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**Managing uncertainties  
An ethnography of diabetes  
management in Malawi**

**Misheck Julian Nkhata**

Thesis submitted for the Degree of Doctor of Philosophy

Department of Anthropology

Durham University

## Contents

Abstract.....	iv
List of figures .....	v
Abbreviations and Acronyms .....	vi
Meanings .....	vii
Acknowledgements .....	ix
<b>Chapter 1</b> Introduction and background.....	13
1.1. Mrs Joyce Jenala .....	13
1.2. Background.....	18
1.3. Diabetes research in Malawi .....	22
1.4. Structure of the thesis.....	25
<b>Chapter 2</b> Anthropology of diabetes and uncertainty .....	29
2.1 Management of diabetes.....	30
2.1.1 “Control” of diabetes.....	30
2.1.2 Monitoring and surveillance technologies.....	31
2.1.3 Beyond biomedicine .....	32
2.1.4 “Non-compliance” and diabetes management .....	34
2.2 Uncertainty and chronic diseases .....	37
2.2.1 Meanings of uncertainty.....	39
2.2.2 Uncertainty: pragmatics, productivity and imagined futures .....	40
2.3 Conclusion .....	45
<b>Chapter 3</b> Reflections on methodology.....	47
3.1. Study setting and context.....	49
3.1.1. Queen Elizabeth Central Hospital, Blantyre .....	53
3.1.2. St Joseph’s Mission Hospital, Chiradzulu.....	56
3.2. Negotiating access.....	58
3.3. Research design .....	61
3.4. Participants.....	61
3.4.1 Interviews.....	63
3.4.2 Participant observation.....	65
3.4.3 Documents and media .....	66
3.5. Data management and analysis .....	67
3.6. Ensuring no harm: consent, benefits, and confidentiality .....	68
3.7. ‘Patient’, ‘Doctor’ or ‘Student’: (perceived) roles in the field .....	70

3.8.	Reflections on doing fieldwork at ‘home’ .....	73
3.9.	Conclusion .....	75
<b>Chapter 4</b>	<b>‘Shuga’ and its ‘causes’: ‘lifestyle’, ‘being born with it’ and pollution.....</b>	<b>77</b>
4.1	‘Shuga’ or diabetes: <i>What’s in a name?</i> .....	77
4.2	What is ‘shuga’? Types of diabetes – Constructions of diabetes .....	79
4.3	‘Causes’ of diabetes .....	83
4.3.1	Unknown causes .....	84
4.3.2	‘Diet’ and ‘lifestyle’ .....	85
4.3.3	“Chemicals” and “toxins” in food, water and medicines .....	89
4.3.4	Born with it, “heredity” or “genes” .....	93
4.3.5	“Weak” or “disabled” pancreas, and ageing.....	95
4.4	Conclusion .....	98
<b>Chapter 5</b>	<b>Becoming “<i>munthu wa shuga</i>”: Certainties and uncertainties .....</b>	<b>101</b>
5.1	Knowing diabetes through diagnosis .....	105
5.2	Diabetes education as “ <i>reminding one another</i> ” .....	111
5.3	Uncertainties in diabetes education.....	114
5.3.1	‘Shuga’ is diet, diet is ‘medicine’, medicine is ‘life’ .....	115
5.3.2	Uncertain target .....	119
5.4	Contradictions and uncertainties.....	122
5.5	The immorality of “non-compliance”/ “experimentation” .....	125
5.6	Conclusion: Uncertainties and subjectivity in diabetes.....	128
<b>Chapter 6</b>	<b>“Experimenting” as diabetes management.....</b>	<b>132</b>
6.1	<i>‘Thupi limanena’ The body speaks</i> .....	133
6.2	<i>“Only when something is wrong” – improvising the glucometer</i> .....	138
6.3	Trying as “experimenting”: <i>‘being your doctor.’</i> .....	146
6.4	“Non-compliance” is neither resistance nor irresponsibility .....	150
6.5	Conclusion: uncertainty and “experimentation” .....	156
<b>Chapter 7</b>	<b>Complex therapeutic landscapes of diabetes management.....</b>	<b>159</b>
7.1	Herbal medicines in diabetes management.....	160
7.1.1	The proliferation, ‘professionalisation’ and appeal of herbal medicines..	160
7.1.2	<i>‘Cleansing the body’</i> .....	169
7.1.3	Use of herbal medicines in practice.....	175
7.2	Religion and managing diabetes.....	183
7.2.1	Religion and healing in Malawi .....	183

7.2.2	Prayer, faith, and medicines .....	186
7.2.3	God's "grace" and "miracles" .....	191
7.3	Conclusion .....	193
7.3.1	'Purification' of bodies .....	193
<b>Chapter 8</b>	<b>Social relations and "trying harder" in diabetes management .....</b>	<b>196</b>
8.1	Relations with family members and friends .....	198
8.2	Relations among patients .....	201
8.3	Patient relations with health care workers .....	207
8.4	What prevents 'trying' .....	209
8.5	When trying 'fails', keeping on trying, try harder .....	213
8.6	Conclusion .....	218
8.6.1	Trying and "trying harder" in complex therapeutic landscapes .....	219
<b>Chapter 9</b>	<b>Managing is about/because of uncertainties .....</b>	<b>221</b>
9.1	Uncertainties of diabetes and anthropology of uncertainties .....	223
9.2	Managing uncertainties, managing diabetes .....	226
9.3	Re-active patients of diabetes management .....	230
References	.....	234
Appendices	.....	244
Information Sheet	.....	244
Consent Form	.....	246

## Abstract

Diabetes is a chronic condition characterised by raised levels of blood glucose in the body due to its inability to produce any or enough, or effectively use insulin. It is a growing problem worldwide, with over 425 million people living with it, 79% of whom live in low and middle-income countries. This thesis shows how patients experience, live with, and manage diabetes as a form of uncertainty. It is based on twelve months of ethnographic fieldwork using interviews, participant observation, and informal conversations in patients' homes, herbal and diabetes clinics at a rural mission hospital and a referral teaching hospital in the Southern Region of Malawi.

Few studies have explored diabetes and its management using qualitative or ethnographic methods in Malawi, and most African countries. Mostly, studies have quantitatively assessed knowledge, 'experiences' of living with diabetes, 'quality' of care and highlighted barriers and challenges of diabetes management among health care workers and patients. Anthropological studies of diabetes, mostly from Western countries, characterise its management as "tinkering" – highlighting changes and adjustments in practices that are meant to suit patients' bodies and circumstances, and 'bio-tactics' – patients' idiosyncratic strategic negotiation, implementation and recalibration of self-management advice to make it relevant in social lives and "diabetes bodies liveable". Studies on uncertainty reveal the pragmatics of managing it, and its productiveness in terms of envisioned futures, hope, and other uncertainties.

This thesis shows how people responded to the uncertainties of diabetes and its management within complex therapeutic landscapes in three ways: "experimenting", improvising and "trying harder" within unique social relations. These modes of responses were mutually constitutive, overlapping and informed each other. The thesis argues that a distinct kind of "re-active patient" is being constituted in these circumstances. The "re-active patient" maintains aspects of "active patienthood" which requires medical literacy and taking care of him/herself, but also engages in a different repertoire of responses including "experimentation" and improvisation using herbal medicines, religion, and forms of reading their bodies.

## List of figures

Figure 1 Map of Malawi .....	53
Figure 2 Diabetes Education Session, Queens Hospital.....	55
Figure 3 Waiting room (left) and Table during diabetes clinic .....	57
Figure 4 Herbal Medicine Sellers .....	162
Figure 5 Poster, Signpost and Newspaper Advert on healing and deliverance.....	184

## Abbreviations and Acronyms

CHAM	Christian Health Association of Malawi
EHP	Essential Health Package
FBS	Fasting Blood Sugar (also known as Fasting Blood Glucose (FBG))
HbA1c	Glycosylated haemoglobin
IDF	International Diabetes Federation
NCD	Non-communicable diseases
Queens	Queen Elizabeth Central Hospital
RBS	Random Blood Sugar
WHO	World Health Organisation

## Meanings

**Glycosylated haemoglobin:** Expressed as a percentage of the normal haemoglobin (standardized range 4–6.1%; 20–44 mmol/mol), glycosylated haemoglobin (HbA1c) provides an index of the average blood glucose concentration over the life of the haemoglobin molecule (approximately 6 weeks). Both type 1 and 2 diabetes patients are supposed to aim for HbA1c reading below 7.0% (53 mmol/mol) to reduce the risk of long-term microvascular complications (Gale and Anderson 2012).

**Hyperglycaemia** A raised level of glucose in the blood which occurs when the body does not have enough insulin or cannot use the insulin to turn glucose into energy [IDF – Glossary, <https://www.idf.org/aboutdiabetes/what-is-diabetes/glossary.html>].

**Hypoglycaemia** A lowered level of glucose in the blood which occurs when a person with diabetes has injected too much insulin, eaten too little food, or has exercised without extra food. A person with hypoglycaemia may feel nervous, shaky, weak, or sweaty, and have a headache, blurred vision, and hunger [IDF – Glossary, <https://www.idf.org/aboutdiabetes/what-is-diabetes/glossary.html>].

***Mgaiwa*** *Mgaiwa* is made from whole maize seeds milled without dehulling and degerming. *Mgaiwa* is considered of lower quality. During diabetes clinics, patients are told to eat this type of *Nsima*.

***Nsima*** There are three most common types of *Nsima*. White *Nsima* (*Nsima yoyera*), *Mgaiwa*, and ‘*Gramil*’. Most people eat *Nsima yoyera* which is made from dehulled, degermed and fermented maize seeds. ‘*Gramil*’ was the name of a company

that used to manufacture maize flour. The flour is made by dehulling and degerming maize seeds.

Type 1 diabetes

People with type 1 diabetes cannot produce insulin. The disease can affect people of any age, but onset usually occurs in children or young adults.

Type 2 diabetes

People with type 2 diabetes cannot use insulin to turn glucose into energy. Type 2 diabetes mellitus is much more common than type 1 and occurs mainly in adults, although it is now also increasingly found in children and young adults.

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*For*  
*Rose*  
*&*  
*Misheck Harry*



# Chapter 1

## Introduction and background

### 1.1. Mrs Joyce Jenala

I start this thesis by introducing Mrs Joyce Jenala (pseudonym)<sup>1</sup>, a 37-year-old type 2 diabetes patient whom I first met at the Diabetes Clinic at Queen Elizabeth Central Hospital (locally known as Queens Hospital) in November 2016. She was diagnosed with diabetes in 2009. Her story highlights the main themes of this thesis: uncertainties that patients face as they live with and manage diabetes; and how these are managed within and by maintaining particular social relations, improvisation, “experimentation” and “trying harder”.

Mrs Jenala is a former executive committee member of the Diabetes Association of Malawi (DAM). After leaving her position in the committee, she started volunteering at the diabetes clinic every Tuesday. Her roles included the following: sorting and distributing ‘results’<sup>2</sup> to patients; ensuring patients in the waiting room are on a queue and wait their turn for consultation; triaging – ensuring patients with extremely low or high sugar level are urgently seen by doctors; distributing syringes from DAM or directing patients where to get them; providing diabetes education, and motivating patients by sharing her experiences.

