patients and their families in Tanzania.

Additionally, poor accessibility to affordable diabetes drugs from public hospital pharmacies force many patients and their families to buy drugs from private pharmacies at prohibitive prices. As a result, some opt to buy lesser quantities of drugs based on the financial resources that they have, others take the drugs less often, or decide to go without any, while others seek alternative care services through traditional healers and/or herbalists. These observations are consistent with those made in Ghana, where Aikins (2002) observed that inaccessibility to biomedical treatment due to high costs coupled with critical lack of institutionalised economic support for people with diabetes led to most patients' non-adherence and/or becoming infrequent attendees at biomedical care and management programmes. Similar observations were made by Kagee, Le Roux, and Dick (2007) in South Africa where associations were noted between medical costs and few clinic visits by patients with diabetes. As in Cameroon (Paschal et al., 2008), Tanzania does not have accessible health insurance schemes for most of its population, hence the costs of diabetes drugs and related care services are far too high to bear for most poor families who are living under the poverty line of \$1-2 per day (Oxfam International, 2006). Poor access to care due to lack of financial resources has proved to be a constraint not only in relation to diabetes but also in relation to other disease services in Tanzania following the introduction of the cost-sharing programme in the 1990s (Mamdani & Bangser, 2004). Similarly Birenbaum (1984) in the USA and McKinlay (1972) in Scotland as well as Shaikh and Hatcher (2004) in Pakistan have

shown that the structure of health care provision and payment for healthcare services pose as much of a challenge to the patient's decision to seek care as they do to their ability to adhere to care and treatment programmes.

The current cost of diabetes drugs was acknowledged by most participants to have far reaching negative implications, both on the health of the patients and on the welfare of their families. Some patients, for example, reported diverting resources from basic family needs including food, to the purchase of medication and payment of transport costs to the clinic. This negative financial impact on family welfare often limits patients' access to biomedical health services, consequently affecting their adherence to diabetes care and management programmes. These findings are consistent with Khowaja, Khuwaja, and Cosgrove's (2007) observations in Pakistan where they acknowledged that diabetes is a particularly costly disease to manage. According to Khowaja and colleagues, diabetes costs affect individuals, families, society, healthcare institutions and national productivity as a whole.

Good dietary principles are key to successful diabetic treatment and management (Watkins, Drury, & Howell, 1996). However, as noted in the current study, adherence to the prescribed diet, much as most respondents acknowledged it as an effective strategy to manage diabetes, posed a number of challenges most of which are related to lack of financial resources to buy the recommended items.

Unlike many diseases where a cure is expected following treatment after diagnosis, diabetes requires lifelong treatment and so presents a particular challenge to patients, their families and/or their social networks. The treatment outcome for diabetes defies the expectations and belief patterns of most patients, their families and/or social networks. Converse to the patients' expectations, for example, once diagnosed, patients are told that the drugs they are supposed to take daily have no curative powers, rather they are intended to control the signs and symptoms of the disease. This information undermines the reputation of the biomedical care system and its effectiveness. As a result many patients, their families and/or social networks visit faith healers for prayers and blessing of the particular drug used. They may also seek alternative care, hence the observed swing between the biomedical and traditional care systems as indicated in

Figure 7.4. The observed behaviour presented here is consistent with observations in Cameroon (Paschal et al., 2008), where patients reported using both biomedical and traditional medications while looking for a cure, as revealed by one patient:

I take both traditional medicine and biomedicine because it is more effective in curing me. But some patients take just one of them. It cannot be as effective as combining both. [50-year old female urban Cameroon diabetes patient]

Apart from the search for a cure, patients and their families in the current study were also reported to use alternative care services for other reasons. These included their dissatisfaction with the nature of services provided by the biomedical health system. As seen earlier, the biomedical health system posed a number of challenges to care seeking which include the lack of 'patient-centred' care services; long waiting times and queues for care services; poor doctor-patient relations; and more critically the lack of availability of affordable drugs at public hospital pharmacies. This observation is consistent with Good's (1987) model and Kroeger's (1983) framework categories (Chapter Two). According to Kroeger's model, the individual's utilisation of biomedical care services depends on the characteristics of the service, patients' opinions and attitudes towards service providers, and acceptance of the medical care system as a whole. The observations are also in line with Kiawi et al.'s (2006) findings in Cameroon where patients were reported to seek alternative or complementary care services from folk healers and other sources mainly because they did not have the money to pay for similar services at biomedical care facilities. Similar observations were made by Walrave (1996) in Tanzania where he noted that poor accessibility to drugs at clinics led patients to seek alternative care services from the traditional health system. According to Aikin's (2002) observations, ethnomedical medicines in Ghana were perceived to be cheaper than biomedical drugs. Although cheap, the use of alternative care services for the treatment of diabetes was noted to have a significant impact on the overall care and management of diabetes. As noted in the current study, some patients come back to the diabetes clinic after extensive use of alternative care services from traditional healers with no improvement. Unfortunately, by the time they do so their condition has significantly deteriorated, making it difficult to manage and leading many to lose their sight or have their legs amputated. These observations are similar to those made by Kiawi et al. (2006) in their study in Cameroon where patients

were reported to go back to biomedical care services in crisis after failing to get relief from traditional healers. Patients did this when their health had significantly deteriorated, making treatment extremely difficult.

Finally, this section looks at the role of the family in the care and management of diabetes. According to Anderson et al. (1995), 95 percent of diabetes self-care is usually provided by people with diabetes or their family members and/or social networks. Similarly, in Ghana Aikins (2002) observed that a large proportion of diabetes management occurs outside the biomedical sphere, and this is where the role of the patient, family members and/or social networks comes into play. In the current study, family members and/or social networks were found to play a leading role not only in influencing patients' decisions to seek care but also in the nature of the services sought, where and when. Furthermore, as highlighted by most patients in the present study, family members and/or social networks continue to play a significant role in providing social support (i.e. instrumental and/or emotional support) in the course of care and management of diabetes. In particular, spouses and older children were reported to provide financial resources towards the costs of transport to and from the clinic, medical tests, drugs and recommended food.

According to the international literature, emotional support coming from spouses, children, close relatives and friends has been positively associated with blood glucose control (Murphy, Williamson, & Nease, 1994). Similar studies by Nagelkerk, Reick, and Meengs (2006) in the USA have shown spousal support to be associated with low levels of depression, higher motivation to adhere to treatment and a greater level of understanding of the treatment regimen. Others (DiMatteo, 2004) in the USA have found social support to be a significant predictor of self-care management behaviours, including dietary adherence, physical activity, glucose testing and taking medications as recommended.

Studies by Kagee, Le Roux, and Dick (2007) in South Africa found that social support provided by the health care worker at the clinic is important in helping patients feel at ease with health care workers and therefore with the biomedical care system. However, as observed in the current study (Chapter Six), the nature of care services provided by

some health care workers through the biomedical care system was reported to be ‘client unfriendly’, sometimes discouraging some people with diabetes from utilisation of biomedical care services. Similarly, the biomedical care system was reported to be lacking in patient empowerment on issues related to self-care and management including administering their own insulin, thus making some patients dependent on health care workers. In the USA Nagelkerk, Reick, and Meengs (2006) report that lack of understanding about self-care is a barrier to self-care management. Rubin Peyrot, and Saudek (1989) indicate that effective self-care management can only be achieved when patients are provided with the skills and knowledge to manage their condition. In conclusion, the overall message that Figure 7.5 appears to convey is that a positive diabetes care and management outcome is a product of the patient’s avoidance of alternative services and adherence to the biomedical care and management programme. This behaviour hinges on the interplay of factors ranging from the patient’s socio-economic status, beliefs and perceptions about diabetes, environmental factors to the overall nature of the health care delivery system.

7.3 Strengths and Limitations

This section discusses strengths and limitations of this study.

7.3.1 Strengths

A number of strengths may be attributed to the current research. Firstly, the current research has contributed uniquely to the knowledge about health-seeking and health related behaviour among people with type 2 diabetes mellitus in sub-Saharan Africa, and in Tanzania specifically. As stated earlier in the literature review, information on health-seeking and health related behaviour for type 2 diabetes mellitus in this setting was lacking. This information will be vital in the development of relevant intervention initiatives against type 2 diabetes. Moreover, the information will be critical for future research and policy formulation.

Secondly, the methodology and the theoretical framework upon which the data collection and analysis was based allowed the researcher to delve deep into a range of issues around the subject of health-seeking behaviour. Through a purposive sampling

method I was able to identify and interview a diverse set of participants for the study. These included people with diabetes and their caregivers, health care workers at the respective diabetes clinics, selected community members in the catchment areas of the study, and key national health officials. The data collection methods used for the study were also diverse, consisting of in-depth and key informant interviews as well as focus groups (FGDs). The triangulation of the information generated from these diverse sources using three distinct qualitative data collection methods gave the study methodological strength. According to Patton (2002) such triangulation of methods and varied sources of data provide internal validity and reliability of the data collected. Further, although the current study sample size was partly predetermined due to logistical limitations, saturation of themes was observed during data collection and analysis providing evidence that the sample size was adequate.

Thirdly, the use of a theoretical frameworks developed from a wide range of literature drawn from both developed and developing countries including sub-Saharan countries (Chapter Two) provided the study with another strength. This includes theoretical and analytic triangulation of the information generated from the current research. In particular, McKinlay's (1972) theoretical framework provided significant insights in exploring the factors influencing health-seeking and health related behaviour for type 2 diabetes mellitus among the adult population in Tanzania. The framework also was vital in the development of the current research objectives and instruments used in data collection and analysis. Additionally, triangulation of the data analysis process was achieved through the sharing of emerging themes with my two supervisors in New Zealand. According to Patton (2002) these kinds of triangulation reduce systematic biases and distortions that might have arisen during data analysis, and increase credibility, verification and validity of the study.

In addition, the use of Miles and Huberman's (1994) (Chapter Three) systematic data analysis approach, which consists of three interwoven stages (data reduction, data display, and drawing conclusions from the data) facilitated the management of the enormous amount of qualitative data which was generated in the study. It was useful in identifying key categories and concepts which were grouped under the different themes developed at the data display stage.

7.3.2 Limitations

At the initial stage of this study, I was somewhat frustrated when I realised that there had not been any qualitative studies done on diabetes in Tanzania. Since many studies tend to focus on information gaps identified from previous work, this was not possible in the current study. As such it was difficult to decide what information the study would gather and what should be left out. In light of this limitation, the study relied mostly on reports of studies carried out elsewhere in developed and developing countries as well as some from sub-Saharan Africa. Further, I later realised that with the exception of McKinlay's (1972) theoretical framework, which is mainly based on studies carried out in developed countries, there had not been any sound theoretical framework in the general area of health-seeking and health related behaviour among adult patients with type 2 diabetes mellitus in sub-Saharan Africa.

However, during interpretation of the findings McKinlay's (1972) theoretical model proved limited in addressing some of the issues emerging from the study. These included diverse cultural belief barriers which often led to self-care, use of home remedies and consultation with traditional healers in the process of health-seeking behaviour. This led to the need for a review of related current theoretical models particularly in developing countries to address these issues (Chapter Two).

Another study limitation emanates from one of the research methods used in data collection. While FGDs were used as one of the methods to collect qualitative data, I realised that on some occasions they introduced biases in the data collected. The influence of "group think" during the FGDs (Chapter Four) frequently occurred during the discussions. It was common to hear participants in the group discussions giving responses like "...I agree with my colleague" or "...as my colleague said". Also, when patients were asked about their relationship with health care workers during the FGDs, participants were more likely to express a neutral position as compared with the individual interviews, showing the possible influence of the need to appear to be in consensus with others. This neutral position taken by some patients could also be influenced by the need to appear to be grateful for the care that health care workers were providing irrespective of its poor quality or they were simply unwilling to publicly criticise health care workers. One of the reasons for using a multi-method approach

including FGDs and individual interviews was to identify the possible impact of such biases. However, the FGDs were effective in stimulating ideas within the group and participants found them to be a learning opportunity.

Working with two languages, as was the case in the current study, provides a challenge in maintaining consistency and accuracy of the information as it is transcribed in one language and translated into another. Other studies suggested the need for a professional interpreter to mitigate this problem (Stejskal, 2009). In the present study, all the study instruments were developed in English and later on translated into Kiswahili to suit the respondents who were Kiswahili speakers. Next, all FGDs were transcribed into Kiswahili and these and other data from other interviews were then translated into English before analysis was carried out. Although I worked with a research assistant who was a native Kiswahili speaker and experienced English speaker, we were both conscious of the risks of losing the meaning of the content due to the use of two languages. Acknowledging this limitation, efforts were made to use Kiswahili phrases followed with a tentative English translation in brackets where possible to ensure vital cultural meaning was maintained. Nevertheless, it is inevitable that the process of translation resulted in some loss of data integrity.

The data analysis in the present study was carried out manually. The use of manual analysis as opposed to using computer software might have introduced some human error in searching for specific information in the whole data set. Computer software, such as NVivo, is useful for importing documents directly from a word processing package in order to code them. Electronic coding is fast and it makes coding stripes visible in the margins of documents so that the researcher can see at a glance which codes have been used and where. Use of NVivo can add rigour to the data analysis process by allowing the researcher to carry out quick and accurate searches and can add to the validity of the results by ensuring that all instances of a particular usage are found (Welsh, 2002).