My first conversation about diabetes with Mrs Jenala was conducted in Room 1, the waiting room for patients who were supposed to attend consultations with medical doctors. We started by talking about how she knew she had diabetes. Like many others, she did not suspect she had diabetes until she collapsed in her bathroom and was taken to one of the private hospitals run by the Medical Aid Society of Malawi (MASM). At the hospital, she tested positive for malaria, and was started on treatment. However, when she regained consciousness, she started taking plenty of water and urinating often, which prompted one of the nurses to ask if she had diabetes. The nurse told her she was showing

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<sup>1</sup> I use pseudonyms for all informants in the study.

<sup>2</sup> During the diabetes clinic at Queens Hospital, results from measuring Fasting Blood Sugar (FBS) are attached with Biochemistry Request and Report Forms and given to patients. Patients present these to doctors during consultation.

signs and symptoms of the disease. The nurse also asked her if she had children; Mrs Jenala told her that she did. She also told the nurse that she had given birth by caesarean section because, at five kilograms, the baby was too big for a 'natural' birth. The nurse told her that it was probable that she had had "*diabetes that one gets when they are pregnant*" [gestational diabetes<sup>3</sup>]; that it may not have been diagnosed as that was not part of the standard tests for pregnant women then.

Upon learning about this, one of the doctors ordered that a glucose test be administered. Mrs Jenala said, "*I got tested and my sugar level was 600 [mg/dL]<sup>4</sup>, and after some hours it went down to 500 [mg/dL]...They told me to come again after a week. Then I was [at] 420 [mg/dL]. I was told to come again after three weeks*" [Interview, 08112016]. When she went back after three weeks, she was referred to the diabetes clinic at Queens Hospital. However, within those three weeks, she had had her prescription glasses changed four times because according to Mrs Jenala, "*when shuga<sup>5</sup> goes up, it goes to the eyes*" [Interview, 08112016]. At the diabetes clinic, she was counselled on what she was supposed to eat. According to Mrs Jenala, attending the clinic allowed her to "*see the impairments that come because of diabetes*", and this taught her to be more 'careful'.

After diagnosis, Mrs Jenala got a prescription for metformin<sup>6</sup>. However, in 2013, four years after her diabetes diagnosis, her medication was changed from metformin to insulin. When I spoke to her in September 2017, she was injecting 20 units of Lente insulin in the morning and 15 units in the evening. Doctors had also prescribed metformin, which she was getting from the pharmacy but was not taking. This is what health care workers refer to as "non-compliance" – not following doctors' advice and instructions, and according to biomedicine, a significant problem in diabetes management. During my visit to her home in September 2017, she showed me several packets of metformin tablets that she had received from Queens Hospital. She had stopped taking metformin because, according to her, she would get diarrhoea every time she took it. Mrs Jenala also engaged in other acts of "non-compliance". There were many

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<sup>3</sup> According to the American Diabetes Association (2017), gestational diabetes is diagnosed in the second or third trimester of pregnancy where the patient had neither pre-existing type 1 nor type 2 diabetes. For some women, gestational diabetes will end at delivery while for others it becomes type 2 diabetes.

<sup>4</sup> Within biomedicine, a normal sugar level ranges from 70mg/dL to 126mg/dL.

<sup>5</sup> *Shuga* means both diabetes and sugar in Chichewa, the language spoken in most parts of Malawi.

<sup>6</sup> Metformin is one of the two oral antidiabetic medication that are prescribed in hospitals in Malawi. The other medication is glibenclamide.

times that she missed insulin doses. There were also times that she did not eat when and what she was supposed to. For instance, on my final visit to her home, I arrived at 10:00 am, and by then, she had neither had breakfast nor had she injected insulin.

Mrs Jenala had been engaging in acts of “non-compliance” for some time. In 2013, she stopped taking her diabetes medicine altogether. Mrs Jenala was a member of a Pentecostal Church called Living Waters International; however, she also attended church services by pastors and ‘prophets’. It was at one of those churches where she was told that the Lord had cured her after the pastor had prayed for her. She said: *“Preachers and evangelists deceived me. ...They did not tell me to stop taking medicine, but I felt it was a way of professing that I had greater faith”* [Interview, 16092017]. When she got home after the prayers, she threw her diabetes medicine in a bin. The following day, she tested her sugar level, and it was 490mg/dL. Even though she could feel that her ‘shuga’ had gone up, she still did not take diabetes medication. She said, *“I was eating like everyone else, but I kept telling myself not to think about the fact that I had shuga...I could feel in my body that I was not all right”* [Interview, 16092017]. Despite continuing to experience symptoms, she still believed she had been ‘cured’ of diabetes. One day, she collapsed while shopping in Blantyre City. A passer-by took her to Queens Hospital, the nearest public hospital. According to Mrs Jenala, she was taken to Queens Hospital because she was wearing a ‘diabetes bracelet’<sup>7</sup>.

When she regained consciousness, she told the health care workers who were treating her that she had diabetes and had stopped taking medicine. Among the health care workers was Dr Loveness Ndalama, a consultant and lead clinician in the diabetes clinic at Queens Hospital. Dr Ndalama suggested that she should be one of the educators to discourage other patients from stopping taking medicine. According to Mrs Jenala, Dr Ndalama said, *“based on your experience, you could be one of the educators to talk about these things when doing health talks. You should also tackle these things that despite the faith, God should work through the medicine”* [Interview, 16092017]. That was how she started volunteering at the diabetes clinic.

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<sup>7</sup> These are blue wristbands made by the International Diabetes Foundation to raise diabetes awareness.

Apart from using hospital medicine, Mrs Jenala was also using herbal medicines for managing diabetes. She had ‘tried’ several locally made herbal medicines over the years. However, she said she was uncertain of their efficacy as her sugar level would go up and down during the time that she used them. She was concerned that claims that herbal medicines “cure” diabetes would lead some patients to stop taking their medicine. She was also concerned that herbal medicine might damage internal organs, a theme that I heard several times from health care providers like Dr Ndalama. Therefore, as a means of balancing between the potentially harmful effects of the herbal medicines and their perceived efficacy, Mrs Jenala said, “*occasionally I can take, for example, Chinese tea bags to detoxify the body. However, it is not always [that I do this]*” [Interview, 16092017].

Mrs Jenala was one of only ten participants in this study who was using a glucometer, a diabetes self-monitoring device. Patients that are on insulin are advised to monitor blood glucose level several times a day, before meals and before going to bed (National Institute for Health and Care Excellence 2015). Instead of testing and monitoring her sugar level every day, Mrs Jenala had improvised how she used her glucometer: only testing when she noticed that there was a “problem”. Like other patients that had glucometers, she was using it sparingly because she could not afford to buy testing strips. Because her glucometer could store several readings from previous measurements, Mrs Jenala used to show these to her doctors during clinic appointments. She once said: “*These are glucometer readings that I recorded for the doctor. When I have an appointment, I record how I have been for the preceding three months*” [Interview, 16092017]. None of the other participants who had glucometers was doing this.

At the beginning of fieldwork, it was surprising to me that Mrs Jenala, a volunteer who also provided diabetes education for other patients, was also engaging in “non-compliance”. It was also surprising considering that she had said seeing patients with complications had made her to be ‘careful’. Over the course of fieldwork, I learnt of other patients, including diabetes educators and health care workers, who were also engaging in “non-compliance” for multiple reasons. Her story, and those of other patients and health care workers I spoke to, highlight the complex “therapeutic landscapes” (Leach, et al. 2008) in which patients manage diabetes in Malawi, of which uncertainty is an important aspect. As a widow who did not have formal employment, and engaged in small-scale businesses like selling glucometers, testing strips, and other things she could

find, Mrs Jenala lived quite a precarious life. Her experience of diabetes is enmeshed in her social life and the stress that it brings. Like those of others, her story of the management of diabetes included other daily personal struggles: finances, conflicts with siblings and parents, and the uncertainties of diabetes itself. Her limited resources meant that she struggled in supporting her two children, which, she said, often stressed her. On one occasion, she said she was admitted to a hospital because her '*shuga*' was very high because of stress from a business opportunity that resulted in a loss of money. At another time, she said her raised sugar levels were because of stress resulting from conflicts with her siblings. Other uncertainties that she experienced were pertaining to diabetes itself. She experienced diabetes as a daily, ongoing uncertainty: one day, her sugar level would go up, and on another day, it would go down. She did not know when, and sometimes why, her '*shuga*' went up or down.

This thesis is about how people deal with and manage uncertainty, using diabetes and its management by patients and health care workers as an entry point. I explore what Jenkins, et al. (2005a:247) described as "uncertainty of situated actors faced with a particular adversity". The actors are patients, their 'guardians', and health care providers. The particular adversity that these actors faced is diabetes and its symptoms. I explore three different kinds of uncertainties: those that emerge in the context characterised by weak and inadequate health systems, poverty, and infectious diseases, within which patients are situated and manage disease; uncertainties around perceptions and experience of diabetes as a disease; and uncertainties that emerge from practices of managing it.

My argument is that diabetes management is about managing uncertainties through "experimentation" to see what work or does not, improvisation and "trying harder" within particular social relations. I argue that "experimenting" is made possible and necessary by the uncertainties that surround diabetes, how it is perceived and the expectations of health care workers on how diabetes patients ought to be. Diabetes, its symptoms, and management are experienced *within* and *with* patient bodies, and sometimes alongside other diseases and illnesses. Health care workers must determine the amount of medicine that a patient must take. Patients must determine whether eating certain foods will or will not cause their '*shuga*' to go up. The outcome of these practices is a "Re-active patient" who is supposed to be medically 'literate' responsible, and

employs a repertoire of practices within and beyond biomedicine and uses the body as an 'experimenting' site, and symptoms as indicators of success or failure.

That chronic diseases raise uncertainty and disruption in patients' lives has been shown in several studies (Mishel 1999; Royer 2000). Uncertainty is also viewed as a challenge in the management of chronic diseases. However, exploring how people (patients, health care workers, caregivers) manage these uncertainties, and hence disease, is significant as it raises questions as to what practices are implemented, how they are implemented and to what ends. In this ethnography, the focus is on how "experimenting" and improvisation are conducted as part of managing uncertainties inherent in diabetes and its management, what is involved in experimenting, and why, despite being explicitly prohibited by health care workers, patients still "experiment". This reveals what patients and health care workers are striving for as part of diabetes management, and with what outcomes.

## 1.2. Background

Diabetes is a chronic condition that occurs when the level of glucose in the blood is raised because the body cannot produce any or enough of the hormone insulin or use insulin effectively (International Diabetes Federation 2017). The pancreas produces insulin which transports glucose from the bloodstream into body cells. In the cells, glucose is converted to energy. Raised levels of glucose, also known as hyperglycaemia, results from lack of insulin (pancreas not producing enough of it) or inability of cells to respond to or use it effectively (International Diabetes Federation 2017). Hyperglycaemia is said to result in damage to body organs (heart, blood vessels, eyes, kidneys, and nerves) if left unchecked over time, leading to disabling and life-threatening complications. On the other hand, hypoglycaemia refers to a lowered level of blood glucose. For someone who has diabetes, hypoglycaemia is a result of injecting too much insulin, eating too little food, or having exercised without extra food (International Diabetes Federation 2017).

According to the International Diabetes Federation (IDF), diabetes is diagnosed by observing raised levels of blood glucose (International Diabetes Federation 2017). The criteria for diagnosing diabetes is a Fasting Plasma Glucose (also called Fasting Blood Glucose (FBG) or Fasting Blood Sugar (FBS)) which is equal to or above 126 mg/dL (7.0

mmol/L) (American Diabetes Association 2017; International Diabetes Federation 2017). Fasting is defined as “no caloric intake for at least 8 [hours]” (American Diabetes Association 2017S15). Alternatively, diabetes can be diagnosed if one has a two-hour plasma glucose  $\geq 11.1$  mmol/L (200 mg/dL) following a 75g oral glucose load.