However, Welsh (2002) cautions that the use of NVivo computer software is less effective in searching through the thematic ideas to gain a deeper understanding of the observed behaviour based on the available data. Others have stated that computer

software is less useful in addressing issues of validity and reliability in the thematic ideas that emerge during the data analysis process and this is due to the fluid and creative way in which themes emerge (Crawford, Leybourne, & Arnott, 2000). Still others like Denzin and Lincoln (2003) have argued “*Why would you want to engage in work that connects you to the deepest part of human existence and then turn it to a machine to ‘mediate’?*” Part of interpretive work is gaining a sense of whole – the whole interview, the whole story and the whole body of data” (2003). According to Denzin and Lincoln, no matter how helpful computer programs may prove for managing the parts, we can see only their fragments on the screen. These fragments may seem to take on an existence of their own, as if objective and removed from their contextual origins and from our constructions and interpretations (Denzin & Lincoln, 2003). It is based on these observations that I preferred to analyse the present research data manually. Even so, Crawford and colleagues concluded that it is important for researchers to recognise the value of both manual and electronic tools in qualitative data analysis and management, and that they should not prioritise one over the other but instead remain open to, and make use of, the advantages of each.

Furthermore, the study also experienced some logistical limitations. The data collection, for example, was carried out in Dar es Salaam city and its communities where most of the streets have no names and the houses have no numbers (Figure 3.3). About 70 per cent of the city’s population is living in houses built on unsurveyed plots (World Bank Report, 2002) making the task of locating patients and their caregivers difficult. To reach some of the patients and their caregivers I needed the assistance of other patients who knew where the respondents were staying and could escort me there. Where contact phone numbers were available, I called them and got directions to the closest location where some of the respondents were kind enough to meet me or send their relatives to meet and collect me.

Another limitation of the study had to do with the actual timing of the study. While all the patients, their caregivers, health care workers and community members selected for the study were accessible for interviews, only a few key national health officials were available for interviews. At the time of the study most of the key national officials were involved in preparations for annual national budgets and some were away attending the

National Budget Session which normally takes place in June. This problem hampered the data collection schedule. Nonetheless, some key national health officials were accessible for interview after two to three weeks effort to secure appointments.

Lastly, in view of the varying distances that the majority of the patients and their caregivers live from biomedical care facilities, the poor infrastructure, transport and related logistic problems, it was not possible for me to send the transcripts of the information generated during the in-depth interviews and FGDs for them to comment on and to verify what was recorded, transcribed and analysed. Instead, respondent validation was done immediately after every interview and FGD. Through this process some issues were identified, and omissions and errors were included in the interview notes. This strategy enhanced the reliability and validity of the information collected (Patton, 2002).

7.4 Quality of the Research

Confirmability and credibility (Lincoln, 1995) are two ways in which the validity of qualitative research can be assessed. According to Tobin and Begley (2004), confirmability (comparable with objectivity or neutrality) is concerned with establishing that data and interpretations of the findings are not a figment of the researcher's imagination, but are clearly derived from the data. In the current research confirmability was enhanced during the data analysis and report writing processes through the following: first, by reviewing the data (an audit trail) in the form of memos and notes that I was making during the data collection process; second, through a review of the recorded tapes; third, consultations were made where needed with the research assistant in the course of data transcription and translation to ensure the accuracy of the recorded information; fourth, through the presentation of preliminary results of the study in different forums including the University of Otago, Wellington PhD Research Day and the University of Otago International Research Network where constructive comments were received and incorporated into the data; and finally, through intensive consultations with my supervisors at the University of Otago, Wellington throughout the course of data analysis, interpretation and report writing.

Credibility (comparable with internal validity) similarly addresses the issue of 'fit' between respondents' views and the researcher's representation of these views (Schwandt, 2001). According to Schwandt, credibility poses the questions of whether the explanation fits the description and whether the description is credible. Credibility can be demonstrated through a number of strategies: triangulation, peer debriefing and member checks (Lincoln, 1995). Robson (1997) states that triangulation is the process of empirical research by using multiple approaches and/or sources of information to draw conclusions. He argues that by using multiple approaches and/or sources of information, the strengths of one will compensate for the weaknesses of another, thereby improving the quality of data—particularly its credibility.

In the current study the literature I reviewed to familiarise myself with the health-seeking and health related behaviour for type 2 diabetes has formed a key referral point for my study findings. The study design, development of data collection tools, analysis and report writing were guided by different theoretical frameworks (Chapter Two) which enabled me to provide rich and logical descriptions of the study findings. Equally so, the use of multiple qualitative methods of data collection from different sources (Chapter Three) enhanced my efforts to triangulate the findings of the study and draw relevant conclusions.

Peer debriefing is another strategy used in enhancing credibility. It refers to exposing the researcher's analysis and conclusions to colleagues or other peers (Robson, 1997). Following the pre-test study I had an opportunity to share the findings with my research assistant and supervisors whose feedback was instrumental in reviewing my approach for the data collection for the main study. Closely related to peer debriefing is member checking: this strategy has been advocated by Polit, Beck, and Hungler (2001). According to Polit et al. (2001) this strategy involves giving feedback on the findings and interpretation to participants and noting their reaction. In the current study member checking was effected through respondent validation which was done immediately after key informant and in-depth interviews as well as focus group discussions. Through respondent validation I was able to correct errors in the recorded information following each interview as well as recording missing data where omissions were made.

7.5 Study Implications

This section discusses the implications of the study. It focuses on three major areas where the current findings could be utilised strategically to influence current diabetes trends in Tanzania. These include policy implication and service delivery, primary health care, and advocacy and community mobilization.

7.5.1 Policy Implications and Service Delivery

The findings of the current study echo other calls made earlier for a policy on non-communicable diseases (NCDs), particularly diabetes, in Tanzania. The May 2000 WHO Global Strategy for example, underscores the need for priority initiatives in the prevention and control of NCDs, particularly in developing countries. The Global Strategy has three main objectives: 1) to map the emerging epidemics of NCDs and to analyse their social, economic, behavioural and political determinants with particular reference to poor and disadvantaged populations, in order to provide guidance for policy, legislative and financial measures related to the development of an environment supportive of control; 2) to reduce the level of exposure of individuals and populations to the common risk factors for NCDs, namely tobacco consumption, unhealthy diet and physical inactivity, and their determinants; and 3) to strengthen health care for people with non-communicable diseases by developing norms and guidelines for cost-effective interventions, with priority given to cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. Further, the Global Strategy sets out the roles and responsibilities of member states along with international and local partners in supporting this initiative. Subsequently WHO (2001) underscored the global strategy on NCDs (including diabetes mellitus) prevention and control by addressing the risk factors for these diseases in an integrated manner. According to WHO, addressing the risk factors for NCDs is crucial for prevention since the risk factors are entrenched in the framework of society and influenced by many areas of national policy.

The WHO emphasis on prevention of communicable diseases is understandable given the cost implications of managing and controlling some of these diseases. Thus, understanding the risk factors exposing the population into the risks of diabetes becomes critical. A 5-year follow-up survey of 1250 newly-diagnosed cases of diabetes

in Dar es Salaam revealed a 29 per cent mortality rate for those treated with insulin and a 16 per cent mortality rate for those not requiring insulin (McLarty, Kinabo, & Swai, 1990a). McLarty and colleagues found that most deaths were due to severe diabetic ketoacidosis, and infections were responsible for most deaths in patients with diabetes requiring insulin. Infection, cardiovascular and renal causes were responsible for deaths in patients with diabetes not requiring insulin. McLarty and colleagues concluded that diabetes in sub-Saharan Africa, including Tanzania, is a serious disease with a poor prognosis. They suggest that more effort is required to increase public awareness about diabetes, to improve diabetes detection, management and follow-up. Other studies in sub-Saharan Africa observe that the increase in mortality risk associated with insulin treatment may reflect the danger of insulin treatment itself particularly without proper self-monitoring of blood glucose (Gill, Mbanya, Ramaiya, & Tesfaye, 2009). The currently available routine care for people with diabetes in Tanzania often does not include blood glucose monitoring other than urinalysis (when urine strips are available). It is based on the costs involved in the treatment of this disease and the levels of human lives that a need for prevention efforts is underscored.

Effective execution of the prevention and control of NCD in Tanzania and developing countries in general will require adoption of a policy framework aimed at ensuring integration of diabetes care and management into the primary health care delivery system. Such policy, as shall be seen in the next section will ensure government commitment in the provision of adequate human resources, drugs and equipment, as well as accessibility and affordability of these services by people with diabetes.

However, WHO Reports indicate that many countries in sub-Saharan Africa, including Tanzania, do not have a policy framework for non-communicable diseases (NCDs). Such policy framework should incorporate prevention, organisation of care, import duties on medicines and supplies, subsidies for medicines and care, education, disease monitoring, and allocation of appropriate resources (WHO, 2002; 2000). Governments, multilateral and bi-lateral donors have been called upon to recognise the growing burden of NCDs, including diabetes, in developing countries and to take appropriate measures. It is in light of these concerns that an expanded Millennium Development Goal for NCDs was proposed (Fuster & Voute, 2005; Horton, 2005).

The lack of policy frameworks for NCDs like diabetes is partly explained by limited levels of information and lack of advocacy to support the need for such frameworks. The data that has been generated from the current study, therefore constitutes an important source of information for policy formulation as well as programme interventions aimed at serving people with diabetes. Effective advocacy for a policy framework needs to understand the drivers of health-seeking and health related behaviour for people with diabetes in an increasingly pluralistic health care system (i.e. comprising traditional and biomedical care systems) (Shaikh & Hatcher, 2005). As revealed in the current study, the dual use of traditional and biomedical care systems by patients, their family members and/or social networks before and after the patient's diagnosis with diabetes is a common practice. This suggests that traditional medicine will continue to play a significant role in the care and management of diabetes and other NCDs and communicable diseases in Tanzania. A policy review should acknowledge the role of traditional medical practitioners and provide guidelines for development of modalities for integrating their services into the biomedical care system to ensure quality care and management of diabetes in Tanzania.

7.5.2 Primary Health Care Implications

The 2000 WHO Global Strategy underscores the need for prevention and control of NCDs including diabetes (WHO, 2000). Primary health care therefore is a fundamental part of effective early intervention for type 2 diabetes mellitus education and treatment. It also plays a vital role in primary prevention. Through primary health care facilities the patients, family members and/or social networks, can access vital information for prevention, management and control of diabetes mellitus. Data from the current study suggest the need to make diabetes care services not only accessible but also affordable for the people. The decentralized primary health care delivery services in Tanzania, therefore, are ideal for effective implementation of the global strategy for prevention of NCDs including diabetes mellitus.

One of the prime strategies identified by the current study for management and control of diabetes is the provision of adequate education and counseling of diabetes patients and their family and/or social networks. The findings also suggest the need for general public education about this disease in order to promote early detection. However,

increased public awareness and knowledge about diabetes is likely to trigger increased public demand for care services thus challenging the ability of the current limited number of clinics in Tanzania to provide biomedical care services. It is for this reason that expansion of diabetes care services to primary health care facilities is proposed. The proposed policy framework, therefore, needs to ensure adequate integration of accessible and affordable diabetes care and management services throughout the primary health care delivery facilities in the country. This proposal is in line with earlier recommendations by the International Diabetes Federation Africa Region Task Force (2006, Appendix 1). These health care facilities will also need to be equipped with competent skilled health care workers, adequate equipment and related material resources.

One of the major challenges people with diabetes and their families face in the care and management of this disease according to the current study is the poor availability and affordability of drugs. It is for this reason that an overarching policy framework was proposed in section 7.5.1 to address this problem by ensuring accessibility to drugs including insulin. Equipment and drugs are a major problem, particularly in public hospitals, and where available through private pharmacies the prices are out of reach for most families, forcing patients to reduce the prescribed dose and at times stop completely. This has negative implications for patient adherence to diabetes care and management programmes as well as for the overall treatment outcomes. Further, as Aspray and Unwin (2001) noted in their earlier study in Tanzania, eye and renal screening at diabetes clinics are lacking or underdeveloped. Aspray and Unwin further noted that work was underway to develop methods of rapidly evaluating services as well as developing evidence-based guidelines for treatment of chronic conditions including diabetes in Tanzania within primary health care facilities (Aspray & Unwin, 2001). Furthermore, as observed in the current study, the limited knowledge levels of health care workers and drug shortages have had a negative impact on health care delivery with a consequent negative influence on health-seeking behaviour among people with diabetes. Through advocacy, policy makers also need to understand the importance of effective delivery of diabetes care services at the primary care level by ensuring availability of skilled health care workers, medical equipment and drugs.

Furthermore, illness is expensive in terms of costs of care and loss of family income (World Bank, 1993). In many societies, the illness of one person can affect the whole community (Beran & Yudkin, 2006). Diabetes and other chronic diseases place a large financial burden on people with diabetes and their families in many countries, often leading many households into poverty (Sachs, 2001). In Tanzania the cost sharing policy which was introduced through the Health Sector Reform has made accessibility and affordability of health care services through primary health care difficult for many patients. Furthermore, although the government subsidizes diabetes drugs to make them affordable to patients, the allocated resources are far from adequate and in practice these drugs are often out of stock. Patients then have no choice but to buy these drugs from private pharmacies where the prices are too expensive for most people. This situation has had major implications in relation to patients' adherence to care and management programmes. First, some patients opt to buy a limited amount of drugs and only use these when their sugar levels go up, while others simply go without. Secondly, some patients use a combination of these drugs with local medications usually obtained from herbalists. Finally, some opt to use the services of traditional healers and only visit the biomedical clinic when their condition has worsened. All these behavioural options have a serious negative impact on the overall care and management of diabetes, resulting in unnecessary complications, taking the lives of those whose conditions are beyond treatment.

The problem of limited financial resources to meet the various costs of care and management of diabetes as observed in the current study, particularly in the absence of access to comprehensive health care insurance, makes the burden of managing diabetes unbearable for many. The proposed national policy framework, therefore, will need to include clearly defined and applied eligibility criteria, or other means of financing care for patients whose families cannot meet care costs. Such support should apply across the different care services, including consultations with doctors, laboratory tests, and medicines. The eligibility criteria need to be easily verifiable and should not cause undue treatment delays. Prevention of diabetes is needed not only to avert much of the suffering of people with diabetes, but also to prevent increased use and costs engendered by diabetes complications. Government subsidies for medical costs, however, may only be effective in enhancing diabetes care seeking and treatment when

the government has a guaranteed supply of drugs and other related services at the primary health care level. Equally, priority to horizontal and vertical management programmes at secondary and primary care levels should be stepped up both by promoting service demand through patient education about diabetes and at the same time ensuring provision of timely quality care services to patients.

Similarly, through a policy framework on NCDs, all actors – government, policymakers, development partners (donors), non-governmental organizations (NGOs), and other stakeholders – should be mobilized and committed to playing a central role in creating an environment that will empower and encourage individuals, families, and communities to adopt positive, life-enhancing behaviours aimed at preventing diabetes. A multi-sectoral approach should be adopted in the implementation of such policies to ensure that government service sectors that have a pivotal influence on health care are mobilized in supporting initiatives aimed at addressing diabetes. As with other communicable diseases including TB, malaria and HIV/AIDS, multi-sectoral approaches have great potential for addressing the advancing tide of globalization and its effect on both urban migration and the obesity epidemic often associated with diabetes (Zimmet, 2000). Through this approach, all ministries, departments and agencies (MDAs) as well as local government authorities (LGAs) for example, should integrate diabetes prevention initiatives in their ongoing workplace programmes on HIV and AIDS to safeguard the health and welfare of the workforce. In tandem with these initiatives, a high level political commitment is needed to address issues such as food availability, cash crops, and urbanization, all of which have a major role in determining the success or failure of prevention and care for people with diabetes in Tanzania.

7.5.3 Implications for Advocacy and Community Mobilisation

The development and adoption of a policy framework aimed at addressing diabetes in Tanzania needs an effective advocacy strategy. The data generated from the present study will provide a rich source of information for development of relevant advocacy initiatives for policy on prevention and control of NCD in Tanzania. Through advocacy initiatives both the policy makers will be mobilized about diabetes burden to address structural issues identified in the present research. According to the present findings

effective national policy on NCDs including diabetes needs to highlight the importance of public health promotion aimed at educating the family and community as a whole to take an active role in diabetes prevention, control and treatment. This is line with Beran and Yudkin's (2006) earlier report which suggested that family members and communities in sub-Saharan Africa need education about participation in diabetes care. The report also proposed that community leaders need to be organised towards educating and mobilising their community members around early care seeking and management of diabetes. There is a need for coordinated efforts in designing diabetes risk behavioural change communication initiatives through multi-sectoral collaboration focusing more on diabetes prevention and control, while also addressing the needs of people with diabetes (Oldenburg, McGuffog, & Turrel, 2000). Through this initiative both public and private sectors, government institutions, community social organisations, and community gatekeepers should be mobilised for a joint approach in addressing this growing epidemic.

Central to effective advocacy is the establishment of coalitions with key partners strategically positioned to influence policy and action. As is evident from countries in sub-Saharan Africa, diabetes associations, for example, can play a vital role both in advocacy and in improving patterns of diabetes care (Ramaiya, 2005). Apart from providing care and treatment, these organisations can also carry out advocacy activities focusing on creating public awareness of the growing diabetes burden, costs, and availability of treatment. Even more importantly, these organisations can lobby for government commitment and support of ongoing care and treatment services as well as public education initiatives throughout the country. The World Diabetes Day, for example, provides a yearly opportunity for diabetes associations to raise public awareness about diabetes (Beran, Yudkin, & Courten, 2005). The Tanzania Diabetes Association (TDA) and local societies across the country have been using this opportunity to carry out advocacy activities although limited in scope. With adequate funding these organisations should be able to carry out a range of advocacy initiatives in the country while providing a rallying point for people with diabetes for both education and social support.

As mentioned earlier, the policy framework on diabetes care and management should provide guidance for special efforts needed to forge working partnerships between the biomedical and traditional care systems since both systems appear to be utilised equally by patients in the care and management of diabetes (Chapter Six). The call for incorporating traditional health practitioners into the biomedical care system is not new. As observed in the current study, people with diabetes continue to use the services of traditional healers and/or herbalists both before they are diagnosed with diabetes and after initiating care and treatment at clinics. It was in light of these observations that participants in the current study called upon the biomedical care system to develop a mechanism for educating traditional healers and/or herbalists about type 2 diabetes mellitus so as to engage their support in the identification of suspected cases and early referral of patients to biomedical care facilities. Although education of traditional healers has occurred in Cameroon through the CAMBoD project (Mbeh, Edwards, Assah, Ngufor, Fezeu, & Mbanya, 2007) more education of these healers is needed in other sub-Saharan African countries. This is congruent with what Beran and Yudkin (2006) in sub-Saharan Africa and Shaikh and Hatcher (2005) in Pakistan suggested, namely that traditional healers need to be integrated into the formal biomedical system of care and trained in appropriate referral skills to the formal health sector.

The recommendations of the participants in the current study were consistent with those made under the Alma Atta Declaration (1978). Kofi-Tsekpo (2004), for example, has argued that this declaration resolved that traditional medicine should be incorporated into the biomedical care systems in developing countries if the objective of “Health for All by the Year 2000” was to be realised. Notwithstanding this strategy, many African countries were no closer to the realisation of this objective at the end of the 20th century. This led the WHO African Region to adopt a resolution for “Promoting the role of traditional medicine in the biomedical care system: A strategy for the African Region” (Kofi-Tsekpo, 2004). This strategy provides for the institutionalisation of traditional medicine in biomedical care systems among WHO African Region member states. Furthermore, the OAU (Africa Union) Head of State and Government declared the period 2000-2010 as the African Decade for African Traditional Medicine (Kofi-Tsekpo, 2004). This was further followed by the WHO Director’s declaration of the 31st August every year as the “African Traditional Medicine Day”. All these

declarations signify the recognition of the importance of traditional medicine in the biomedical care system within the African context. The policy framework for NCDs, therefore, should take up the challenge of providing appropriate mechanisms for institutionalisation of traditional medicine into the biomedical care system to make these resolutions a reality.

While acknowledging the fact that the concepts and treatment modalities for diabetes might be perceived differently by health care workers and traditional practitioners, such differences should in essence be the focus of the needed orientation of traditional practitioners into the biomedical care system. Forging an effective partnership between the two care systems therefore would require three core elements: i) health care workers should have a genuine and open mind in working collaboratively with herbalists, traditional and faith healers in the respective communities; ii) health care workers should have a clear understanding about cultural beliefs affecting treatment modalities of diabetes as practised by herbalists, traditional and faith healers; and finally iii) further research should be carried out on the effectiveness of traditional treatment modalities with a goal of establishing a synergy between the two care systems.

7.6 Reflections on the use of McKinlay's (1972) Theoretical Model

Given the lack of viable theoretical models of health-seeking behaviour from sub-Saharan countries, including Tanzania, the current study mostly relied on McKinlay's theoretical framework which was derived from a review of various studies carried out in developed countries as a basis for the conceptualization of the study, development of study instruments and the analytical framework for the data. Helpful as it was in shedding light on the factors most likely to influence health-seeking and health related behaviour for type 2 diabetes, it appears to be limited in explaining some of the behaviours observed in the current study.

Most of the studies upon which McKinlay's theoretical framework was built were carried out in developed countries where the socio-economic and political environment is very different from that in sub-Saharan countries. For example, McKinlay's model focuses on factors relevant to transforming needs into demands which include health

care insurance and/or free medical care. As in developed countries, medical care in most sub-Saharan countries is not free. However, unlike in developed countries, health care insurance in sub-Saharan countries is a new phenomenon.

As part of health care reform, for example, Tanzania has in the past ten years or so adopted a cost sharing health care system that requires patients to pay some cash upfront for biomedical care services. For many families whose income is less than a dollar a day coming up with funds for biomedical care services is a major challenge. The absence of medical insurance makes the situation even more hopeless. It is for this reason that patients seek alternative care services from traditional healers, faith healers and/or herbalists. These services are cheaper and the patient might not need to travel far for such services. Even more interestingly the patients are not required to pay money upfront for the services and in some situations they can pay in kind instead of cash (e.g. in clothes, chickens, food and/or working in the healer's farm). McKinlay's model appears to be limited in explaining these behavioural observations which apparently are quite well explained and supported by earlier observations in Nyamongo's (2002) model.

Furthermore, unlike in McKinlay's model based on developed countries where health care services are readily accessible and delivered through more organized biomedical health care facilities, health care services in most sub-Saharan countries are provided through pluralistic health care systems (i.e. traditional and biomedical health care systems). By virtue of his focus on the utilization of biomedical care services, his model is limited in explaining the factors influencing patients' utilization of non-biomedical health care systems. For example, accessibility to the services provided through these parallel health care systems appears to be influenced by diverse socio-cultural, political, and economic factors. The current study, for example, provides extensive evidence of the diverse use of the services provided through these two health care systems, some of which were in conflict with one another, at times to patients' detriment. These findings are also congruent with the arguments presented in Kroeger's (1983) and Young's (1981) models of the use of traditional and faith healers.

Furthermore, distance to the health care facility for some patients in the current research, like in McKinlay's model, was noted to have significant influence on their health-seeking behaviour especially when coupled with high transport costs and poor infrastructure (e.g. poor roads and a limited number of buses). This challenge notwithstanding, some patients still managed to seek care at the facility of their choice. The observed variations in the health-seeking behaviour among patients facing more or less the same challenges of distance and transport costs begged for an explanation. As it turned out, the belief that the patient and his/her family and/or social networks have in the nature and quality of health care services appears to have an upper hand in the decisions to seek care and where such services are sought. Family members would go to great lengths to meet the costs if they have a strong "belief" in the nature of care their patient is likely to get as remarked by one patient:

...I think in some cases cost is not an issue. I have seen people transport their patient all the way from Dar es Salaam to Tanga or Bagamoyo or Ruvuma in South Tanzania for treatment at the traditional healers whose services they just heard about! The big issue here is the belief that the patient and his/her family members have about the nature and quality of services being provided be it at the traditional healers or at the modern health care facility! (PtIRAM118)

These observations are in line with Young's model (1981) which highlights individuals' knowledge and faith as well as beliefs in the efficacy of treatment as the driving force for one's decision to seek care at the health care facility in question. The pathway to care and treatment for most diseases in sub-Saharan countries is strongly influenced by socio-cultural beliefs and practices. Nyamongo's (2002) and Good's (1987) models, for example, see the health-seeking behaviours as being influenced by diverse socio-cultural beliefs and practices that are characterized by the use of self-medication, use of home remedies and/or consultation with traditional healers. Indeed, the findings of the current study appear to affirm the arguments in these models.

In conclusion, McKinlay's model was a useful tool in informing the data collection instruments and an analytical framework for the current research. However, the model was limited in explaining some of the factors influencing health-seeking and health related behaviour and the specific contexts in which they occur. The current in-depth qualitative data has managed to provide additional explanations to address this limitation as seen in Table 7.1. Additionally, the current findings affirm similar

observations from other models derived from in-depth qualitative studies carried out in developing countries and sub-Saharan Africa, i.e. Young (1981), Good (1987), Kroeger (1983) and Nyamongo (2002). The combination of the current findings with those observed in the mentioned models has led me to provide a tentative modification of McKinlay's framework as presented in Table 7.1

Table 7.1: Modified McKinlay's Analytical Orientation and/or Approaches to Health-seeking Behaviour

<i>McKinlay's Original Version</i>	<i>McKinlay's Key Focus</i>	<i>Modified Version</i>	<i>Additional Focus</i>
Economic	Financial barriers such as income, health insurance cover, the cost of health services and availability of free medical drugs		
Geographic	The geographical proximity of health services		
Socio-demographic	Includes gender, age, social class and education		
Social-psychological	Individual motivation, perception and learning		
Socio-cultural	Values, norms, beliefs, definitions of situations, and lifestyles of different socio-economic groups		
Organizational or health delivery system	Aspects of biomedical health care organizations and those working in them		
		Patient's knowledge, belief and perceptions	Nature and severity of signs and symptoms, previous experiences with

		about symptoms	diabetes. Patient's knowledge, faith/belief in the efficacy of treatment
		Family and/or social networks	Family, relatives, friends and neighbours
			Health care policies, service accessibility and affordability of care services, presence of competing alternative care services etc. Pluralistic health care delivery systems (Biomedical and/or traditional)
		Patient's pre-existing health conditions	Presence of other chronic diseases such as hypertension

While the health-seeking behaviour observed in the current research appears to be explained by most of the factors presented in McKinlay's framework, as shown in columns 1 and 2 in Table 7.1, the framework appears to be limited in explaining other behaviours that were observed in the current study. An attempt to explain such behaviours has been made through the introduction of the factors presented in column 3 and their respective focus in column 4. For example, while McKinlay's model used "geographical proximity" as a factor in explaining the health-seeking behaviour among patients, the findings from the current research suggest that this was not so important in this context. Patient and family members and/or social networks' knowledge about the nature of care services available at the biomedical and/or traditional health care sources and the faith and/or belief in the efficacy of treatment, appear to offer a better explanation than "geographical proximity" in explaining some of the health-seeking behaviours observed in the current research.