There are three types of diabetes: type 1, type 2, and gestational diabetes. When describing Mrs Jenala’s experiences, I noted that gestational diabetes might occur in the second or third trimester among pregnant women. While a distinction between type 1 and type 2 diabetes is necessary for therapy, the American Diabetes Association (2017) has noted that, for some patients, it may not be possible to determine the type of diabetes at diagnosis; other tests may be required to make that determination. Alternatively, the type of diabetes may become evident over time. Type 1 diabetes is a result of absolute insulin deficiency (Holt and Kumar 2013), caused by the destruction of insulin-secreting beta cells in the pancreas resulting in little or no insulin production by itself. Symptoms of type 1 diabetes include abnormal thirst and dry mouth, frequent urination, lack of energy/fatigue, constant hunger, sudden weight loss, and blurred vision (International Diabetes Federation 2017). Type 2 diabetes, the most common type, is a condition whereby the body becomes resistant to insulin (inability of the body to respond adequately to insulin) or does not produce enough of it. Type 2 diabetes patients have relative (rather than absolute) insulin deficiency and have peripheral insulin resistance<sup>8</sup> (American Diabetes Association 2017). Symptoms of type 2 diabetes include excessive thirst and dry mouth, frequent and abundant urination, lack of energy or tiredness, tingling or numbness in hands and feet, recurrent fungal infections, slow healing wounds and blurred vision (International Diabetes Federation 2017). As the onset of type 2 diabetes is gradual and without acute metabolic disturbance as in type 1, it is difficult to determine the exact time of its beginning.

According to the International Diabetes Federation (2017), appropriate management of diabetes involves prevention or delay in the emergence of complications. Prevention and management of diabetes can involve promotion of ‘healthy’ lifestyles, medication for blood glucose control, examination and management of complications and regular blood

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<sup>8</sup> Insulin resistance occurs when cells in muscles, fat, and liver do not respond well to insulin and cannot easily take up glucose from blood (<https://www.niddk.nih.gov/health-information/diabetes/overview/what-is-diabetes/prediabetes-insulin-resistance>).

glucose monitoring (World Health Organisation 2016b). 'Healthy' lifestyle includes the adoption of a particular diet, increased physical activity, and maintenance of 'healthy' body weight. Type 1 diabetes patients are supposed to adopt a 'healthy' lifestyle alongside daily insulin injection to keep glucose levels within the proper range since they cannot produce (enough) insulin. For type 2 diabetes patients, a 'healthy' lifestyle may be enough to control blood glucose levels. However, if sugar levels are not 'adequately controlled', type 2 diabetes patients may be prescribed oral antidiabetic medication to deal with raised glucose levels (hyperglycaemia). Insulin may be prescribed if the patient continues to present with raised glucose levels.

Diabetes is a growing problem in low- and middle-income countries. According to the IDF, of the 425 million people who were living with diabetes worldwide in 2017 (a prevalence rate of 8.5%), 79% were in low and middle-income countries (International Diabetes Federation 2017). In 2016, the World Health Organisation (WHO) reported that 25 million people were living with diabetes in Africa, a prevalence rate of 7.1% (World Health Organisation 2016b). Diabetes prevalence ranges from 0.8% in Benin to 24.6% in Mauritius (International Diabetes Federation 2017). In Malawi, studies have reported varying prevalence rates for diabetes. A cross-sectional survey conducted in 2009 among a nationally representative sample of 3056 adults aged 25 – 64 years reported a prevalence of 5.6%<sup>9</sup> (6.5% among men and 4.7% among women) (Msyamboza, et al. 2011). A recent population-based survey in rural and urban Malawi among adults aged above 18 years reported a diabetes prevalence of 2.4% (Price, et al. 2018). The difference between the prevalence reported by Msyamboza and others (2014), and that by Price and others (2018) is remarkable considering that both studies used "identical definitions" of diabetes (FBG of at least 7.0 mmol/L or self-report of a previous diagnosis) and no population-level interventions on diabetes have taken place in Malawi in the period preceding both studies. Price, et al. (2018) suggested that the difference reflects the large sample size (N=28,891) and use of laboratory testing that was used in their study rather

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<sup>9</sup> Msyamboza and others (2014) suggest that the prevalence of diabetes in Malawi could be higher considering that their study did not use oral glucose tolerance tests, which are more accurate compared to fasting blood glucose tests, and that most of the participants were not tested for sugar level.

than point-of-care testing used by Msyamboza and others (2014)<sup>10</sup>. None of these studies has reported the prevalence of type 1 and type 2 diabetes separately.

Using the rate reported by Price and others (2.4%), the prevalence of diabetes in Malawi is lower than the reported prevalence in Africa (7.1%) (World Health Organisation 2016b). Malawi is also among 19 countries in Africa with a reported prevalence below 2.5% (International Diabetes Federation 2017). However, diabetes is still a significant challenge as its prevalence has been growing over the years (Gowshall and Taylor-Robinson 2018). In 2016, the WHO reported that 1% of total deaths in Malawi were attributed to diabetes (World Health Organisation 2016a). The International Diabetes Federation (2017) estimated that in 2017, there were 9,819 diabetes-related deaths in Malawi. Moreover, a high proportion of people that have diabetes in Malawi remain undiagnosed. According to Price and others (2018), about 41% of people that had diabetes were undiagnosed. The International Diabetes Federation (2017) reported a higher proportion, estimating that the number of people with undiagnosed diabetes in Malawi was 149,400: 76% of diabetes cases. This high proportion of undiagnosed diabetes suggests that the prevalence of the disease could be higher. It also means that many people are living with diabetes without knowing it, and only get to be diagnosed when they seek medical care for other ailments.

Of late, governments and international bodies, including the World Health Organization (WHO), have recognised the importance of diabetes (and other non-communicable diseases) as significant factors contributing to mortality globally. In Malawi, non-communicable diseases were included in the Essential Health Package (EHP)<sup>11</sup> in 2011. In the same year, the Malawi Ministry of Health (MoH) established the Non-communicable Diseases and Mental Health Unit (Ministry of Health 2018). Its objective

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<sup>10</sup> It is also important to note that even though Price et al (2018) suggest that they used an “identical definitions” to those used by Msyamboza et al. (2014), there was a slight variation. Price et al. (2018:220) defined diabetes as “fasting blood glucose >7.0 mmol/L [126mg/dL] or previous diagnosis” while Msyamboza et al. (2014:3) defined diabetes as “fasting capillary whole blood glucose level >6.1 mmol/L (>110 mg/dl) or currently on medication for diabetes mellitus (documented in the health booklet)”. Further to this, the sample for Price et al. (2018) was adults aged above 18 years while Msyamboza et al. (2014) had a sample of adults aged 25 – 64years. This suggests the difference may not be as the current reported prevalence rates.

<sup>11</sup> The EHP is the minimum package of services mandated to be available at the primary care level for conditions affecting most of the population, with a particular focus on the poor.

is to lead in programs and interventions aimed at the prevention and management of non-communicable diseases<sup>12</sup>. In 2013, the NCDs and mental health unit produced an action plan for the prevention and management of non-communicable diseases in Malawi (Ministry of Health 2013). Among the critical activities for the plan is conducting epidemiological and operational research on diabetes and other NCDs. The same call for research in diabetes has been made in the Malawi Health Research Agenda of 2012 (Ministry of Health 2012). In the research agenda, research priorities for diabetes include epidemiology (determinants, distribution, trends and burden), prevention (feasibility of screening and developing strategies for prevention), diagnostics (assessing strategies for diagnosis and monitoring response to treatment) and treatment (approaches to improve access and to evaluate cost-effectiveness). The focus in these policy documents is mostly on quantitative research studies. In the next section, I review some of the research on diabetes in Malawi, highlighting the critical gaps in research that this PhD study seeks to address.

### 1.3. Diabetes research in Malawi

There is limited research on diabetes in Malawi, with even fewer qualitative studies<sup>13</sup>. The literature on diabetes covers four main categories: assessment of knowledge; experiences of living with diabetes; barriers and challenges; and ‘quality’ of care. Quantitative and qualitative studies have assessed ‘knowledge of diabetes’, its causes and various management practices including physical activity, diet, and medication. Mostly using cross-sectional study design, and different questions to assess knowledge, these studies show ‘inadequate knowledge’, or high proportions of participants who were not ‘knowledgeable’, of diabetes. For example, among type 1 diabetes patients, Phiri, et al. (2017) found that while most of their participants (68%) ‘knew’ the causes of diabetes, almost half (48%) had difficulties differentiating symptoms for hypoglycaemia and hyperglycaemia. Fifty-eight per cent (58%) of the participants had ‘inadequate knowledge’ of managing hyperglycaemia, with only 6% mentioning injection of another dose of insulin.

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<sup>12</sup> During the time that I conducted fieldwork, the NCDs and Mental Health Unit was formulating guidelines for management of diabetes. One of the components of the guidelines is diabetes education.

<sup>13</sup> A search on online databases using search terms Qualitative and Diabet\* and Malawi yielded the following results: SCOPUS (five), EBSCO (eight), Web of Science (six) and PUBMED (seven) [Date: 15062019].

Among older type 1 diabetes adolescents, Chingatichifwe, et al. (2014:283) reported that 88.9% were not 'knowledgeable' about the definitions of stroke, diabetes, and hypertension. Further to this, 65.1% were 'not knowledgeable' about healthy lifestyles as regards prevention of the three conditions, while 85.7% could not identify their complications. One qualitative study among type 2 diabetes patients in the outpatient department at a rural hospital in southern Malawi showed 'positive' attitudes towards it (Ogunrinu, et al. 2017). Participants were said to have 'general knowledge' of how medication and nutrition affected their condition, bodies and sugar levels, and had an awareness of "what was exercise and its importance" for diabetes management (Ogunrinu, et al. 2017:121).

Ogunrinu and others (2017) went further to explore patients' self-management practices: the second theme identified in the literature. They reported that participants in their study said they had 'applied' what they had learned in diabetes education by eating *mgaiwa*<sup>14</sup> rather than *white Nsima* [*Nsima yoyera*]<sup>15</sup>, and 'integrating' exercises into their daily lives. Participants also reported taking medicine daily as required by health care workers. However, this was interrupted when they did not have money to buy medicines, in which case, herbal medicines were used as an alternative. Use of herbal medicine when biomedical drugs were unavailable was also reported by Angwenyi, et al. (2018) in their study among patients with different chronic conditions, including diabetes. Angwenyi, et al. (2018) also reported patients' recognition of the importance of a 'proper' and balanced diet, and awareness of food restrictions in terms of low salt, oil and sugar consumption.

Not all studies showed this awareness of diet and 'applying' lessons from diabetes education. For example, Chingatichifwe, et al. (2014:286) show that their participants were "inconsistent in practising healthy lifestyle" as they ate fewer fruits and vegetables and "[engaged in] less physical activity, and practised sedentary behaviour". Similarly, Phiri, et al. (2017) reported that 52% of their participants did not recognise the importance of diet for glycaemic control, and 65% mentioned the failure to 'manage diet' as a challenge. Among the participants in the study by Phiri, et al. (2017), the reason for

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<sup>14</sup> *Nsima* is stiff porridge made from cooking a mixture of water and flour. *Mgaiwa* is a type of *Nsima* made from whole maize flour.