Furthermore, while McKinlay's (1972) work noted the role of family and social networks as a factor in influencing patients' health-seeking behaviour, this factor did not feature in his initial theoretical framework as shown in Table 7.1. The family and/or social network factors appear to have been underscored in the Young, Good, Kroeger and Nyamongo models and confirmed through the findings of the current research as shown in columns 3 and 4. Similarly, McKinlay's model omitted the influencing role of patients' knowledge, beliefs and perceptions about signs and symptoms in the decisions to seek care as highlighted in Sheeran and Abraham's Health Belief Model (HBM) and confirmed as important by the current research. As observed in the current research, the nature and severity of signs and symptoms, as well as previous experiences with diabetes were among the factors influencing health-seeking behaviours among the patients. Alongside the patient's perceptions of the signs and symptoms of the disease was the patient's pre-existing health condition or presence of chronic disease such as hypertension which was noted as a factor in explaining the health-seeking behaviours noted among some of the patients in the current study. However, this was not among the factors highlighted in McKinlay's model.

Finally, while the current study acknowledges McKinlay's model on the role of the organizational or health delivery system together with the health care workers providing care services in influencing patients' health-seeking behaviour, it goes further to highlight the influential role of traditional and faith healers and/or herbalists (pluralistic health care delivery systems) in the provision of health care services. Based on the current research findings, the presence of pluralistic health care systems coupled with existing health care policies (i.e. free vs. cost sharing medical care), service accessibility and affordability of care services, presence of competing alternative care services etc. as shown in columns 3 and 4 appear to have an influencing role in the diverse health-seeking behaviour patterns observed among the patients. These findings appear to support earlier observations in Kroeger's and Nyamongo's models.

7.7 Priority Areas for Future Research

The current findings have significant research implications. This is the first qualitative study carried out in Tanzania on type 2 diabetes mellitus. As already revealed from the

findings presented in this thesis, the study raised a number of issues, some of which require further research. First, while exploration of the factors behind the increasing prevalence of diabetes in Tanzania was not the objective of the current study, the findings presented here allude to the need to explore these factors. Currently, diabetes appears to affect people of all walks of life irrespective of age, economic status, gender and race. What are the factors that may be contributing to the increasing prevalence of diabetes across the population and specifically among young children? What are the lifestyle factors that may explain the observed increase of diabetes in ethnic groups that were previously less affected by diabetes? What explanations are there for the growing prevalence of diabetes among Africans living in rural communities? Further research to explore these and related factors that may explain the increasing prevalence of diabetes in the Tanzanian population and may enhance the information generated from the current study in the development of relevant and effective interventions.

Secondly, the findings of the current study suggest that the socio-economic burden of managing diabetes is beyond the means of many families in Tanzania. There appears to be a need to explore the socio-economic impact of diabetes on affected families in Tanzania to generate tangible data that could be used in informing national policy aimed at enhancing management of diabetes and support for patients with diabetes and their families.

Thirdly, as revealed in the current study, most services are poorly organised and difficult to access both physically and financially. Similarly, health care providers appear to have limited skills both in the diagnosis and management of diabetes. Understanding of diabetes management is generally poor among health care workers not only in Tanzania but in sub-Saharan Africa as a whole (Beran & Yudkin, 2006). Health care workers need to keep abreast of current diabetes knowledge and the best medical practices for better management of diabetes. However, before embarking on capacity building for health care providers it is necessary to determine the nature of the knowledge and skills that these health personnel require in order to identify deficiencies and to develop effective training packages. Similarly, country-wide diabetes clinic performance guidelines for diabetes care and management in primary care settings should be developed and incorporated into the training packages to enhance quality

service delivery. To this end, a training needs assessment would be needed to delineate the nature of training required and the type of health care personnel that need it most. The training needs assessment should also identify the nature of medical equipment and related care and management materials needed for timely diagnosis and provision of quality care and organisation of care for people with diabetes at biomedical care facilities.

Furthermore, given the acknowledged utilisation of the traditional health care system by patients both before and after they are diagnosed with diabetes, there is a need for a study to explore and evaluate the opportunities for and impact of integrating traditional medical services and those offered by the biomedical care system, to enhance the overall care and management of diabetes. This assessment could identify the tasks which could be carried out by traditional healers in diagnosis and treatment and should explore the nature of training that might be needed for traditional medical practitioners with the goal of ensuring quality care for people with diabetes. Real improvements in diabetes care and outcomes in sub-Saharan Africa including Tanzania require active teamwork between local biomedical care facilities, diabetes associations, and traditional practitioners. The national government needs to take responsibility for instigating widespread involvement of these players as a strategy to enhance effective care delivery for people with diabetes (Gill, Mbanya, Ramaiya, & Tesfaye, 2008). Health care seeking and treatment delays due to visiting traditional healers can have direct negative, even fatal, consequences for patients with diabetes. Efforts are therefore required to engage with health care practitioners outside the government sector to improve care services for people with diabetes.

Finally, participants in the present research called for a national public health campaign about diabetes to promote early care seeking and adherence to recommended care and management of diabetes. While patient education on the care and management of diabetes is critical and health care workers need to be well equipped to provide such education, the findings of the present study call for such education to go beyond patients attending the biomedical care facilities. The public at large needs to be educated about diabetes with a special focus on recognizing the signs and symptoms of diabetes and the urgency of taking action for early diagnosis and treatment. To this effect, there is a need

for formative research aimed at determining the levels of public knowledge and understanding of diabetes. A better understanding of lay knowledge and health-related attitudes, beliefs and behaviours associated with diabetes is vital for developing cost-effective public health communication interventions in Tanzania.

7.8 Conclusions and Recommendations

This thesis revealed a number of factors that influence health-seeking and health related behaviour among adults with type 2 diabetes mellitus in Tanzania. The findings add substantial value to the existing literature in developed and developing countries as well as sub-Saharan African countries. Indeed, the findings fill a gap caused by limited scope of qualitative literature related to type 2 diabetes in Tanzania.

Decisions to seek care, according to the current findings, are influenced by a number of factors: first, severity of signs and symptoms of the disease; second, the recognition of signs and symptoms by patients, family members and/or their social networks; third, availability of resources to seek care; and finally, the perceived barriers and nature of health services delivery at the health care facilities.

The current findings show limited levels of awareness and knowledge about diabetes among people with diabetes and their families and/or social networks as well as community members. The limited awareness and knowledge often lead to poor recognition of the signs and symptoms of the disease with consequent delays in seeking care at biomedical facilities. Equally so, the limited level of knowledge about diabetes was reported to be a source of indirect stigma and discrimination for people with diabetes. These observations call for extensive community-level counselling services for patients, their families and social networks, as well as national public health education campaigns to promote awareness and knowledge about diabetes aimed at stigma reduction. Such initiatives will enhance the adoption of prevention and control measures against diabetes, and promotion of early care seeking and management of this disease.

The pathway to care and treatment at the onset of signs and symptoms of diabetes follows a number of stages, each having significant implications for the eventual

treatment outcome. To start with, the signs and symptoms of diabetes are subjected to a lay diagnosis by the family members and/or social networks using the existing traditional health belief systems. Based on the diagnosis, decisions are then made by the family members on the nature of care to be sought, and where and when it should be sought. Often, based on the results of the lay diagnosis, the nature of care and sources for such care become a choice between traditional and biomedical care services. As observed in the current study, through the influence of family members and/or social networks the services of traditional health practitioners, especially for diseases with unknown origin or cure, become the first choice of care before eventually turning to the biomedical services. It is in light of this observation that the study recommends that the biomedical care system develops a mechanism for educating traditional health practitioners about diabetes so as to engage their support in referring patients to biomedical care facilities as soon as they notice signs and symptoms of this disease. This will enhance early diagnosis of diabetes and its effective management.

Secondly, the decision to seek care at biomedical facilities for many patients appears to be hindered by a lack of financial resources to pay the transport costs to health care facilities, and for medical tests and prescribed medication. Travel distances from patients' residences, coupled with inadequate and poor public transport infrastructure were reported to negatively influence the decisions to seek care at biomedical facilities. It is in light of these observations that the current study recommends that the government increases its efforts to improve care seeking for people with diabetes by addressing structural, administrative and financial issues, including plans to decentralise the delivery of diabetes services to primary health care facilities and existing dispensaries thus enhancing patients' ability to seek care earlier.

Third, once diagnosed with diabetes and given a care and management programme the majority of patients acknowledged facing a number of challenges in adhering to their routine clinic appointments for check ups and the recommended intake of prescribed drugs. While these challenges were attributed to a lack of financial resources to meet the costs of transport and medication, the majority of patients pointed to the 'unresponsive' nature of the health care delivery system as a major barrier to their continued use of biomedical services. The cited shortcomings of biomedical services included a lack of

friendly care services and affordable drugs; lack of medical equipment; a lack of skilled health care workers; and long waiting times for care services at the clinic. These and other related factors were reported to influence patients, their family members and/or social networks to seek alternative care services through traditional practitioners. These observations led the current study to recommend that the government should take measures to ensure high quality care and management of diabetes through addressing a range of factors, including the introduction of more patient-centred care services at the public health clinics, increasing the quality and number of health care providers, and improving procurement accessibility of affordable diabetes drugs for people with diabetes.

Fourth, while acknowledging that biomedical services were the state of the art in the care and management of diabetes, many patients were reported to waiver from the use of these services and to seek those provided by traditional practitioners at times, propelled by their fear and/or the desire to be seen to do something about their health—looking for a cure. Others are influenced by their family members and/or social networks. The influence of aggressive and extensive promotion of traditional services by traditional practitioners through print and electronic media for “magic cures” for diabetes and other communicable diseases including HIV/AIDS is pervasive. In light of this observation the current study recommends that the government takes pro-active measures in providing guidelines on the promotion of cures for chronic diseases like diabetes and HIV/AIDS by traditional practitioners or other individuals claiming to have such unproven cures.

Effective management of communicable and NCDs calls for joint national and international cooperation through networks of local and international organisations like WHO, UNAIDS and the IDF. However, for some diseases, when these international organisations falter in their efforts to raise the profile of such diseases less effort tends to be directed at addressing them. WHO, for example, has been blamed for not doing enough in raising the profile of diabetes care and management on the global agenda (Beran & Yudkin, 2006). Among the noted shortcomings include a lack of adequate attention to the problems of managing patients with chronic diseases and lack of inclusion of insulin in the WHO essential drugs list. Furthermore, the International

Diabetes Federation, for example, still operates as an association of National Diabetes Associations, rather than an international organisation with staff and projects. The establishment of an office as part of the secretariat would achieve substantial progress in improving care for people with diabetes in the least developed countries. Similarly, the task of procurement and quality assurance for insulin that is now being made available through the essential drugs and medicines division of WHO, could be handled by an NGO, as for asthma drugs, and the International Diabetes Federation might consider taking such a role. Efforts to improve the outcomes for diabetes should take an emergency approach similar to those for HIV/AIDS to address the growing trends of diabetes in sub-Saharan Africa. Such efforts should include training health care workers, functioning health care systems, continuing availability of affordable diabetes drugs and monitoring reagents, and functioning referral systems. In summary, improvements in biomedical care systems are a vital component of improving health and health care for patients with many chronic conditions such as diabetes across sub-Saharan Africa.

Finally, effective care and management programmes for diabetes call for a policy on NCDs and guidelines that will put basic health systems together to address this disease nationally and internationally. This approach has been used to address communicable diseases such as HIV/AIDS, malaria and TB. Former US President Bill Clinton, for example, has been advocating the development of health care structures for effective HIV/AIDS care and treatment. In his words: “Until we build the human and physical infrastructure needed to deliver effective treatment, programmes will not succeed” (Clinton, 2003). This is essential at the national and international levels if we are to control the growing trends of diabetes in sub-Saharan Africa including Tanzania.

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Appendices

Appendix 1: Type 2 diabetes clinical practice guideline for sub-Saharan Africa

What should be done and when

Primary Level		
Initial visit	Three Month visit	Annual visit
History and diagnosis	Relevant history	History and examination –as at initial visit
Physical Examination:	Weight	Biochemistry–as at initial visit
-Height & weight (BMI)	Blood pressure	
-Waist /hip circumference	Foot inspection	
-Blood pressure	Biochemistry:	
-Detailed foot examination	-Blood Glucose	
-Tooth examination	-Glycosylatted haemoglobin	
-Eye Examination	- Urine protein	
-Visual acuity + Fundoscopy*	Urine protein	
-Biochemistry:	Education advice	
-Blood Glucose*	Nutritional advice	
-Glycosylatted haemoglobin*	Review therapy	
Lipids (TC, HDLC, LDLC, TG)*		
-Creatinine, sodium, Potassium*		
-Urine :Glucose, ketones, protein		

Education		
Nutrition advice		
Medication if needed		
Secondary Level		
All the above	All the above	As initial visit
Eye examination		
ECG		
-Biochemistry:		
-Blood Glucose*		
-Glycosylated haemoglobin*		
-Lipids (TC, HDLC, LDLC, TG)*		
-Creatinine, Sodium, Potassium*		
Tertiary Level		
All the above and microalbuminuria	All above	All the above and microalbuminuria
*If facilities are available—otherwise refer		
TC=total cholesterol, HDLC=high-density lipoprotein, LDL=low -density lipoprotein, TC=triglycerides		

**Appendix 2: Key diabetes qualitative and quantitative studies on
sub-Saharan Africa and Tanzania**

Main journal articles referred to in this study	
Title: Diabetes in Tanzania: Insulin supply and availability–Simpson, 2003	
Setting	Urban hospitals in Dar es Salaam, Zanzibar and Tanga in Tanzania
Study design	Quantitative
Participants	Regular diabetic clinic attendees mainly using insulin
Data collected and how	Questionnaire and interview about clinic attendance, the use of insulin, hospital running of clinics, local beliefs, and cultural differences
Key findings	In Dar es Salaam and Tanga 80% and in Zanzibar 100% found that their insulin supply was interrupted. The reason for this was lack of money. Patients coped with the problem by doing nothing or obtained traditional medicine. A few patients bought insulin from a private pharmacy.
Title: Self-reported health and glycaemic control in Tanzanian and Swedish people with diabetes–Smide et al., 2002	
Setting	Urban referral hospital in Dar es Salaam, Tanzania
Study design	Quantitative
Participants	Random sample selection of people with diabetes
Data collected and how	Questionnaire about glycaemic control and other health self report.
Key findings	There was no relationship between self-reported health and glycaemic control except that Tanzanians with poor glycaemic control had lower scores in the mental health domain.
Title: The paradox of the cost and affordability of traditional and government health services in Tanzania–Muela et al., 2000	

Setting	Urban-rural in Ifakara, the capital of Kilombero district in Tanzania
Study design	Qualitative ethnographic study
Participants	Clients of traditional healers
Data collected and how	Field observation of both biomedical and traditional health facilities in Ifakara and interviews with clients of traditional healers
Key findings	People's ability to pay for health care in Tanzania is not only determined by cost but a series of economic and social factors, such as method of payment (i.e. in cash or in kind). Traditional healers offer flexibility on when and how fees are to be paid. This is well adapted to the economic constraints in Tanzania society. The role of social networks in coping with illness costs is more important.
Title: Knowledge, attitudes, and behaviour relating to diabetes and its main risk factors among urban residents in Cameroon: a qualitative study–Kiawi et al., 2006	
Setting	Urban Cameroon
Study design	Qualitative study
Participants	Purposively selected to include a range of community key participants and articulate community members
Data collected and how	In-depth interviews by using a pre-tested, semi-structured interview guide to investigate lay knowledge, attitudes, and behaviours relating to diabetes and its main risk factors.

Key findings	<p>Awareness of diabetes, knowledge of its causes, clinical course, and complications were limited.</p> <p>Many participants believed diabetes was caused by excessive sugar consumption rather than excessive energy intake, obesity, or physical inactivity. Obesity, particularly in men, was largely perceived positively as a sign of “good living”.</p>
Title: Diabetes, Medicine and Modernity in Cameroon — Awah, PK. and Peter Phillimore, 2008	
Setting	Urban administrative district and rural district in north west Cameroon
Study design	Qualitative study —Ethnographic study
Participants	People living with diabetes, their families and indigenous healers
Data collected and how	Ethnographic fieldwork with individual and/or group interviews to examine popular understandings of type 2 diabetes, and conflicts and ambiguities in the management of diabetes care, in two areas (urban and rural) where some basic biomedical services for diabetes were already established in Cameroon. Later compared such responses in urban and rural contexts.
Key findings	<p>Findings suggest -unresolved tension between two approaches to health and the treatment of illness. On the one hand, the impulse of many patients — and their families — is commonly to combine forms of treatment in a manner that may be seen as pluralistic, a kind of therapeutic hybridity.</p> <p>The continuing importance of indigenous healing practices, and explanations for diabetes in terms of ancestral intervention or witchcraft, are considered in the light of recent anthropological debate about the ‘modernity</p>

	of witchcraft' in Africa.
Title: Cure or control: complying with biomedical regimen of diabetes in Cameroon–Pascal et al., 2007	
Setting	Rural and urban health districts of Cameroon
Study design	Qualitative study
Participants	Patients were chosen based on catchment areas of known people with diabetes in a setting with diabetes clinics
Data collected and how	Participant observation with daily interaction with patients in their natural setting about cultural aspects of complying with biomedical regimen of diabetes
Key findings	<p>Results indicate negative feelings towards biomedicine, low awareness about biomedical therapy for diabetes and dissatisfaction with biomedical treatment of diabetes.</p> <p>Cultural pressures on patients are responsible for patients' partial acceptance of and adherence to biomedicine prescriptions.</p> <p>There is a lack of basic knowledge about diabetes and diabetes risk factors among people with diabetes.</p> <p>Compliance with biomedical therapy was hindered by several cultural beliefs.</p>
Title: Healer shopping in Africa: new evidence from rural-urban qualitative study of Ghanaian diabetes experiences–Aikins, 2005	
Setting	Two urban towns and two rural towns in Ghana
Study design	Qualitative study
Participants	Urban and rural people with diabetes
Data collected and how	Individual and/or group interviews, and ethnographies were conducted to explore experiences and illness practices
Key findings	Analysis identified four kinds of illness practice: biomedical management, spiritual actions, cure seeking

	(passive and active), and medical inaction. Many participants ranked biomedicine above other health systems and emphasised biomedical management as ideal self care practice. Poor diabetes services access and high cost as well as cure seeking led some participants into healer shopping.
Title: Living with diabetes in Rural and Urban Ghana: A critical social psychological examination of illness action and scope for intervention–Aikins, 2003	
Setting	Urban and rural Ghana
Study design	Qualitative study
Participants	Urban and rural Ghanaians with diabetes
Data collected and how	Semi-structured individual interviews to examine critically the link between illness experience and action particularly from type 1 and 2 diabetes mellitus
Key findings	<p>Most respondents drew interchangeably from common sense, scientised, and religious knowledge modalities in defining health, illness, and diabetes.</p> <p>They perceived diabetes caused disruption to: body-self, social identity, family/social relationships, economic circumstance and nutrition. The common sense and scientific knowledge on health, illness and diabetes framed illness action goals that merged with biomedical goals, specifically drug and diet management.</p>

Appendix 3: Ethical Approvals

Appendix 3.1 University of Otago Ethics Approval



06/167

ACADEMIC SERVICES
Manager, Academic Committees, Mr G K (Gary) Witte

17 November 2006

Dr R Edwards
Department of Public Health (Wgnt)
Wellington School of Medicine
and Health Sciences

Dear Dr Edwards

I am writing to let you know that, at its recent meeting, the Ethics Committee considered your proposal entitled "**Health seeking behaviour among adults with type 2 diabetes in an urban community in Tanzania**".

As a result of that consideration, the current status of your proposal is:- **Approved**

For your future reference, the Ethics Committee's reference code for this project is:- **06/167**.

Yours sincerely,

Mr G K (Gary) Witte
Manager, Academic Committees
Tel: 479-8256
Email: gary.witte@stonebow.otago.ac.nz

c.c. Professor P R Crampton Acting Head Department of Public Health (Wgnt)

Appendix 3.2 Muhimbili University of Health and Allied Science



**MUHIMBILI UNIVERSITY COLLEGE
OF HEALTH SCIENCES**

OFFICE OF THE DIRECTOR OF RESEARCH AND PUBLICATIONS

P. O. BOX 65001 ● DAR ES SALAAM ● TANZANIA

TELEPHONE: Direct: 255 22 2152489

Telegrams: UNIVMED

Telex: 41505 MUHMED TZ

Telefax: 255 22-150465

E-mail: drp@muchs.ac.tz

Ref.No.MU/RP/AEC/Vol.X/27

20th February, 2007

Lucy Nguma,
School of Nursing,
MUCHS.

**RE: APPROVAL OF ETHICAL CLEARANCE FOR A PROPOSAL TITLED
"HEALTH SEEKING BEHAVIOUR AMONG ADULTS WITH TYPE 2
DIABETES MELLITUS IN AN URBAN COMMUNITY IN TANZANIA"**

Reference is made to your submission requesting for ethical clearance for the above-mentioned proposal activity.

I am pleased to inform you that the Chairman has, on behalf of the Academic Board approved ethical clearance for your activity from February 19th, 2007 to February 19th, 2008. You will be expected to provide a six monthly progress report and a final report at the completion of your study. Renewal of ethical clearance will be required in case you wish to continue with your study after one year.

Prof. E.F. Lyamuya

CHAIRMAN, COLLEGE RESEARCH & PUBLICATIONS COMMITTEE

COLLEGE RESEARCH & PUBLICATIONS COMMITTEE.
MUCHS. P. O. Box 65001.
DAR ES SALAAM

c.c. Principal, MUCHS.
c.c. Registrar, MUCHS.
c.c. Dean, School of Nursing, MUCHS.

Appendix 3.3: The district medical officer letter of approval to carry out the pre-test study in Temeke district

TEMEKE MUNICIPAL COUNCIL

ALL COMMUNICATIONS TO BE ADDRESSED TO MUNICIPAL DIRECTOR

P.O.Box. 45232
Tel: 2850142



TEMEKE MUNICIPAL MEDICAL OFFICE OF HEALTH
DAR ES SALAAM
TANZANIA.

Date 28/02/07

The Medical Officer /C
Temeke Municipal Hospital

REF; PERMISSION TO CONDUCT HEALTH RESEARCH ACTIVITIES IN TEMEKE MUNICIPALITY.

Please refer to the above heading.

Permission has been granted to Mr./Mrs/Ms/Prof./Dr. Lucy Nguma
From (Institution) MUMCHS Address
Tel. No..... Emailto
collect data for research work at your institution.

The research title is
Health seeking behaviour among adults with type 2
diabetes mellitus in an urban community Temeke

S/he has submitted a proposal for the mentioned study to the MMOH Office as a pre - condition prior to authorisation.

The researcher has been instructed and agreed to submit the research progress reports and final results to the MMOH prior to any publications.

Data collection will start from 28/02/07 to 28/03/2007
Sample size.....

This research work is part of academic fulfilment for Diploma/Advanced Diploma/Degree/Master/PhD /its part of the ongoing research in your Institution.

I am kindly requesting you to give him/her the necessary assistance so as to accomplish this task timely.

Yours Sincerely

Mushombi Mkamba

For; Temeke Municipal Medical Officer of Health

MUNICIPAL MEDICAL OFFICER
TEMEKE

Copy 1. MO /C
2. student (Lucy Nguma)

Appendix 3.4: The district medical officer letter of approval to carry out the main study in Ilala district

ILALA MUNICIPAL COUNCIL

ALL COMMUNICATIONS TO BE ADDRESSED TO THE MUNICIPAL DIRECTOR

P.O. BOX **20950**
PHONE NO: **2128800**
 2128805
FAX NO. **2121486**



**MUNICIPAL OFFICE
ILALA**

Ref: IMC / MED / R.18 / 5VOL.X17

Date: 26/02/ 2007

Medical Officer In charge
Amana Hospital
ILALA MUNICIPALITY

RE: PERMISSION TO COLLECT DATA FOR A RESEARCH WORK.

Please refer to the heading above.

Lucy Nguma is a Postgraduate student doing a PHD degree at University of Otago in New Zealand, requested to conduct a study on "**HEALTH SEEKING BEHAVIOUR AMONG ADULT MEN AND WOMEN WITH TYPE 2 DIABETES MELLITUS IN AN URBAN COMMUNITY TANZANIA**". After going through the proposal she is granted a permission to conduct the above- mentioned study in Amana Hospital.

Data collection will be done for ^{Research} ~~Project~~..... starting on 12./ 03/ 2007 – 25./ 06/ **2007** at your facility.

This study is part of academic fulfillment of a PHD Degree.

We here by request your assistance as the researcher has accepted our condition of producing a copy of study **results** and **recommendations** to Municipal Medical Officer of Health (MMOH) as well as to your Facility.


District Research Coordinator
MMOH – Ilala Municipality

For:
Copy to: Researcher

Appendix 3.5: The district medical officer letter of approval to carry out the main study in Kinondoni district

KINONDONI MUNICIPAL COUNCIL

ALL CORRESPONDENCES SHOULD BE DIRECTED TO THE MUNICIPAL DIRECTOR

Tel: 2171022

In reply please quote:

Ref. No.FD/K/133 VI 195



MUNICIPAL MEDICAL OFFICER
OF HEALTH,
KINONDONI MUNICIPAL COUNCIL
P.O. BOX 61665,
DAR ES SALAAM

Date:26/2/2007

MO I/C
MWANANYAMALA HOSPITAL
KINONDONI MUNICIPALITY.

RE:RESEARCH PERMIT

Lucy K. Nguma

The above-mentioned is a postgraduate student doing a PhD degree at the **University of Otago in New Zealand**. She has been given permission to conduct a research on **health seeking behavior among adult men and women with type 2 diabetes mellitus in an urban community** at your hospital from 26th February to 26 June 2007.