<sup>15</sup> *Nsima* made from highly refined flour made from fermented, de-hulled and de-germed maize seeds. This is a staple carbohydrate eaten in Malawi. It is most common and considered of a higher quality than *mgaiwa*.

“failure to manage diet” was the difficulty in preparing a ‘balanced’ diet considering the amount, frequency, and type of food they are allowed to eat. Phiri and others (2017) did not elaborate further on this point. Other studies have suggested other reasons, challenges, or barriers to diabetes management at the individual and health system levels. Among patients, Ogunrinu, et al. (2017) reported that barriers to proper management of diabetes included lack of money to buy food and medication, and pain which is experienced after engaging in daily physical exercise. Wood and others (2015) identified poverty, lack of NCD knowledge, lack of confidence in the health system, and resorting to traditional healers as barriers that hinder accessing medical services.

Studies that have focussed on the provision of services for diabetes management have assessed ‘quality of care’ for diabetes, highlighting challenges at the health system level. These studies have shown that most health facilities in Malawi lack essential commodities for the management of diabetes. For example, a clinic audit of primary care facilities that assessed the processes of care and availability of medications and equipment in working order found that none of the facilities had protocols for management of diabetes, and education materials (Wood, et al. 2015). Only one of the five facilities that were assessed had oral medication for diabetes, while none of them had insulin or glycosylated haemoglobin (HbA1c). Only two facilities had a working glucometer. A recent assessment of the availability of essential supplies for the rapid diagnosis, treatment and management of diabetes in 55 primary care facilities found that only 38% had glucometers (Chikowe, et al. 2018). Only four per cent (4%) of the facilities had recommended first-line medicines for type 1 and type 2 diabetes, with metformin, glibenclamide<sup>16</sup> and insulin available in 15%, 9% and 4% of the facilities, respectively. Qualitative research findings from key informant interviews in Mangochi District show stock out of some medicines for diabetes management and reagents (Assayed, et al. 2014). For example, at the time of their study, Assayed and others (2014) found that there was only glibenclamide and one type of insulin.

The literature that I have reviewed so far has not explored patients’ experiences of symptoms, meanings they attach to diabetes and practices of managing it. While some of the literature has been based on qualitative studies, they have not explored the

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<sup>16</sup> Oral antidiabetic medication

theoretical implications of diabetes experiences and management. Only one study, Cooper, et al. (2018), explored the lived experiences of sexual difficulty among type 2 diabetes patients in Malawi and South Africa. In this study, sexual dysfunction was perceived as a significant problem among patients who, spontaneously and without being prompted, mentioned it during interviews. Two themes emerge from this work. Firstly, patients were uncertain as to why they experienced sexual dysfunction, and whether it was caused by diabetes or its medication. Secondly, sexual dysfunction culminated in perceptions of low self-esteem from loss of masculinity and manhood because of the inability to have sex like the one they used to before diabetes. Inability to have sex further resulted in strained marital relationships, insecurity, fear of abandonment and mistrust as partners accused each other of infidelity.

The studies reviewed above have highlighted the paucity of research on diabetes in Malawi. Most studies were conducted in rural areas, some of which focussed broadly on non-communicable diseases. Most of them also attempted to 'assess knowledge' on diabetes management using quantitative methods, albeit sometimes without clear criteria. Except for Cooper, et al. (2018), the other qualitative studies have not attempted a theoretical explanation of the issues they raise. Most importantly, none of the studies has addressed the practices of diabetes management and the contexts within which they are enacted. This review also reflects on diabetes research in Africa more generally, where there are limited ethnographic studies that aim at a theoretical understanding of the experiences and management of diabetes. This study contributes insights to this small body of literature by using ethnographic methods to understand how patients, family members, and health care providers live with and manage diabetes in Malawi.

#### 1.4. Structure of the thesis

The main argument of this thesis is that "experimenting", improvisation and "trying harder" are means of managing the uncertainties experienced by people managing diabetes in Malawi. In Chapter 1, I have introduced the topic of diabetes and its management in Malawi. Through a narrative of the experiences of Mrs Joyce Jenala, I have introduced some of the key themes that I deal with in this thesis: uncertainty, improvisation, and "experimentation". I also explored some of the literature on diabetes

and its management in Malawi to show that most research is atheoretical, public health informed studies rather than long term ethnographic.

In Chapter 2, I review anthropological studies of diabetes management and uncertainty. In studies on diabetes management, I address four areas: meanings of control, use of medical technologies, use of herbal medicines and “non-compliance”. I show the multiplicity of meanings of control in diabetes management, how the use of technologies in diabetes management influences practices but also patients’ body experiences. I also show that studies have highlighted “non-compliance”, which has been theoretically explored as tinkering (Mol 2008) and bio-tactics (Guell 2009), with little emphasis on uncertainty as a lens of understanding it. Studies on uncertainty showed that its management is characterised by pragmatism, hope and orientation towards the future. This orientation towards the future highlights the productiveness of uncertainty in terms of practices and an ideal future aspiration. I link these two different areas of research by considering uncertainties in the experience and management of diabetes to highlight “experimentation” and improvisation.

In Chapter 3, I describe the setting in which diabetes is managed/the study took place in Malawi and the methods that I used in collecting and analysing ethnographic data. I also describe processes of negotiating access to the ‘field’, my experiences of, and reflection on, what is referred to as “(doing) anthropology at home”(Jackson 1987) and my position as a researcher. I show that negotiating access was not a once off activity, but rather an ongoing process in the course of doing research. I also reflect on my position as a researcher conducting fieldwork in my home country, and how this meant research was entangled in my relations and was on going in a multiplicity of settings.

In Chapter 4, I present ethnographic findings on understandings of diabetes (*‘shuga’*) in terms of its meanings and perceptions of its causes. I start by showing that based on its local names, excessive sugar is implicated in diabetes causation. I also show the multiplicity of causes, how patients use one or more than one cause at the same time to make sense of their disease, and the uncertainties that this entail. I also show that diabetes is perceived as the accumulation of sugar and ‘chemicals’ in the body, and argue that this implicates modernity in terms of agricultural practices and diet. I argue that

these perceptions and ideas influence what patients consider as “proper” management of diabetes and what they can do as part it.

In Chapter 5, I describe how patients knew they had diabetes and learned how to live with it as “*munthu wa shuga*” (a person that has *shuga*) to highlight the uncertainties that this entails. Knowing that one has diabetes starts with uncertainties before and during diagnosis. After diagnosis, patients are told of further uncertainties about when sugar levels will go up, and that patients have to deal with these. Other uncertainties pertain to contradictions in differences in messages: how much to eat, what to eat, and when to eat. The final point I make is that health care workers emphasize the immorality of “non-compliance” – that patients must follow everything they were taught by, among other things, not “experimenting” to prevent complications and death.

Despite being explicitly prohibited, I show in Chapters 6 and 7 that patients “experiment” as part of the management of diabetes and that these “experiments” are possible based on what they are taught within biomedical facilities as part of making ‘*munthu wa shuga*’ (a person that has *shuga*). “Experiments” are driven by the experience of uncertainty in living with diabetes, the ideas from diabetes education that “*the body speaks*” and that patients have to be “*their own doctors*”. I describe patients’ “experiments” with food, herbal and biomedical medicines as they sought to get a ‘good *shuga*’, which is also an uncertain target. In Chapter 7, I highlight the complex therapeutic landscapes within which these “experiments” take place, with a focus on religion and the use of herbal medicines. This chapter links with ideas of diabetes causation in terms of use of “chemicals” that pollute the body and how they are managed through “cleansing”.

In Chapter 8, I show that diabetes management practices took place in unique social relations with health care workers and family members. I argue that “experimenting” and improvisation were facilitated or constrained by family members. Family members with whom patients shared meals also influenced “non-compliance” to diet. Some patients accessed some services and medicine through relations with health care workers and belonging to the diabetes association. Patients also “experimented” with others as they shared their results of experiments or medicine, and engaged in group surveillance as they looked out for those who were managing poorly. In this regard, contrary to diabetes messages, diabetes management was not an individual activity, but was shared with

other patients and ‘guardians’. I conclude the chapter by considering the consequences of failure in “experimenting” and improvisation. In doing so, I highlight a final aspect of diabetes management: that patients kept on trying. Further to this, by engaging in different “experiments” and improvising, patients were “trying harder” in order to get a ‘good *shuga*’.

In Chapter 9, I conclude by highlighting that managing uncertainty is a core part of what is considered diabetes management and control. Patients and health care providers managed uncertainty, and hence diabetes, through “experimenting” and improvising within social relations. In doing so, I build on work that has highlighted diabetes management as “tinkering” and described managing uncertainty as pragmatic. Instead of tinkering with biomedical drugs in collaboration with health care workers and in response to circumstances, “experimenting” that I describe involves patients’ practices that are done independently of doctors within complex therapeutic landscapes and social relations, and which are aimed at attaining a ‘good *shuga*’ which is also an uncertain target. Therefore, uncertainty allows for (and necessitates) “experimentation”, which, alongside improvisation, are vital practices of diabetes management among both patients and health care providers in Malawi. Through these practices, a “Re-active patient” emerges who pays attention to their body and responds by using a multiplicity of therapies by ‘experimenting’ and improvising to attain a ‘good *shuga*’.

## Chapter 2

### Anthropology of diabetes and uncertainty

In Chapter 1, I showed the paucity of literature on diabetes (management) in Malawi; among the available research, only one study attempted a theoretical understanding of experiences of diabetes symptoms. In this chapter, I review the broader anthropological literature on diabetes, its management, and uncertainty to highlight its theoretical contributions. The objective for doing so is to show that uncertainty is a useful frame for understanding diabetes and its management in this context.

Susan Whyte proposed that anthropological studies of ‘non-communicable diseases’ interrogate chronicity by focusing on meanings of control, temporality and sociality around diseases in the context of policy, health care systems and life conditions (Whyte 2012). She proposed a pragmatic analysis of perceptions and practices to show “how differently situated people live with, and try to control, chronic conditions in a context of health care more orientated to acute health problems” (Whyte 2012:71). Many studies have addressed control in diabetes management by analysing “non-compliance” to biomedical advice in terms of its forms, rationale and its grounding in patients’ social-cultural values.

On the other hand, anthropological studies of uncertainty have addressed how it emerges in particular situations and its management. Key questions addressed in this literature include “what does uncertainty do” and “what do people do about it”? The literature shows that in responding to uncertainty, people engage in pragmatic activities (Whyte 1997), draw upon social relations (Haram and Yamba 2009a), and how these responses entail other uncertainties. I bring together these two strands of anthropological literature by considering the management of diabetes as a form of uncertainty. I start by reviewing the literature on diabetes management in terms of control, monitoring of sugar level, and “non-compliance”, a key ‘problem’ in diabetes management according to biomedicine.

## 2.1 Management of diabetes

### 2.1.1 “Control” of diabetes

Within biomedical facilities, “diabetes management” tends to be framed in terms of individual control of diet, sugar level, themselves, or diabetes itself. To achieve this, diabetes patients are “taught a range of skills to take control and [assume] ‘ownership’ of their condition” including nutrition management, exercise and “training in managing blood glucose levels through self-monitoring where appropriate” (Holt and Kumar 2013:46). What is often not considered from a biomedical perspective is the possibility that such control may be elusive and unattainable in patients’ lived experiences (Mol 2009). Consequently, anthropological studies have interrogated how control takes on different meanings, alternative means to achieve it, and how objects and technologies are appropriated to achieve it.