Kindly provide her with the necessary assistance.
Best wishes,

Aleswa Zebedayo
(For Training Coordinator)
Kinondoni Municipal Council

Copy: To above mentioned Candidate.

Appendix 3.6: The medical officer in charge letter of approval to carry out the study in Amana diabetes clinic

ILALA MUNICIPAL COUNCIL

ALL COMMUNICATIONS TO BE ADDRESSED TO THE MUNICIPAL DIRECTOR

P.O. BOX 20950
PHONE NO: 2128800
2128805
FAX NO. 2121486



**MUNICIPAL OFFICE
ILALA**

Ref: IMC / MED / R.18 / 5VOL.X17

Date: 26/02/ 2007

Medical Officer In charge
Amana Hospital
ILALA MUNICIPALITY

*Ye Diabetic clinic
Please attend this matter
accordingly Shehamba!!*

RE: PERMISSION TO COLLECT DATA FOR A RESEARCH WORK.

Please refer to the heading above.

Lucy Nguma is a Postgraduate student doing a PHD degree at University of Otago in New Zealand, requested to conduct a study on **"HEALTH SEEKING BEHAVIOUR AMONG ADULT MEN AND WOMEN WITH TYPE 2 DIABETES MELLITUS IN AN URBAN COMMUNITY TANZANIA"**. After going through the proposal she is granted a permission to conduct the above- mentioned study in Amana Hospital.

*20/3/07
See D. Sidiyasa
2/4/07*

Data collection will be done for starting on 12/03/ 2007 - 25/06/ 2007 at your facility.

This study is part of academic fulfillment of a PHD Degree.

We here by request your assistance as the researcher has accepted our condition of producing a copy of study **results** and **recommendations** to Municipal Medical Officer of Health (MMOH) as well as to your Facility.

M. Mwangi
District Research Coordinator
For: **MMOH – Ilala Municipality**
Copy to: Researcher

K.N.Y
MGANGA MKUJI
AMANA HOSPITAL

K.N.Y
MGANGA MKUJI
AMANA HOSPITAL

Appendix 3.7: The medical officer in charge letter of approval to carry out the study in Mwanayamala diabetes clinic

KINONDONI MUNICIPAL COUNCIL

ALL CORRESPONDENCES SHOULD BE DIRECTED TO THE MUNICIPAL DIRECTOR

Tel: 2171022

In reply please quote:

Ref. No.FD/K/133 VI 195



MUNICIPAL MEDICAL OFFICER
OF HEALTH,
KINONDONI MUNICIPAL COUNCIL
P.O. BOX 61665,
DAR ES SALAAM

Date:26/2/2007


MO I/C
MWANANYAMALA HOSPITAL
KINONDONI MUNICIPALITY.

RE:RESEARCH PERMIT

Lucy K. Nguma

The above-mentioned is a postgraduate student doing a PhD degree at the University of Otago in New Zealand. She has been given permission to conduct a research on health seeking behavior among adult men and women with type 2 diabetes mellitus in an urban community at your hospital from 26th February to 26 June 2007.

Kindly provide her with the necessary assistance.
Best wishes,


Aleswa Zebedayo
(For Training Coordinator)
Kinondoni Municipal Council

Copy: To above mentioned Candidate.

A ccepted

D. Z. Kereby

*Att
Dr Kaselate / ase assist
Date
30/02/07*

Appendix 4: Study interview guides

Appendix 4.1: In-depth interview guide for people with type 2 diabetes mellitus

Good morning/afternoon. Let me start by thanking you for taking your time to come and talk to me. As I explained in my Contact Form I am carrying out a study on “Health-seeking and health related behaviour for type 2 diabetes mellitus among adults in Dar es Salaam” as part of my PhD requirements. The purpose of the study is to explore the socio-cultural perceptions, beliefs and other factors that may be influencing health-seeking behaviours for diabetes care and treatment with the goal of improving services related to this disease. In the process of collecting information for this study we are talking to other people such as patients’ caregivers; health care providers; key national health officials and selected community members. You have purposively been selected

in this study. As such, I am asking you to take this task seriously by sharing your opinions and ideas openly and candidly on the subject as this will facilitate the development of relevant interventions related to diabetes in this country. The information collected here will be confidential and is going to be used for only the intended purpose of improving diabetes care and management in Tanzania. To keep a more accurate record of our discussion, I am proposing that we use a tape recorder. Do you mind if I use a tape recorder? Observe for any objections and if none... proceed. I can see there is no objection to our using a tape recorder, so I thank you once again for your cooperation.

Background information:

Age:

Sex:

Education level:

Occupation:

Marital status:

Hypertension:

Diabetic foot:

Duration of diabetes illness:

Name of the clinic:

Theme 1: Socio-psychological factors (Probe for motivation, knowledge, understanding, perceptions and attitudes (stigma related issues) myths and misconceptions about diabetes and health services utilisation

Let us start by looking the existing knowledge, understanding and perception about diabetes:

1. Tell me how did you hear about diabetes before you were diagnosed with this disease? (*Probe: If you had heard about it before, what was your first main source of information?*)

2. What do you think causes type 2 diabetes? (*Probe: Can one get diabetes from a person with diabetes? If yes, how?*)
3. What are the major symptoms and signs of type 2 diabetes? (*Probe: Did you experience these symptoms before you were diagnosed with this disease?*)
4. Is type 2 diabetes treatable? If yes, how? If no, why? Is it preventable? If yes, how? If not, why? Is it curable? If yes, how? If not, what is the reason?
5. How big is the problem of type 2 diabetes mellitus in this community?, what are the reasons for it? (*Probe: What types of people are at risk of getting diabetes and why?*)
6. What are the complications one is likely to get if he/she is not treated in time? (*Probe: Tell me if you are likely to get one of the diabetes complications? what are the reasons?*)
7. What in your understanding should the patient do for successful treatment of diabetes?
8. How did you feel when you were first diagnosed with diabetes? (**Probe: Did you try to keep your family and other people from knowing about it? If yes or no, why?**)
9. How can you describe the relationship between people with type 2 diabetes and in the community without the disease? (**Probe: How do people in this community associate type 2 diabetes with other diseases?**)

Theme 2: Health-seeking behaviour (Probe for factors influencing health-seeking behaviour (HSB))

Let us now reflect on the process of health-seeking behaviour for care and treatment of type 2 diabetes: -

10. Before you were diagnosed with type 2 diabetes, did you know that you might have been suffering from this disease? If yes, how? (*Probe: If no, what first triggered you to seek treatment before you were diagnosed with this disease?*)
11. How long did it take between the time you noted the signs or symptoms of the disease and the time you decided to seek care at the health care facility? (*Probe: Did you seek care elsewhere before you decided to go for treatment at the health care facility? If yes, where did you seek care? What is the reason for that?*)
12. What would you say was a major influence on your decision to seek care at the health care facility? (*Probe: After initiating treatment at the diabetic clinic, did you seek care anywhere else? If yes, where and what is the main reason?*)

13. Tell me about the use of traditional healer's services in your *ever sought diabetes services from a traditional healer?, what made you do so? What kind of services did you get?*)

Theme 3: Demographic, socio-cultural and economic factors in health-seeking behaviour

Let's look at the decision making process at the household level:

14. What are some of the barriers that you face in seeking care at a health care facility? **(Probe: for finance, age, marital status, gender, or education)**
15. To what extent does the cost of treatment of your problem affect the welfare of your family?
16. What are the major constraints that you have in adhering to your prescribed treatment programme? **(Probe: If not mentioned probe for prescribed drugs and diet)**

Theme 4: Geographic and Health delivery system factors (Probe for push and pull factors for utilisation of diabetes care services)

17. How far is your home from the health facility? **(Probe: Does the distance from their residence to the health care facility affect his/her decisions to seek care? If yes or no, why?)**
18. How long, on average, do you have to wait at the clinic before seeing the doctor/diabetes specialist? **(Probe: what can you say about it?)**
19. How many times did you visit the health care facility with the same complaints or symptoms before they tested you for type 2 diabetes?
20. What can you say about answers and explanations your getting from the health workers on all questions and issues related to your diabetes treatment **(Probe: How would you describe your relationship with the health care workers?)**
21. Have you had problems in managing your disease? If yes, did you communicate this problem to the health care providers? If yes, what was their response?
22. Have you ever gone to the health care facility and failed to get your medication? If yes, how many times have you experienced such a problem since you started this medication schedule? **(Probe: What did you do?)**

Theme 5: Care and support from caregivers and/or social net works (Probe for care and support from family members and friends)

23. What support do you get from family and friends in taking care of your disease? **(Probe: Who would you say provides most of your care/support and what are the**

tasks that this caregiver carries out for you? What should be done to assist you in self-care management?

24. What would you say are the major challenges you have been facing in taking care of your disease? (*Probe: How have you been addressing these challenges?*)

25. In your opinion what should be done to help people with diabetes attend the health care facility as required? (*Probe: What do you think the health care workers can do to help people with diabetes adhere better to their medical regimen? What needs to be done to empower patient caregivers in taking care of people with diabetes at the household level?*)

Conclusion: *Are there any questions you would like to ask me?*

THANK YOU FOR YOUR COOPERATION

Appendix 4.2: In-depth interview guide for caregivers of people with diabetes

Good afternoon. Let me start by thank you for consenting to participate in this study. As I explained in my Contact Form I am in the process of carrying out a study on “Health-seeking and health related behaviour for type 2 diabetes mellitus among adults in Dar es Salaam” as part of my PhD requirements. The purpose of the study is to explore the socio-cultural perceptions, beliefs and other factors that may be influencing health-seeking behaviours for diabetes care and treatment with the goal of improving services related to this disease. In the process of collecting information for this study, we are talking to people with type 2 diabetes and other people including health care providers, key national health officials and selected community members. You have been identified by patient ‘X’ as one of her/his caregivers, hence I would like to ask you some questions regarding her/his care. Please feel free to tell me all that you know about her/his care since by doing so you will be providing information that will be useful in improving her/his care and that of other patients with the same problem in this country. The information collected here will be confidential and is going to be used for only the intended purpose of improving diabetes care and management in Tanzania. To keep an accurate record of our discussion, I am proposing that we use a tape recorder. Do you mind if I use a tape recorder? Observe for any objections and if none... proceed. I can see there is no objection to our using a tape recorder, so I thank you once again for your cooperation.

Background information:

Age:

Sex:

Marital status:

Education level:

Occupation:

Relationship:

Duration of care provision:

Residential area:

Theme 1: Socio-psychological factors (Probe for knowledge, understanding, perceptions, attitudes and misconceptions about diabetes and health services utilisation)

1. Let me start by having you describe your relationship with patient ‘X’: how are you related to ‘X’ and how long have you been providing care for her/him?
2. What is your experience so far in providing care and support to ‘X’?
3. Had you heard about diabetes before you learned that ‘X’ had diabetes? If yes, what was your main source of information?
4. What do you think causes diabetes? (***Probe: Can one get diabetes from a person with diabetes? If yes, how? If no, why?***)
5. What are the major symptoms and signs of type 2 diabetes? (***Probe: Did your patient experience these symptoms before she/he was diagnosed with this disease?***)
6. How is type 2 diabetes treated? How is it preventable? How is it cured?

7. How big is the problem of type 2 diabetes in this community? What are the reasons? *(Probe: What types of people are at risk of getting diabetes and what are the reasons?)*

8. What are the complications one is likely to get if she/he is not treated in time? *(Probe: Do you think 'X' is likely to get one of these complications? What are the reasons?)*

9. Based on your experience, would people with diabetes rather not have their health condition known to other people? If yes, what makes them do so? *(Probe: Do people with diabetes sometimes feel uncomfortable telling other people that they have diabetes? If yes, what makes them feel that way?)*

10. How is the relationship between people with diabetes and people without in the community? *(Probe: How do members of the community think of people with diabetes because of their health problem? what is the reason for that? What do people in your community associate diabetes with? What is the reason for this?)*

Theme 2: Health-seeking behaviour (Probe for factors influencing health-seeking behaviour) (HSB)

Let us now reflect on the process of health-seeking behaviour for care and treatment of diabetes:

12. Before 'X' was diagnosed with type 2 diabetes, did she/he know that she/he might have been suffering from this disease? If yes, how? *(Probe: What first triggered her/him to seek treatment before she/he was diagnosed with this disease?)*

13. How long was it between the time she/he experienced the signs or symptoms of the disease and the time he/she decided to seek care at the health care facility? *(Probe: Tell me where else did she/he seek care before she/he decided to go for treatment at the health care facility? If yes, where did she/he go?)*

14. In your opinion what were the major factors in 'X's decision to seek care at the health care facility? *(Probe: After initiating treatment at the diabetes clinic, has 'X' sought care elsewhere? If yes, where did she/he go and what made her/him go there?)*

15. Tell me about people in your community and use of traditional healers services for diseases like diabetes? *(Probe: Have you ever sought diabetes care for 'X' from a traditional healer? If yes, what made you do so? What kind of services did you get?)*

Theme 3: Demographic, socio-cultural and economic factors in health-seeking behaviour

Let's look at the decision making process at the household level:

16. What are some of the barriers that you face in seeking care for 'X' at a health care facility? **(Probe: for finance, age, marital status, gender, and/or education)**

17. To what extent does the cost for 'X's treatment affect the welfare of your family?

18. What are the major constraints that 'X' has been facing in adhering to her/his prescribed treatment regimen? (*Probe: If not mentioned, probe for prescribed drugs and diet*)

Theme 4: Geographic and health delivery system factors (Probe for push and pull factors for utilisation of diabetes care services)

19. How far is your home from the health facility? (*Probe: how does the distance from their residence to the health care facility affect the decision to seek care for 'X' at the clinic?*)
20. How long, on average, do 'X' have to wait at the clinic before seeing the doctor/diabetes specialist? (Probe: what can you say about it?)
21. How many times did 'X' visit the health facility with the same complaints or symptoms before she/he was tested for diabetes?
22. What do you think about the answers and explanations that your patients receiving from the health workers on all issues related to her/his care and treatment? (*Probe: How would you describe 'X's relationship with health care workers?*)
23. Have you encountered any problems in managing 'X's disease condition? If yes, did you communicate this problem to the health care providers? If yes, what was their response?