The multiplicity of meanings of control is shown by Broom and Whittaker (2004) in a study among type 2 diabetes patients in rural and urban Australia. Within biomedicine, taking control, and being responsible for one’s disease meant following what doctors had told them to do. As such, patients’ agency is limited. When patients spoke of control for diabetes, they highlighted the disruption that diabetes causes for their lives. They evoked “metaphors about the disorder of the illness experience and about the diabetes patients’ desire to assert a positive identity and agency in the management of their disease” (Broom and Whittaker 2004:2381). Little, et al. (2017:104) described a similar perception among patients in India in which a diabetes diagnosis was perceived as a loss of autonomy; being subservient to doctors, caretakers and family members; and a move “from being in control of one’s well-being to being controlled by the disease”. For Broom and Whittaker (2004), patients responded to being ‘out of control’ by refusing the authority of health professionals and asserting the authority of embodied experience over abstract expertise of the doctors. In India, patients showed this resistance to authority by refusing to obey doctors’ advice and creating their own treatment regimens (Little, et al. 2017).

Naemiratch and Manderson (2007) suggest that control means different things over the course of having diabetes. They argue that for diabetes patients, there is a trajectory from the control of patients by diabetes to control of diabetes by patients. Based on research

among type 2 diabetes patients in Thailand, they argued that at diagnosis, patients had no control of diabetes. Diabetes was controlling the patient. Over time, as diabetes was treated, and visible signs diminished, the individual patient was in control of diabetes. Diabetes takes over control once complications begin to appear. For most participants, biomedical diabetes control merged with ideas of dieting and dietary control and was understood to mean patients had to stop eating a particular food. However, patients perceived such control as a vehicle for the exercise of power by doctors. Hence, patients resisted such control and replaced it with adjustment (for example, adjusting diets before consultations).

These studies have highlighted in various settings, the different positions that patients assume regarding control of diabetes: how control can be diminished by disease but also health care professionals, how control can change over time, and how patients may respond to being 'in' or 'out' of control. These experiences call into question the many ways in which diabetes management proceeds: whether it is through asserting authority against doctors or engaging in "hyper-compliance" – striving to conform strictly to prescribed regimens (Broom and Whittaker 2004).

### 2.1.2 Monitoring and surveillance technologies

In many higher-income countries, control of diabetes tends to involve patients' use of glucometers to monitor blood sugar levels to ensure they are maintained within a "normal" range (Mol 2000). Health care workers use these readings to determine how patients are managing diabetes and prescribe proper treatment. Anthropologists have shown that technologies do not always do what their manufacturers and users intend them to do. Either technologies malfunction or may (often) be appropriated in ways that are different from how they were designed (See Hadolt, et al. 2012). Moreover, the context within which technologies are used may influence how they are used. For example, among type 1 diabetes students from four universities in the United Kingdom, Balfe and Jackson (2007:776) have shown that on the one hand, diabetes technologies (insulin pumps, glucometers) allowed young people "to discipline their bodies and position their identities as 'normal'". On the other hand, these technologies also posed as a threat to young people by highlighting their 'difference' from other students. For some students, the use of technologies was thus perceived as socially disruptive.

Use of technologies has an impact on the practice of biomedicine. In the Netherlands, Mol (2000) has highlighted the transformative nature of medical technologies. Firstly, blood sugar monitoring technologies can change the way health care is organised, as patients can know their blood sugar level without going to a health facility. While this implies patients may be less dependent on health professionals, such measurements require self-discipline and acting on the results of the measurement by eating or injecting insulin. This suggests a different form of relations between patients and health care workers, but also new responsibilities for the patients.

Secondly, sugar-monitoring technologies have influenced a change in what is considered a “normal” blood sugar level and the bodily experience of diabetes. For example, diabetes patients may ‘know’ hypoglycaemia through symptoms like shivering, sweating, and discomfort, which Mol and Law (2004:44 - 45) have referred to as, “a subjective, private and personal way of knowing the body from inside”. Glucometers allow a different mode of ‘knowing’ using numbers. Since the glucometer is supposed to be an ‘objective’ measure of sugar level in the body, patients may be asked to test themselves, rather than rely on these embodied feelings, to verify that their sugar is indeed low or high (Mol 2000). In doing so, numbers from monitoring devices are privileged over embodied feelings of the patients in the management of diabetes resulting in refining or making bodily experiences and feelings redundant, uncertain, or less critical. However, technologies may not be readily available or, if they are, may not be usable. How patients and health care workers use technologies in practice and forms of diabetes management that emanate from using them are of both theoretical and practical import. This is significant, especially in low-income countries considering that most studies of these technologies have been in high-income countries.

### 2.1.3 Beyond biomedicine

Use of “alternative therapies” for management of diabetes and other chronic conditions is an everyday practice in Africa. Reasons for using traditional medicine include high costs of biomedical drugs in private pharmacies (Kolling, et al. 2010) or the chronic nature of diabetes which entail using medicines for life (Awah, et al. 2008). Both Awah, et al. (2008) in Cameroon and Rutebemberwa, et al. (2013) in Uganda, found that traditional medicine was cheaper than biomedical drugs. Other reasons for using herbal medicine

include the perception that it can 'cure' rather than just "controlling" diabetes and the stigma attached to some practices of diabetes management (for example linking weight loss to AIDS) (Awah 2006; Awah and Phillimore 2008).

Some theoretical studies have highlighted meanings attached not only to use of herbal medicine but also biomedical drugs. These meanings are used to explain how these medicines are used in practice. For example, among Indian and Pakistani migrants with diabetes in Edinburgh, the use of herbal medicines was thought to counter the "side effects" of biomedical drugs (Porqueddu 2017). They opted for herbal medicines that were said to tackle 'causes' of disease rather than symptoms and did so without causing 'side effects' unlike biomedical drugs. Awah and Phillimore (2008) drew on notions of "modernity" to explain the use of traditional medicine among diabetes patients in Cameroon. They argue that biomedical clinics emphasised that diabetes was a "modern" disease caused by "modern" lifestyles and hence amenable to treatment by "modern" medicine only rather than traditional medicine. Despite this, diabetes patients opted for traditional medicine because of high costs for accessing biomedical treatment but also because, for the majority of patients, the biomedical explanation and prognosis of diabetes were considered unconvincing. Awah and Phillimore (2008) showed that even though patients considered diabetes as a "modern" disease, its causality was attributed to broken social relationships within society. As such, ancestral protection or nullifying the threat from witchcraft was considered the means for restoring health.

In Ghana, de-Graft Aikins (2005) has argued that patients move between biomedicine (preferred and persistently used), ethnomedicine and faith healing driven by the physical and psychological burden of dietary management, cost of medicines and a search for a cure. Studies that have explored religious and spiritual aspects of diabetes management have shown two themes. The first one has to do with perceptions of diabetes causation. For example, owing to the suddenness and mysteriousness of symptoms, people in rural areas in Ghana attributed diabetes to witchcraft and sorcery (de-Graft Aikins 2003; 2005). Therefore, managing diabetes required traditional religious healing. The second theme is about the role of prayer and Christian communion in mediating and intervening in daily experiences and practices. According to de-Graft Aikins (2003), the success of diabetes management using biomedical drugs and diet was dependent on the incorporation of spiritual elements through prayer.

Most of the research on the use of herbal medicine has tended to consider them as separate and disconnected from biomedical practices. However, some recent studies have shown connections between and appropriation of “modern” practices by practitioners of herbal medicines (Hampshire and Owusu 2013). In Malawi, few studies have explored the use of herbal medicines in diabetes management. Like other African countries, anecdotal reports show the growing popularity of ‘Chinese’/herbal medicine, Pentecostal churches, and traditional healers that claim to ‘cure’ various diseases, including diabetes. In neighbouring Tanzania, Langwick (2008) has shown that the emergence and proliferation of herbal medicine was part of a neoliberal project that emphasises self-reliance and re-commoditization of traditional medicine as market-based herbals. For some, traditional or herbal medicines are perceived to be as, or even more, effective than biomedical drugs. Therefore, the popularity of herbal medicines raise questions as to how, why and in what circumstances they are used as part of complex therapeutic landscapes of diabetes management in Malawi.

#### 2.1.4 “Non-compliance” and diabetes management

In several African countries, surveys that have assessed “compliance” to biomedical management with regard to diabetes medication, physical exercise and what is often referred to as a ‘diabetes diet’ or ‘healthy diet’ show that most patients do not “comply” (Cohen, et al. 2010; Shams and Barakat 2010; Worku, et al. 2015). They show that diabetes patients often appear not to follow biomedical advice on how to manage diabetes, referred to as “non-compliance”. On the other hand, anthropologists have problematised these notions, situating management of diabetes in broader life experiences and interrogating taken for granted biomedical categories like “compliance”, or “non-compliance”. They have highlighted that apparent “non-compliance” often results from or reflects particular social-cultural factors or patients’ strategies to improve illness experiences.

Anthropological studies on “non-compliance” in diabetes management have addressed the following questions (among others): what forms does it take? Why are patients not “complying”? What factors inform ways in which it takes place? Finally, they have interrogated whether “compliance” or lack of it, is a suitable frame for understanding people’s caring and management strategies? In Cameroon, Awah and Phillimore (2008)

have shown that “compliance” to biomedical management entailed several levels of conformity and self-discipline through keeping the regular appointment and monitoring of blood sugar level, self-monitoring of diet and changes in food consumption, and most importantly, acceptance of biomedical treatment as the only way to manage diabetes. Among other ways, “non-compliance” involved the use of traditional medicine, which was tolerated by some biomedical clinic staff. Patients’ perceptions of diabetes, difficulties of changing diets due to commensality, misgivings about weight loss in the era of HIV and AIDS, and the chronic nature of diabetes and the costs for lifetime management were some of the factors that prevented biomedical “compliance”.

Three concepts have been used to explain patients’ practices of diabetes management that, within biomedical facilities, are considered “non-compliance”. These concepts are ‘hybrid medical practices’ (Ferzacca 2000), ‘bio-tactics’ (Guell 2009) and ‘tinkering’ (Mol 2008). The idea of hybrid medical practices captures idiosyncratic regimes of self-care and the cultural logic that informs these practices. According to Ferzacca (2000:29), hybrid medical practices are informed by the “many of the cultural referents and social values that circulate through medical advice and practice... yet produced with both particular and general objectives in mind”.

While Ferzacca (2000) highlights the cultural logic and social values that informs practices of diabetes management, Guell (2009:228) emphasizes the “idiosyncratic strategic implementation and use of recommendations”. Guell (2009; 2012) used the concept of ‘bio-tactics’ to describe patients’ practices of diabetes management among Turkish Berliners in Germany. She showed that her informants “actively engaged in self-care practices and these were born out of a necessity to make experience and expectations (of managing one’s diabetes) habitable in the absence of outside formal care”(Guell 2012:512). Guell (2012) described her participants’ practices as follows: “They used their ingenuity to, first of all, access self-care advice, and then to translate it and amended it to make it suitable and workable to their lives. Their tactics are thus not about resisting adherence but recalibrating standard strategies”. Guell (2009) was influenced by the work of de Certeau (1988) who described how chronically ill bodies are disciplined not necessarily for ethical reasons, but for practical reasons as they strive for a ‘good’ life. For Guell (2009:80), “bio-tactics” are “practical exercises of making illness and ill bodies liveable”.