Theme 5: Care and support from social networks (Probe for care and support from caregivers including family members and friends)

24. What are the kinds of support that your patient needs most from you and/or other family members? (*Probe: Have you been able to provide such support? If no, what is the reason for that?*)
25. What are the main challenges that you have been facing in taking care of 'X'? (*Probe: How have you been addressing these?*)
26. What in your opinion do you think the caregivers can do to help people with diabetes adhere better to their medical regimen? (*Probe: What do you think should be done to help people with diabetes attend the diabetes clinic as required? Probe: What needs to be done to empower caregivers in taking care of people with diabetes?*)

Conclusion: Q: Are there any questions you would like to ask me?

THANK YOU FOR YOUR COOPERATION

Appendix 4.3: In-depth interview guide for health care workers

Good morning. Thank you for consenting to participate in this study. I am in the process of carrying out a study on “Health-seeking and health related behaviour for type 2 diabetes mellitus among adults in Dar es Salaam” as part of my PhD requirements. The purpose of the study is to explore the socio-cultural perceptions, beliefs and other factors that may be influencing health-seeking behaviours for diabetes care and treatment with the goal of improving services related to this disease. In the process of collecting information for this study, we are talking to people with type 2 diabetes and other people including patients’ caregivers, key national health officials and selected community members. As one of the health care workers attending these patients I would like to ask you some questions on the overall care and treatment of diabetes in Tanzania. As such, I am asking you to take this task seriously by sharing your opinions and ideas openly and candidly on the subject as this will facilitate the development of relevant interventions related to diabetes in this country. The information collected here will be confidential and is going to be used for only the intended purpose of improving diabetes care and management in Tanzania. To keep a more accurate record of our discussion, I am proposing that we use a tape recorder. Do you mind if I use a tape recorder? Observe for any objections and if none... proceed. I can see there is no objection to our using a tape recorder, so I thank you once again for your cooperation.

Background information.

Age.....

Gender.....

Level of education...

Designation.....

Duration of time working at the diabetes clinic...

Duration of special diabetes training....

Number of patients she/he sees per day....

Name of the clinic

Theme 1: Socio-psychological factors (Probe for motivation, knowledge, understanding, perceptions and attitudes (stigma related issues), misconceptions and magnitude about diabetes and health services utilisation in the community)

Let us now start by asking you to share your experience of diabetes in this community:

1. How would you describe the diabetes situation in this community? (*Probe: What would you say are the factors contributing to diabetes in this community?*)
2. Based on your experience do you think most health care workers are familiar with the signs and symptoms of diabetes? (*Probe: If no, what is the explanation for this? What should be done?*)
3. Based on your experience, would you say that most of your patients were knowledgeable about the signs and symptoms of diabetes before they were diagnosed

with it? If no, what do they say first triggered them to seek treatment? (*Probe: What are the most common signs and symptoms described by your patients?*)

4. In your experience, what type of people are more at risk of getting diabetes?

Theme 2: Health-seeking behaviour (Probe: for factors influencing HSB)

5. Where else do you think people with diabetes seek care before they come to the health care facility? What makes them go there?

6. What do you think about people in this community and the use of traditional healers' services for diseases like diabetes? what type of treatment do these healers normally provide? *Probe: How does the treatment provided by these traditional healers affect the nature of care that you provide to your patients?*

7. Based on your experience do traditional healers have any influence over the patient's decision to seek care at a health facility? If yes, what is the reason?

8. Overall, what would you say are the major influencing factors in the patient's decision to seek care at the health care facility? (*Probe: After initiating treatment at the diabetes clinic, do some patients continue to utilise the services of traditional healers? If yes, how can you explain this?*)

Theme 3: Demographic, socio-cultural and economic factors in health-seeking behaviour)

Let's look at the decision-making process at the household level:

9. What are the barriers for people with diabetes in seeking care at your health care facility? (*Probe: finance, age, marital status, gender, education if not mentioned; If so, how?*)

10. In your opinion, what do you think are the major constraints that most people with diabetes face in adhering to their prescribed treatment programmes? (*Probe: for adherence to drug prescription and diet? Probe: for financial issues.*)

Theme 4: Geographic and health delivery system factors (Probe for push and pull factors for utilisation of diabetes services)

11. Some patients complain of delayed diagnosis simply because the doctors attending them could not diagnose their problem in their initial visits. Based on your experience, would you say that most doctors and nurses are conversant enough in diagnosing most people with diabetes at the health care facility? If no, what is the reason?

12. On average how long does a patient have to wait to see a doctor/diabetes specialist in this clinic? (*Probe: What can you say about this in relation to diabetes services utilisation?*)

13. What problems do you think most of your patients have in managing their disease? (*Probe: what are the major problems patients have in managing their disease?*)

14 Please describe the availability of diabetes medications and related services in this clinic. (*Probe: Are there times when the health facility runs out of diabetes medicines?*)

15. How would you describe the availability of diabetes equipment at this clinic?

16. How would you describe the patients' attendance at this clinic? (*Probe Q: How would you describe the patients' overall adherence to their prescribed treatment programmes?*)

17. What are the existing opportunities outside the biomedical health system which can be used to improve early health-seeking behaviour for diabetes treatment? (*Probe: What are the weaknesses in the existing health care system, which are barriers for accessing early diagnosis and treatment of diabetes?*)

Theme 5: Care and support from caregivers and/or social networks (Probe for care and support from family members and friends)

18. What necessary support do you think your patients get from their family members and/or friends in taking care of their disease? **Who in your experience have been more supportive?** (*Probe: What is the nature of support these caregivers and/or social networks have been providing?*)

19. Based on your experience, what appear to be the most important problems experienced by patients in the course of undergoing a diabetes treatment programme?

20. What are the noticeable differences in patients' adherence to their diabetes treatment programme that can be attributed to the nature of family members' and/or caregivers' support? (*Probe: How can this be addressed?*)

21. In your opinion, what do you think health care providers can do to help people with diabetes adhere better to their treatment programme? (*Probe: What can be done to help people with diabetes to attend the diabetes clinic earlier? What do you think needs to be done in empowering people with diabetes to manage their disease condition? What do you think needs to be done to empower the caregivers in taking care of people with diabetes better?*)

Conclusion: Are there any questions you would like to ask me? (*Respond as needed*)

THANK YOU FOR YOUR COOPERATION

Appendix 4.4: FGD interview guide for people with type 2 diabetes mellitus

Good morning/afternoon. Let me start by thanking you for taking your time to come to talk to us about diabetes. As I explained in my Contact Form my name is Lucy Nguma and I am in the process of carrying out a study on “Health-seeking behaviour among adults with type 2 diabetes in Dar es Salaam” as part of my PhD requirements. My colleague ‘Z’ will be taking notes on our discussions. The purpose of the study is to explore the socio-cultural perceptions, beliefs and other factors that may be influencing health-seeking behaviours for diabetes care and treatment with the goal of improving services related to this disease. In the process of collecting information that will enable us to take such action, we are talking to people with diabetes and patient caregivers, health care providers and selected community members. You have purposively been selected on this subject. As such, we would like you to take this task seriously, by talking openly and candidly to the best of your knowledge about this problem. There are no right or wrong answers. The information collected here is going to be confidential and is going to be used for only the intended purpose of improving diabetes services in Tanzania. In order to keep a more accurate record of our discussions, we are proposing that we supplement the note taking by using a tape recorder. However, before we do so, we would like to ask if there are any of you who would mind if we use a tape recorder. (Check to see if there are some objections. If there are none...proceed. I can see there is no objection to our using a tape recorder, so I thank you once again for your cooperation.

Theme 1: Socio-psychological factors (Probe for motivation, knowledge, understanding, perceptions and attitudes (stigma related issues) myths and misconceptions about diabetes and health services utilisation

Let us now start by looking at the existing levels of knowledge, understanding and perceptions about type 2 diabetes mellitus in this community:

1. Tell me, how many of you knew about type 2 diabetes before you were told that you have type 2 diabetes? (*Get a rough figure and proceed*) (**Probe: For those of you who had heard about this disease before, what were your sources of information?**)
2. What do you think causes type 2 diabetes? (**Probe: Can one get type 2 diabetes from a person with diabetes? Why?**) (**Probe: What are the major signs and symptoms of this disease?**)
3. How is type 2 diabetes treated? How is it preventable? How is it cured?
4. How big is the problem type 2 diabetes in this community? What is the reason? (**Probe: What types of people are at risk of getting diabetes and what are the reasons?**)
5. How do people in this community associate diabetes with other diseases? (**Probe: How does people in this community relate to people who have diabetes? What are the reasons?**)

Theme 2: Health-seeking behaviour (Probe for factors influencing health-seeking behaviour) (HSB)

Let us now reflect on the process of health-seeking behaviour for care and treatment of type 2 diabetes:

6. Tell me whether people in your community use traditional healers' services for diseases like diabetes? (***Probe: what would you say are the major factors that influence them to do so? What kinds of services are available there?***)
7. What would you say are the major factors that influence peoples' decisions to seek care at the health care facility for diabetes treatment? (***Probe: Where do people normally seek care after initiating treatment at the health care facility? what are the main reasons for that?***)

Theme 3: Demographic, socio-cultural and economic factors in health -seeking behaviour

Let's look at the decision making process at the household level:

8. In your opinion, what are the major constraints that most people with diabetes face in attending a diabetes clinic? (***Probe: To what extent does the cost of treatment affect health seeking, and adherence to care and treatment?***)
9. How does the cost of care and treatment for diabetes affect the welfare of your family? If so, how and what do families do to address such problems?

Theme 4: Geographic and Health delivery system factors (Probe for push and pull factors for utilisation of diabetes care services)

10. How does the distance from their residence to the health care facility affect patients' decisions to seek care and adherence to the recommended treatment programme?
11. How long, on average, do you have to wait at the clinic before seeing the doctor/diabetes specialist? (***Probe: what can you say about it?***)
12. How do you feel with the answers and explanations from the health workers on all questions and issues related to your diabetes care and treatment? (***Probe: How would you describe the health care workers at the clinic and your overall relationship with them?***)

Theme 5: Care and support from caregivers and/or social network (Probe for care and support from family members and/or friends)

13. What would you say are the major challenges you have been facing in taking care of your disease? (***Probe: What support have you been getting from your family members and/or friends in addressing these challenges?***)
14. In your opinion what do you think needs to be done to empower people with diabetes to adhere better to their diabetes treatment programme?

15. In your opinion, what do you think needs to be done to empower caregivers to help people with diabetes to adhere better to their medical regimen?

Conclusion: Are there any questions you would like to ask me? (*Respond as needed*)

THANK YOU FOR YOUR COOPERATION

Appendix 4.5: Focus group (FGD) interview guide for community members

Good morning/afternoon. Let me start by thanking you for taking your time to come to talk to us about diabetes. As I explained in my Contact Form my name is Lucy Nguma and I am in the process of carrying out a study on “Health-seeking and health related behaviour for type 2 diabetes among adults in Dar es Salaam” as part of my PhD requirements. My colleague ‘Z’ will be taking notes on our discussions here today. The purpose of the study is to explore the socio-cultural perceptions, beliefs and other factors that may be influencing health-seeking behaviours for diabetes care and treatment with the goal of improving services related to this disease. In the process of collecting information for this study we are talking to people with diabetes and their caregivers, health care providers, and key national health officials. You have purposively been selected on this subject. We would like you to take this task seriously, by talking openly and candidly to the best of your knowledge about this problem. There are no right or wrong answers. The information collected here is going to be confidential and is going to be used for only the intended purpose of improving diabetes services in Tanzania. In order to keep a more accurate record of our discussions, we are proposing that we supplement the notes taking by using a tape recorder. However, before we do so, we would like to ask if there are any of you who would mind if we use a tape recorder. (Check to see if there are some objections. If there are none...proceed. I can see there is no objection to our using a tape recorder, so I thank you once gain for your cooperation.

Theme 1: Socio-psychological factors (Probe: for motivation, knowledge, understanding, perceptions and attitudes (stigma related issues) myths and misconceptions about diabetes and health services utilisation

Let us start by looking at the existing levels of knowledge, understanding and perceptions about type 2 diabetes mellitus in this community:

1. Tell me, how many of you have heard about type 2 diabetes before? (*Get a rough figure and proceed*) (*Probe: For those of you who had heard about this disease before, what were your sources of information?*)
2. What do you think causes type 2 diabetes? (*Probe: Can one get type 2 diabetes from a person with diabetes? If yes, how? If no, why? (Probe: What are the major signs and symptoms of diabetes?)*)
3. How is type 2 diabetes treated? How is it preventable? How is it cured?
4. How big is the problem type 2 diabetes in this community? What is the reason? (*Probe: What types of people are at risk of getting diabetes? and what are the reasons?*)
5. Do you think people in this community associate diabetes with other diseases?
6. If yes which diseases and what is the reason for that? (*Probe: Do you think people in*

this community relate differently to people with diabetes? If yes, how and for what reasons?