With “bio-tactics”, patients are striving for a “liveable life”. An example of “bio-tactics” among Turkish-Berliners is how women living with diabetes negotiated the sociality of diet. According to Guell (2009), Turkish socialisation involves food in abundance, which is said to demonstrate generosity and care towards guests. However, health recommendations are abstract, target individuals and do not acknowledge the communal aspects of food. Hence they are not readily applicable in the messiness and complexity of everyday lives (Guell 2012). To negotiate these recommendations, Guell’s informants took small food portions and cleared their plates to the kitchen as soon as they finished eating to avoid a second helping. Doing so allowed them to remain seated during the meal and join the sociality around food while avoiding overeating (Guell 2012).

Mol (2008; 2009) used the concept of ‘tinkering’ or ‘doctoring’ to describe diabetes management practices among patients and health care workers in a hospital in the Netherlands. She described care as a process of ‘tinkering’ with bodies, technologies and knowledge, and people (Mol 2008). Acknowledging and attending to the unpredictability of bodies with a disease, care “is a matter of attuning to, respecting, nourishing, and even enjoying mortal bodies” (Mol 2008:12). “. For Mol, what constitutes ‘good care’ is a matter of collaborative and continuing attempts to attune knowledge and technologies to diseased bodies and complex lives. ‘Tinkering’ involves attuning doctors’, nurses’, and patients’ activities to one another in diabetes care by attending to patients’ experiences. In trying to attune these practices and activities to each other, tinkering’ involves “experimenting”. According to Mol (2008:55), “Care is not a matter of implementing knowledge and technology, but of experimenting. Besides, these are on-going experiments: “It is a matter of trying things out and of being willing to revisit what has been done before. There is always something that fails. Try again, adjust, improve. Alternatively, when the time is right, let go” (Mol 2008:56). According to Mol, caring is a process with no clear boundaries; it involves multiple, interceding practices. What matters in these practices is the outcome.

Kolling and others (2010) have explored such trying in diabetes management in Tanzania. Their ethnographic study among type 2 diabetes patients in impoverished areas of Dar es Salaam showed how diabetes patients “experiment” with herbal medicine as one of the options that they could try out with the hope for a “cure” (Kolling, et al. 2010). Some patients were advised by relatives to try out herbal medicine. They gave an

example of Rose, an informant who “kept experimenting with new ethnomedicines, hoping to be cured, while still taking the oral tablets prescribed by the doctor at the diabetes clinic at one of the district hospitals” (Kolling, et al. 2010:6). It is how and the things that patients ‘try out’ and the aims of “experimentation” that are the focus of this thesis. I go beyond pointing out what patients were “trying out” to look at why they were doing so (uncertainty), what practices were done as part of it (surveillance, observation), what facilitates it, and the aims and outcomes for “trying out”.

Both Mol (2008) and Guell (2012) have described the practices of diabetes management that deviate from biomedical advice and why patients engage in them. For Guell (2009), “bio-tactics” are used to “make bodies liveable” while for Mol (2008), “tinkering” is about flexibility in medical practice in the quest for ‘good’ care for patients. Both of them also acknowledge some form of uncertainty in diabetes and its management. For example Mol (2008) acknowledges the unpredictability of diabetes and that the results of ‘tinkering’ are uncertain. Guell (2009) also acknowledges the “ambiguities and uncertainties” surrounding diet, physical activities and medication in diabetes management, and the unpredictability of diabetes bodies. Patients used blood sugar testing as a means of addressing this unpredictability by rendering diabetes visible through numbers, hence negotiating risk and reducing anxieties resulting from very high sugar levels. While both Mol (2008) and Guell (2009) acknowledge uncertainty in management of diabetes, it is not the main driver for tinkering and biotactics respectively. In this thesis, I consider uncertainty as central to practices of “experimenting” and “trying harder” which participants used as part of diabetes management. I now turn to reflect on studies on uncertainty and its management, with a focus on disease and illness.

## 2.2 Uncertainty and chronic diseases

In managing and living with chronic diseases<sup>17</sup>, uncertainty is widely considered a key characteristic and challenge. Examples of uncertainties of living with chronic diseases include: patients’ concerns whether the doctors have been honest with them regarding their diseases, whether they are receiving the best care available, and also worry about

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<sup>17</sup> I use this term loosely to point to diseases that people live with and manage for most of their lives. I do not delve into debates on the chronicity of cancer and HIV for these are not relevant to the point I am making.

how their illness will affect their families, friendships and work situations (Royer 2000). In research on HIV and AIDS treatment, uncertainty has been considered as a characteristic of life that makes living with the disease precarious. For example, Whyte (2014b) described conditions within which people live with HIV in Uganda as insecure and of uncertain outcomes. She stated that "...lack of sufficient health services, the absence of state welfare facilities, and widespread poverty mean that life is insecure, and the outcomes of enterprises and problems are uncertain" (Whyte 2014a:20)<sup>18</sup>. People live with and manage the illness in the context of this uncertainty.

A recent review<sup>19</sup> of qualitative studies on experiences of diabetes in sub-Saharan Africa, Zimmermann, et al. (2018) similarly noted that uncertainty is a leading challenge in the management of diabetes. In these studies, uncertainty is related to the living conditions and the context within which diabetes is managed. Such uncertainty comes in forms of interrupted medical supplies, income fluctuation which affects access to treatment, and disruption of clinic visits by weather and costs. While patients in my study described each of these uncertainties, it is the final form of uncertainty that Zimmermann and others (2018) found that is of theoretical importance in making the argument in this thesis. This uncertainty is that diabetes as a condition is difficult to predict and control. For example, in a qualitative study conducted in three public sector community health centres in Cape Town, South Africa, Murphy, et al. (2015) found that patients experienced uncertainty as to how to go about modifying their lifestyle as part of diabetes and hypertension management. They suggested this was partly because health care providers were not forthcoming with information. Murphy, et al. (2015:6) also suggested that patients "expressed anxiety about their current state of health and complained of various symptoms". In other words, expressing anxiety or being anxious was related to or resulted in uncertainty.

In research that engaged uncertainty as a theoretical concept, Mogensen (2009), has shown that it was one of the social consequences of provision of Antiretroviral Therapy in Uganda. According to Mogensen (2009) uncertainty is manifested in the dilemmas and challenges of everyday life of people living with HIV and AIDS in Uganda, who despite the

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<sup>18</sup> In giving this example, I do not suggest that Susan Whyte considers uncertainty as a constraint. In much of her work that I will review below, she has described the creative potential of uncertainty.

<sup>19</sup> The study reviewed 21 papers on experiences of diabetes that were published between 2003 and 2017.

availability of antiretroviral therapy, still struggled to access it. For example, the introduction of ART prompted one of Mogensen's informants, who had been seriously ill for some time, to seek to replace the uncertainty of not knowing her HIV status with the certainty of how she was to go on living her life. However, knowledge of her status was replaced with the uncertainty of how to move on with her life and what to do to prepare for her children's life after her death. Efforts to address these uncertainties led to straining of social relations with the informant's uncles who, despite 'knowing' her status, could do nothing to help her access ART. In this case, "ART made the strains and tensions in their social relations as well as her forthcoming death explicit. The idea that everybody is part of the same family and has rights and access to help from the others could no longer be maintained" (Mogensen 2009:187). What this case reveals are the uncertainties that appear before and after knowing that one has HIV, and the means available to deal with these uncertainties. Moreover, not only are uncertainties exacerbated by structural disadvantage but they are also managed and shaped by social relations with others.

In my research, I found similar uncertainties in the management of diabetes. However, my interest is in how, considering these challenges and difficulties, patients, and health care workers [attempt to] manage diabetes. Specifically, I explore how these uncertainties were created and influenced patients and their relations with other patients, caregivers, and health care providers.

### 2.2.1 Meanings of uncertainty

Haram and Yamba (2009b) have noted that researchers often do not clearly define what they mean by uncertainty. In its usage, there is often imprecision, vagueness and slipperiness (Whyte 2005). Uncertainty is often associated and sometimes used interchangeably, with many words including doubt, insecurity, indeterminacy, ambiguity, ambivalence, obscurity, possibility, chance and scepticism (Jenkins, et al. 2005a). In order to develop an analysis that captures the forms of uncertainty that were playing out in managing diabetes in the Malawian context I studied, I will first outline in more detail how the concept is defined and used, its meanings and implications in research in anthropology. I start with the meanings of uncertainty to highlight the unique ways in which it was manifested, experienced, and managed in the context of diabetes management in Malawi.

Definitions of uncertainty often highlight unpredictability, insecurity, and precarity of events and their outcomes. According to Whyte (2009a:213), uncertainty refers to “a lack of absolute knowledge: inability to predict the outcome of events or establish facts about phenomena and connections with assurance”. For example, not knowing a cause or using various ideas of diabetes causation are examples of a lack of complete knowledge. However, not having absolute knowledge, inability to predict or not having assurance and security are not necessarily uncertainty itself. Whyte (2009a) described uncertainty as a state of mind (intellect, will, intention, and feelings) and minding (to care or to feel concern). Whyte (1997:19) has further suggested that uncertainty is not a “vague existential angst, but an aspect of specific experience and practice”; in other words, it is situated in particular contexts and afflictions. Cooper and Pratten (2015:1) further clarify this idea by suggesting that uncertainty is “a structure of feeling – the lived experience of a pervasive sense of vulnerability, anxiety, hope, and possibility mediated through the material assemblages that underpin, saturate, and sustain everyday life”.

Because of its association with words like unpredictability, lack of knowledge, assurance, and security, uncertainty has often been considered in negative terms to highlight inability, difficulty, and absence of something. Cooper and Pratten (2015:2) noted that as a concept, uncertainty has often been “used in its negative and constraining sense”. A similar observation was made by Haram and Yamba (2009a:13) who suggested that uncertainty is used to denote “non-recurrent and unpredictable phenomena that are intrinsically difficult to counteract, but affect the lives of individuals or a given group of people” and is used “to imply unpredictable outcomes, often of a negative kind that make life precarious...”(Haram and Yamba 2009a:13). However, the outcomes of uncertainty are not always adverse. Uncertainty, as I will show below, can be both productive and positive. Even where uncertainty is considered unfavourable, impinging on life, it can also be productive. New practices and orientations can sometimes emerge from states of uncertainty.

### 2.2.2 Uncertainty: pragmatics, productivity and imagined futures

Research on uncertainty tends to address three different but related questions: where (and how) uncertainty emerges, what uncertainty does, and what people do in response (Jenkins, et al. 2005b). The first question is about tracing what produces uncertainty and

what forms it takes, the second is about the consequences or the productiveness of uncertainty while the third is about people's responses, management, and control. These three questions are closely related to the processes of dealing with uncertainty which can produce other uncertainties. As has been noted by Whyte (1997:19), uncertainty is "a characteristic of both the experience of misfortune and the process of dealing with it". Studies of uncertainty reveal the many areas and levels at which uncertainties are manifested, experienced, managed, and studied. In this thesis, I am interested in uncertainties as experienced by individual actors in particular situations; in this case, the management of diabetes.

Jenkins, et al. (2005b) have noted that studies of uncertainty tend to fall into two categories. The first category includes those studies that are concerned with structural conditions or political economy that form the context within which uncertainty emerges. This category mostly addresses two questions: the production of uncertainty and its consequences. In these studies, uncertainty is a characteristic of the context within which misfortunes appear and are managed. Uncertainty often, though not always, emanates from situations of insecurity. In this case, insecurity is a condition where there is "lack of protection from danger, weakness of social arrangements that provide safety when adversity strikes" (Whyte 2009a:214). Examples of interpretations related to structural conditions tend to see uncertainty as constraining and impinging on the lives of individuals. It is also considered as a state of limited resources for action. This is a negative view of uncertainty, considering it as a problem or challenge that needs to be addressed. An example of this approach is where uncertainty is "correlated with modernity", which impinges, not always positively, on localities (Haram and Yamba 2009a:11). Because of the riskiness and unpredictability of contemporary life, uncertainty is considered as an inevitable force in the subjective experience of life. Others have described the unpredictability of contemporary life as the 'crisis', a context that is described as incoherent, uncertain and unstable.

The second category include studies on uncertainty that are concerned with "individual agency and the human capacity to deal with situations of crisis" (Jenkins, et al. 2005b:10). This category addresses the question of how do people respond to uncertainty. These studies tend to focus on the specific actions of individuals as they live and deal with uncertainty. People respond to, manage, and control uncertainty through actions and

evaluation of the consequences of these actions. These actions are meant to “alleviate the problem and limit uncertainty” (Whyte 1997:3). Broadly, people respond to uncertainty in two ways. Firstly, they may seek a sense of control through scientific information and local knowledge manipulation of social or symbolic resources. Seeking this sense of control constitute what Cooper and Pratten (2015), who borrowed from Mbembé and Nuttall (2004:349), called “people’s relentless determination to negotiate conditions of turbulence to introduce order and predictability into their lives”. In a way, it is about trying to minimise or eliminate the uncertainty.

However, for others, uncertainty is “always a part of engagement in the world [and] it cannot be eradicated” (Whyte 2009a:213). The second response to uncertainty involves people accepting the futility of doing something about the situation to reach full control, order, and predictability as uncertainty is always present. Attaining control of uncertainty may not be possible or preferred. There is what Jenkins, et al. (2005b) refer to as uncertainty of control. Therefore, as a response to uncertainty, some will accept it because it is preferred or beneficial compared to certainty and looking to control uncertainty. It is not a matter of accepting uncertainty or not. What matters is whether there are practical and specific responses to deal with uncertainty. These responses, which are used in attempts to control uncertainty, are “about trying to secure what can be secured in the face of adversity” (Whyte 2009a:215). In doing so, “we actively attempt to create a degree of security and insurance” (Jenkins, et al. 2005b:11). In other words, the aim of dealing with such uncertainties is “a quest for security rather than a search for certainty”(Whyte 1997:3). Seeking security is about strengthening efforts to exert some (and not full) degree of control drawing on social and cultural resources (Whyte 2009a).

This pragmatism characterises how people manage uncertainty. Pragmatism “is an attitude of looking away from first principles...supposed necessities and looking towards fruits, consequences” (James (1974:47) quoted in Whyte 2005). Taking a pragmatic stance is about undertaking rather than undergoing, about doing rather than being, on consequences rather than antecedent trusts (Whyte 2005). It is about seeing people “as actors trying to alleviate suffering rather than as spectators trying to apply cultural, ritual or religious truths” (Whyte 1997:20). Pragmatism may underlie curiosity, exploration (Whyte 2009a), ‘tinkering’ and ‘experimentation’ that people engage in as they address uncertainty. Whyte also noted that people try other things in the hope that they might get

help. According to Whyte (2005:250), “We try to secure that which we value by confronting the problem, recognising the uncertainty of outcomes, reflecting on possible ways forward and interacting to realise intentions”. In the face of failure, people try other things for many reasons, including the hope of success. According to Whyte (1997), the existence of alternatives that people can try out creates uncertainty in that there is no standard guideline for choosing a correct response for a particular problem. Further, in “experimenting” or trying out things, people create other uncertainties.

A vital aspect of this pragmatic stance to dealing with uncertainty is that it is done with, using and in the context of social relations. Uncertainty is a product of social contingencies, which, according to Bledsoe (2002:25) “connote[s] a sense of social ties that underlie all aspects of life”. It is also through social relations that people alleviate or make uncertainty ‘habitable’ (Cooper and Pratten 2015; Jenkins, et al. 2005b; Whyte 1997). Whyte (1997:20) put this idea as follows: “the perils we undergo and the responses we undertake are mediated by the context of meaning we share with others”. She further noted that “[t]he [same] pragmatic attitude of experimentation informs people’s use of government health facilities, drug shops, and private practitioners of biomedicine. They try out various kinds of medicine and use contacts to get the care they think they can rely on” (Whyte 1997:232). Understanding how social relations are implicated in the pragmatics of dealing with uncertainty involves studying how people live in and through uncertainty by examining “changing forms of social dependence in shifting institutional contexts and political economies” (Cooper and Pratten 2015:2). Studying relational aspects of uncertainty also focusses on societal resources, among which are social relations, and access to these, which can determine the possibility of alleviating uncertainty. Attending to social relations highlights the dependencies and interdependencies that characterise situations and the means through which people deal with uncertainty.

Responding to uncertainty can also be about orienting oneself towards and fashioning particular futures and possibilities. This is one of the ways in which uncertainty may be productive. This productivity is evident when considering contexts within which uncertainty emerges, and people’s hopes and aspirations are formed. For example, foregrounding contexts of instability and incoherence illuminates “how uncertainty critically shapes ways of knowing and being” (Cooper and Pratten 2015:1) and “acts as a

source for imagining the future with the hopes and fears this entails”(Cooper and Pratten 2015:2). According to Whyte (2005), as people address adversity, misfortune and uncertainty, they are oriented towards futures they hope or fear, using the available means. They do so in the subjunctive mode, a “mood of doubt, hope, will and potential” (Whyte 2005:251). Studies that have paid attention to temporal aspects of uncertainty point “to how uncertainties shape people’s relationship between the present and the future” by acknowledging the “historical specificity of uncertainty now” (Cooper and Pratten 2015:2). Paying attention to the present and future temporal horizons highlight how people respond to uncertain futures in the form of vigilance, planning, aspirations, despair, and hope. This temporal focus is highlighted in Jennifer Johnson-Hanks idea of vital conjuncture: “socially structured zones of the possibility that emerge around specific periods of potential transformation in a life or lives. They are temporally configurations of possible change, critical durations of uncertainty and potentiality” (Johnson-Hanks 2006:22). The concept of vital conjunctures highlights “...the possible futures that social actors envision hope for, or fear”(Johnson-Hanks 2006:3) and “how these orientations might motivate specific courses of action” (Johnson-Hanks 2006:25).

Imagining futures may entail particular action towards dealing with uncertainty as people seek to attain those aspirations. The means of dealing with uncertainty and their intended and unintended consequences may worsen or create other uncertainties and practices. As noted by Jenkins, et al. (2005b:11), in dealing with uncertainty, “substances, artefacts and techniques – medicines and technologies, or ritual and magic – offer various means of by which we attempt to cope with or control illness and misfortune... With respect to all these, there are generally alternatives available which in themselves encourage further uncertainty about which is the correct response to a particular problem”. Susan Whyte has shown that among the Nyole people of Uganda, the means of dealing with uncertainty included divination to inquire and name possible agents for the misfortune, their motives and suggest remedies for putting the relationship with the agent in order or counteracting it (Whyte 1997). Whyte (1997) found various forms of uncertainty that were ascertained by both the diviner and his/her clients at the outset, during consultations and at the end of the session. For example, divination can reveal many agents as causes, some of whom tell lies (Whyte 1997). Hence, there is the uncertainty of the actual agent that is causing an affliction. For the patients, there is also

uncertainty as to what the agent will do in response to the divination. The language used in divination often expresses doubt, conditionality, and possibility, in short, a lack of certainty; It involves acknowledging the existence of contingency while evoking possible futures (Whyte 2005).

Uncertainty, therefore, can lead to action that is geared towards changing the situation and the self. It also comes from an awareness of the existence of many pathways and hope for desired outcomes. It neither implies a lack of knowledge nor is it addressed with the availability of knowledge. For even where there is knowledge, there can be uncertainty as to what is right or not, what course of action to take or not. Further, uncertainty does not only appear as an outcome of a specific event. In this thesis, I will go on to show that uncertainty fashions futures and possibilities to which people with diabetes in Malawi aspire and hope whether it is in the form of living a life without symptoms, being cured of diabetes or having a 'good *shuga*' when they attend a clinic appointment.

### 2.3 Conclusion

In this chapter, I have shown that anthropological studies on diabetes have problematised the ideas of control and use of technologies in its management. Studies have also explored various means by which patients manage diabetes, highlighting that patients often do not follow what doctors advise them ("non-compliance"). Ethnographic studies that have sought to understand "non-compliance" have employed two concepts: 'tinkering', a collaboration between patients and health care workers, and 'bio-tactics', idiosyncratic strategic changes to recommendations. However, less attention has been paid to uncertainty in diabetes and the forms of practices that emerge in response to it. The many studies on uncertainty have ranged from identifying how uncertainties emerge in different contexts and exploring how people respond to these them. Studies in nursing and public health have suggested that uncertainty is a crucial part of the experience and management of non-communicable diseases. The responses to these uncertainties highlight the pragmatism that patients deal with them, and the productiveness of uncertainty itself.

In this thesis, I consider practices of diabetes management in the face of, and in response to, uncertainty and how these create other uncertainties. My interest is in the how

patients, their relatives and health care workers experience and manage uncertainties. Diabetes, and the Malawian context in which it is managed, present new and unique uncertainties for example whether sugar levels have gone up or not, or the availability of medicine and equipment. In responding to these uncertainties, my study participants said they were “trying” or “experimenting”, and “trying harder”, while calling on various social relations. In this thesis, I describe these “experiments” and process of “trying harder” in terms of what is involved, what motivates them and their implications on diabetes management and the patients themselves. In the next chapter, I describe the methods that I used in researching uncertainties in the context of diabetes management in Malawi.

## Chapter 3

### Reflections on methodology

In this chapter, I reflect on my experiences of conducting ethnographic fieldwork in diabetes management in Malawi. While other research has been conducted within the diabetes clinic at Queens Hospital, most of the people I met there were less familiar with ethnographic methods. Two illustrations highlight how people within the clinics perceived my research and role while conducting fieldwork.

The first of these occurred on my first day at the diabetes clinic at Queens Hospital. Having received permission to start fieldwork, I went to the diabetes clinic to start familiarising myself with what went on. I sat in the Sister's Office<sup>20</sup> as I waited for Sister Maria Mataka. She was the lead nurse at the diabetes clinic to whom Dr Loveness Ndalama had referred me, and who later became one of the 'key' informants for my study. At that time, a female researcher had been coming to the clinic for several weeks to collect data. Her research was part of her degree studies in nutrition at one of the local universities. She was researching dietary practices among diabetes patients using a questionnaire that she was administering to patients. She would go into the shelter where diabetes education was being conducted or the room where patients were waiting to attend consultations with medical doctors. She would then pick out a patient and step outside to administer her questionnaire. As we sat in the Sister's Office, we shared what we were each researching. My colleague had several questionnaires and consent forms. I had my notepad and pen. After wishing each other good luck in our studies, my colleagues asked, "*So, when are you starting [your research]?*" She was surprised when I responded that I had already started right away and that I was not equipped with questionnaires and consent forms as she was.

The second instance occurred five months into fieldwork. Every Tuesday morning, I attended the diabetes education session at Queens or Nguludi Hospitals. Participant observation during the diabetes education session involved sitting with patients as they learnt about diabetes, listening to and engaging in conversations with patients, and taking notes [I reflect on these processes below]. On Tuesday, 28<sup>th</sup> February 2017, I arrived at

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<sup>20</sup> In Malawi, nurses are also called sisters.

the diabetes clinic at 8 am, and Mr Lucius Zimba, a diabetes educator and one of the volunteers from the Diabetes Association of Malawi, was teaching. As he was teaching, a man came to the clinic and was introduced as a clinician from the College of Medicine who was conducting research on Blood Pressure measurements. I gathered that as part of his research, he would be taking measurements on both hands and legs to compare the results. Mr Zimba encouraged patients to go see the clinician after the education session.