Theme 2: Health-seeking behaviour (Probe for factors influencing health-seeking behaviour) (HSB)

Let us now reflect on the process of health-seeking behaviour for care and treatment of type 2 diabetes:

7. Tell me whether people in your community use traditional healers' services for diseases like diabetes? (***Probe: what are the major factors that influence them to seek care from these healers? What kinds of services are available there?***)
8. What would you say are the major factors that influence peoples' decisions to seek care at the health facility for diabetes treatment? (***Probe: Where else do people with diabetes normally seek care after initiating treatment at the health facility? Where do they go and what are the main reasons for that?***)

Theme 3: Demographic, socio-cultural and economic factors in health-seeking behaviour

Let's look at the decision making process at the household level:

9. In your opinion, what are the major constraints that most people with diabetes face in attending a diabetes clinic? (***Probe: To what extent does the cost of treatment affect health seeking, and adherence to diabetes care and treatment programmes?***)
10. How does the cost of care and treatment for diabetes affect the welfare of your family? (***Probe: what do family members do to address such problems?***)

Theme 4: Geographic and Health delivery system factors (Probe for push and pull factors for utilisation of diabetes care services)

11. How does the distance from one's residence to the health care facility affect the patient's decisions to seek care and adherence to a recommended treatment programme?
12. How long, on average, do you think patients have to wait before seeing the doctor/diabetes specialist? (***Probe: What can you say about it?***)

Theme 5: Care and support from caregivers and/or social networks (Probe for care and support from family members and/or friends)

13. In your opinion what would you say are the major challenges that people with diabetes might be facing in taking care of their disease?
14. What do you think needs to be done to empower people with diabetes to adhere better to their treatment programme?

15. In your opinion, what do you think needs to be done to empower family caregivers to help people with diabetes to adhere better to their treatment programme?

Conclusion: Are there any questions you would like to ask me? (*Respond as needed*)

THANK YOU FOR YOUR COOPERATION

Appendix 4.6: Key informant interview guide for key national health officials

Good morning/afternoon. Let me start by thanking you for agreeing to take the time to talk to me about diabetes. As I explained in my Contact Form my name is Lucy Nguma and I am in the process of carrying out a study on “Health- seeking and health related behaviour for type 2 diabetes among adults in Dar es Salaam” as part of my PhD requirements. The purpose of the study is to explore the socio-cultural perceptions, beliefs and other factors that may be influencing health-seeking behaviours for diabetes care and treatment with the goal of improving services related to this disease. In the process of collecting information for this study I am talking to people with diabetes and their caregivers, health care providers and selected community members. You have purposively been selected in this subject. I would like you to take this task seriously, by talking openly and candidly to the best of your knowledge about this problem. The information collected here is going to be confidential and is going to be used for only the intended purpose of improving diabetes services in Tanzania. In order to keep a more accurate record of our discussions, I propose that I supplement my note taking by using a tape recorder. However, before I do so, I would like to ask you if you would mind if I use a tape recorder. (Check to see if there is any objection. If there is none... proceed. I can see there is no objection to me using a tape recorder, so I thank you once again for your cooperation.

Theme 1: Knowledge, understanding and perceptions about diabetes and its magnitude in the community.

1. How would you describe the diabetes situation in Tanzania? (**Probe: for magnitude of the problem; what are the contributing factors**)

Theme 2: Health -seeking behaviour (Probe: for factors influencing health-seeking behaviour (HSB)

2. What would you say are the major influencing factors in most people with diabetes’ decisions to seek care at the health care facility? (**Probe: for the role of the family members and/or social networks in such decisions**)

Theme 3: Demographic and socio-economic factors (probe for economic barriers to health -seeking behaviour)

3. What do you think are the barriers for people with diabetes in seeking care at the health care facility? (**Probe: for finance, gender, age, marital status; if not mentioned; If so how?; probe for waiting time at the clinic**)
4. In your opinion, what are the major constraints that most people with diabetes face in adhering to their prescribed treatment programme? (**Probe: for finance; if not mentioned**)

Theme 4: Health delivery system factors (Probe for push and pull factors for utilisation of diabetes care services)

5. In your experience, would you say most doctors and nurses are conversant enough in diagnosing most diabetic cases at the health facility? If no, what is the reason? What should be done?
6. Patients have reported in their interviews that one of the most important factors influencing their inability to adhere to their treatment programme is lack of availability of affordable oral diabetes drugs and insulin. How can you explain this? What do you think can be done to address this problem?
7. From the interviews the majority of the patients appear to seek care from traditional healers or use herbal treatment. What is explanation for this situation? How do you think the government and health care system should respond to this?
8. Community members in the FGDs have reported that the major problems in seeking care at the biomedical health facility are poor availability of drugs and the relationship between clients and health care workers. How can you explain this? What should be done?
9. The majority of people with diabetes are reported to seek care too late at the health care facility, making their treatment problematic. What in your opinion needs to be done to improve early health seeking for diabetes diagnosis and treatment in this country?

Theme 5: Care and support from caregivers and/or social net works (probe for care and support from family members and/or friends)

10. What would you say are the major challenges most people with diabetes and their caregivers face in coping with diabetes?
11. What more could be done to help and empower people with diabetes and their caregivers to manage and cope with diabetes? (***Probe: if possible diabetes drugs and other services to be provided free of charge***)

Conclusion: Are there any questions you would like to ask me? (***Respond as needed***)

THANK YOU FOR YOUR COOPERATION

Appendix 5: Contact Form

My name is Lucy Nguma and I am currently a PhD student at the University of Otago, New Zealand.

I am carrying out a study on “Health-seeking and health related behaviour for type 2 diabetes among adults with in Dar es Salaam” as part of my PhD.

The purpose of the study is to explore what influences the decisions of patients to seek health care and adhere to treatments for diabetes. We will do so through an interview with yourself which may last about an hour to 90 minutes. The information generated from the study will be used in the development of tools to help improve the delivery of health care services for diabetes in Tanzania.

The information that you share with me will be treated with high confidentiality and will only be used for the purpose of improving diabetes care services in the country. As such, your taking part in this interview will have no effect, good or bad, on any aspect of your health care services that you are receiving now or in the future. Please be assured that you will be free to pull out of the study at any time should you decide to do with no disadvantage to you of any kind.

This form gives permission for Lucy Nguma from the University of Otago Department of Public Health, Wellington School of Medicine, to contact you in the near future to talk to you on various issues related to diabetes.

I _____ have read (or have had read to me) and understand the above explanations and give my permission to be contacted by Lucy Nguma (Researcher).

Participant signature _____ Date _____

Name of the health care staff member _____ Signature _____ Date _____

Student researcher local address in Tanzania

Lucy Nguma
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Dar-es-Salaam
Tanzania
Tel: 255-22-2807903
E-mail: lucynguma@yahoo.co.uk

This project has been reviewed and approved by the University of Otago Human Ethics Committee and Muhimbili University of Health and Allied Sciences Research and Publication Committee

Note: This project involves an open-questioning technique where the precise nature of the questions which will be asked has not been determined in advance, but will depend on the way in which the interview develops. Consequently, although the University of Otago Human Ethics Committee is aware of the general areas to be explored in the interview, the Committee has not been able to review the precise questions to be used

Appendix 6: Information Sheet

Title of the project: Health-seeking and health related behaviour for type 2 diabetes mellitus among adults in an urban community in Tanzania.

Thank you for showing an interest in this study. Please read this information sheet carefully before deciding whether or not to take part. If you decide to take part we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.

What is the aim of the study?

The aim of the study is to explore what influences the decisions of patients to seek health care and adhere to treatments for diabetes. The project is being undertaken as a requirement for a PhD degree in Public Health.

What types of people are we asking to take part?

Adults aged 35 years and above, both males and females, will be chosen from the study community, including: patients diagnosed with diabetes and, where possible, their family caregivers; and community members and health care workers from diabetes clinics. Only people who are willing to take part and able to answer questions and tell their stories will be included.

What will I be asked to do?

Should you agree to take part in this study, you will be asked to take part in a one to one conversation or group conversation. If you agree, I would like to tape-record the conversations to keep an accurate record of our discussions, while I write down some notes and later type up what we discussed into a transcript. I will then send you a copy of the conversation for you to check whether it actually represents our discussions.

What happens if I don't want to take part in this study?

Please be assured that you may decide not to take part at any stage of this study with no effect on your care and without any disadvantage to yourself of any kind.

What will the interview involve?

You will be asked questions about diabetes and diabetes health care in your community. This will include questions about your knowledge of diabetes and its effects, causes, and treatment, and what may help or prevent people with diabetes attending health clinics and using the treatments that are advised by health care staff.

If there are any questions that you feel uncomfortable about answering you are completely free to refuse to answer any particular question(s) and also you may withdraw from the study at any stage without any disadvantage to yourself of any kind.

Can I change my mind and withdraw from the study?

You may withdraw from taking part in the study at any time, with no effect on your care or without any disadvantage to yourself of any kind.

What data or information will be collected and what use will be made of it?

The information gathered for this study will consist of your understanding about diabetes, views, beliefs, feelings and how and why people with diabetes use health care facilities for diabetes care. The information will be used to help improve services for diabetes in Tanzania.

The only people to have access to the unprocessed information collected will be my two supervisors, myself and a research assistant. Some of what you say may be quoted in the reports from the study, but your name or anything that might identify you will not be given. The results of the study will be published and made available locally. Every effort will be made to protect the identity of the people involved in the study.

You are most welcome to request a copy of the results of the study should you wish. The information gathered will be securely stored in such a way that only those mentioned above will be able to gain access to it. At the end of the study any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be kept in secure storage for five years, after which it will be destroyed.

What if I have any questions?

If you have any questions about our study, either now or in the future, please feel free to contact either:

Name and full address of student researcher

Lucy Kinavi Nguma
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This project has been reviewed and approved by the University of Otago Human Ethics Committee and Muhimbili University of Health and Allied Sciences Research and Publication Committee.

Note: This project involves an open-questioning technique where the precise nature of the questions which will be asked has not been determined in advance, but will depend on the way in which the interview develops. Consequently, although the University of Otago Human Ethics Committee is aware of the general areas to be explored in the interview, the Committee has not been able to review the precise questions to be used.

Appendix 7: Key Informants/In-depth Interview Consent Form

I have read (or have had read to me) the information sheet concerning this project and understand the explanation of what it is about. I had an opportunity to ask questions and all my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage from the address provided.

I understand that:

1. My participation in the study is entirely voluntary (my choice);
2. I am free to withdraw from the study at any time without any disadvantage;
3. The data will be destroyed at the conclusion of the study but any unprocessed information on which the results of the study depend will be kept in secure storage for five years, after which it will be destroyed;
4. Any information I provide will be kept confidential to the researcher and her supervisor; and that no material which could identify me will be used in any reports of this study;
5. That no discomfort or risk is associated with my taking part in this study;
6. I understand that no remuneration or compensation will be given in this study;
7. The results of the study may be published and available in the library but every attempt will be made to protect my identity.

I consent to take part in this study.

.....
 (Signature of participant) (Date)

Researcher Name:..... Signature.....
 Date.....

I would like to receive a summary report of the study outcomes: Yes / No (circle one)

This project has been reviewed and approved by the University of Otago Human Ethics Committee and Muhimbili University of Health and Allied Sciences Research and Publication Committee.

Note: This project involves an open-questioning technique where the precise nature of the questions which will be asked has not been determined in advance, but will depend on the way in which the interview develops and that in the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.

Appendix 8: Focus Group Consent Form

I have read (or have had read to me) the information sheet concerning this project and understand the explanation of what it is about. I had an opportunity to ask questions and all my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage from the address provided.

I also understand that:

1. My participation in the study is entirely voluntary (my choice);
2. I am free to withdraw from the study at any time without any disadvantage;
3. The data will be destroyed at the conclusion of the study but any unprocessed information on which the results of the study depend will be kept in secure storage for five years, after which it will be destroyed;
4. Any information I provide will be kept confidential to the researcher and her supervisor; and that no material which could identify me will be used in any reports of this study;
5. I must keep confidential any information that any other participants in the study provide;
6. That no discomfort or risk is associated with my taking part in this study;
7. I understand that no remuneration or compensation will be given in this study;
8. The results of the study may be published and available in the library but every attempt will be made to protect my identity.

I consent to take part in this study.

.....
(Signature of participant)

.....
(Date)

Researcher Name:..... Signature.....
Date.....

I would like to receive a summary report of the study outcomes: Yes / No (circle one)

This project has been reviewed and approved by the University of Otago Human Ethics Committee and Muhimbili University of Health and Allied Sciences Research and Publication Committee.

Note:

This project involves an open-questioning technique where the precise nature of the questions which will be asked has not been determined in advance, but will depend on the way in which the interview develops and that in the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.

Appendix 9: Map 1: Location of Dar es Salaam region showing the three districts under the current Research.