Because there was no nurse present at that time in the clinic, the clinician started measuring blood pressure and recording in patients' health passports<sup>21</sup>. He told the patients that after the clinic, those who would want to take part in his research should see him in one of the rooms next to the shelter. As he was going around, he got to where I sat and asked if I had had my blood pressure taken. I said no. He asked if I was a 'guardian'<sup>22</sup>, and I said no, I was a researcher. He asked what research I was doing. I said my research was on diabetes and its management. He responded by saying he was also doing research on diabetes, and then asked whether my interest was in how they manage it. When I responded that I was interested in how people manage it, he said, "*Aa! It is glibenclamide. That is what it is here in Malawi*" [Field notes, Queens Hospital, 28022017].

These two encounters highlight my roles in conducting participant observation, and how people within the clinic perceived me. The clinician's response suggested that what I was researching was obvious, that I did not need to conduct such research. His response also highlights how biomedical providers often limit diabetes management to the medicine that patients take and instructions that they are supposed to follow. His response and that of the nutrition researcher highlight the kind of research that most health care workers in this context were familiar with: quantitative studies in epidemiology and public health. As a teaching hospital for the nearby College of Medicine of the University of Malawi, many research projects are conducted within Queens Hospital. However, few of these are qualitative or ethnographic. As such, most people were less familiar with

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<sup>21</sup> A patient-held medical record in form of a booklet within which diagnoses, medical history and prescriptions are recorded.

<sup>22</sup> A guardian (also known as caregiver) is a family member who is supposed to support the patient in managing their disease. They also provide basic nursing care – washing, feeding, or toileting for patients that have been admitted to wards.

ethnographic research methods as will be clear when I describe processes of getting ethical approval and negotiating access with gatekeepers.

In this chapter, I start by introducing the context in which I conducted fieldwork and within which diabetes is managed in Malawi. In describing the context, I focus on the Malawi health system and the health facilities where my research was conducted. I then describe the process of negotiating access with gatekeepers to access the field (sites), research design including methods and data management and analysis. I also reflect on how my interlocutors perceived me within the field: as a student, a medical student, a 'doctor', and its implications on fieldwork. I also discuss the idea of doing ethnography at 'home' including how fieldwork was entangled in my personal relationships.

### 3.1. Study setting and context

Malawi has a population of about 17.6 million (National Statistical Office 2019). Most of the population are young people: approximately 64% are aged below 15 years, with only 3% over 65 years (Government of the Republic Malawi 2017). Most of the population live in rural areas, with only 15% living in urban areas. The economy of Malawi is predominantly agro-based with agriculture contributing about 28% of GDP (Government of the Republic Malawi 2017).

The Malawi health system has four levels namely community, primary, secondary, and tertiary which are linked through an established referral system (Government of the Republic Malawi 2017). At the community level, health services are provided at health posts, dispensaries, village clinics, maternity clinics and mostly by Health Surveillance Assistants who provide promotive and preventive health care through door-to-door visitations and mobile clinics (Malawi Government 2011). Primary level health facilities include health centres and community or rural hospitals. Health centres are supposed to serve a population of about 10,000 and provide outpatient and maternity services. Community hospitals are larger than health centres, with a capacity of up to 250 beds, and they provide outpatient and inpatient services and conduct minor procedures (Malawi Government 2011). Secondary level facilities include 26 government-run district

hospitals and 40 Christian Health Association of Malawi (CHAM<sup>23</sup>) hospitals of equivalent capacity. These provide referral services to health centres and community hospitals. They also provide inpatient and outpatient services to communities surrounding them (Government of the Republic Malawi 2017). Tertiary level facilities include four central hospitals that are meant to provide specialist health services at the regional level and provide referral services to district hospitals. However, about 70% of services provided at tertiary facilities are those that should have been provided at primary or secondary facilities, because of dysfunction in the gate-keeping system that is meant to ensure that patients only come to tertiary facilities after a referral from secondary level health care facilities (Malawi Government 2011).

Within the Malawi health system, diabetes management is provided in government district hospitals, tertiary level facilities and private health facilities (including hospitals, clinics, pharmacies and drug stores). Until recently, diabetes was uncommon. Consequently, diabetes services were not prioritised, resulting in poorly organised care at the district level and lack of knowledge and skills for care among health care professionals (Kasiya, et al. 2017). A survey of diabetes management at Queens Hospital in 2007 showed that the diabetes clinic had no protocols or guidelines, and that management and screening of complications were left to the discretion of clinicians (Cohen, et al. 2010). There were no diabetes nurses to provide patient education; instead, doctors and clinicians gave patient education during consultations. Consequently, patient education was brief and did not address most components of what patients are supposed to be taught. To improve services, the University of Malawi's College of Medicine and the Malawi Ministry of Health, with support from the World Diabetes Foundation (WDF), strengthened the diabetes clinic at Queens Hospital and strengthened or established diabetes clinics at district and CHAM hospitals in Southern Malawi since 2008 (ibid.). Strengthening or setting up of clinics was done through staff training, emphasis on patient education and introduction of protocols for diabetes management. Following the successful implementation in the Southern Region, the project was extended to the

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<sup>23</sup> Christian Health Association of Malawi (CHAM) is an association of church-owned health facilities and colleges in Malawi. It was established in 1966. It has 187 health facilities (hospitals, health centres, and training colleges) most of which are located in rural and hard to reach areas. CHAM provides 37% of health services in Malawi, and 75% in rural and hard to reach areas.

Central and Northern Regions of Malawi where diabetes clinics were opened at district hospitals starting from 2015.

According to the Malawi Standard Treatment Guidelines, diagnosis of diabetes is based on “2 abnormal blood sugar measurements (FBS>7mmol/l, 126mg/dL or RBS<sup>24</sup>>11mmol/l, 200mg/dL or HbA1C>6.5%)<sup>25</sup> in an asymptomatic patient or 1 abnormal measurement if a patient has symptoms of hyperglycaemia” (Ministry of Health 2015:121). Management of diabetes involves setting treatment aims for patients knowing that some of them require strict glycaemic control with near-normal glucose value targets while for others, symptom control and avoidance of severe side effects may be the ultimate target (Ministry of Health 2015). There is also regular checking of blood pressure with a target of below 130/80mmHg, discouraging smoking, education about foot care and screening for foot problems, and annual screening for visual acuities and cataracts.

Within most biomedical health facilities, management of diabetes uses the following medicines as listed in the Malawi Essential Medicines List (2015): Glibenclamide (5mg tablets), Metformin (500mg or 850mg tablets), and insulin (Soluble, Human Actrapid 10mL vial). Private hospitals and pharmacies stock other medicines that patients may use, for example, tripride 2. However, these are expensive and hence not affordable for most patients. Management of type 1 diabetes is two daily doses of Lente/protophane insulin (Ministry of Health 2015). The daily dose is approximately half the patient’s body weight. For example, a patient who weights 60kg gets 30 units of insulin per day, divided into two doses (2/3 daily dose, half an hour before breakfast and 1/3 taken half an hour before the evening meal, preferably 12 hours apart). Metformin (500mg) can be added to insulin treatment to improve glycaemic control and curb weight gain in adults (Ministry of Health 2015). Management of type 2 diabetes starts with adjustment of diet or weight reduction (if obese) and increased exercise as this may control blood glucose without the need for drug therapy. The Malawi Treatment Guidelines recommend that “Wherever

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<sup>24</sup> Random Blood Sugar

<sup>25</sup> HbA1c of less than 6.0% is considered normal, 6.0% to 7.5% is good control of diabetes mellitus, 7.6% to 9.0% is considered unsatisfactory control, and HbA1c of more than 9.0% is regarded as very poor control of diabetes mellitus (Nakanga, Crampin and Nyirenda, 2016)

possible, give a 4 – 6 week trial of diet before introducing oral hypoglycaemic agents” (Ministry of Health 2015:129).

According to the guidelines, metformin is the drug of choice for type 2 diabetes in Malawi. If a patient presents with high sugar levels after the 4 to 6-week trial, he or she gets a prescription of Metformin (500mg) twice daily, up to a maximum of 1g (2 tablets) twice daily. If glycaemic control is still poor, daily dose glibenclamide (5mg) is added, increasing to a maximum of 10mg twice daily. The guidelines also stipulate that 20% of type 2 diabetes patients will eventually require insulin (Ministry of Health 2015). For type 2 diabetes patients, insulin is used in the same way as it is used for type 1 diabetes patients, starting with Lente 0.3U/kg bodyweight.

Alongside these medicines, a diabetes patient is supposed to increase fibre intake, reduce refined sugar intake, and eat three meals that contain complex carbohydrates (Ministry of Health 2015). Patients are also supposed to eat more before undertaking exercises that they are not used to doing. Meals that contain complex carbohydrates are meant to reduce the risk of hypoglycaemia. The Ministry of Health also published the National Nutrition Guidelines for Malawi which among other things, include recommendations for the control and prevention of diabetes centred on what they refer to as the 3Ds (Disciplined lifestyle, Diet and Drugs) (Ministry of Health, 2007).

To understand how diabetes is managed informed by these guidelines and the context I have laid out above, I conducted fieldwork at Queen Elizabeth Central Hospital in Blantyre City, St Joseph’s Mission Hospital in Chiradzulu District and outside these facilities (patients’ homes, workplaces and herbal ‘clinics’). Both Blantyre City and Chiradzulu District are in the Southern Region of Malawi (Figure 1 below). I selected these two sites because I wanted to understand experiences of diabetes management among rural and urban patients accessing services at a government hospital with a well-established clinic, and a mission-owned facility with a recently established diabetes clinic. I did this because the government and the Christian Health Association (CHAM) are the main providers of health services in Malawi. I now describe these health facilities to highlight the characteristics that have implications on the uncertainties that prevail and inform the patients’ and health care workers’ “experiments” that take place within them as part of diabetes management.



Figure 1 Map of Malawi

### 3.1.1. Queen Elizabeth Central Hospital, Blantyre

The Queen Elizabeth Central Hospital was built in 1953 as a replacement for several smaller clinics and the Blantyre Mission Hospital<sup>26</sup>, which was struggling with the increasing patient load as a consequence of the growing population (Wendland 2010).

At that time, Malawi (then called Nyasaland) was still a British Protectorate. Then a 400-bed hospital, Queens Hospital was part of the infrastructure (roads, railway lines) that

<sup>26</sup> The Blantyre Mission Hospital was opened in 1896 (Wendland 2010).

the colonial government constructed to quell the resistance to the imposition of the Federation of Rhodesia and Nyasaland in 1953 (Wendland 2010). At present, Queens Hospital is one of the four tertiary care facilities in Malawi. Over the years, bed space has increased to 1100. While it serves as a referral hospital for the Southern Region of Malawi, it also serves as a district hospital for Blantyre. Despite the shortage of supplies and equipment, Queens Hospital has three general theatres, one orthopaedic theatre, two Obstetrics & Gynaecology theatres, two ophthalmology theatres, a burns/plastics theatre, two emergency/trauma theatres, a four-bed ICU unit and CT/MRI and standard X-ray facilities<sup>27</sup>. The hospital has several clinics, including antiretroviral therapy, hypertension, and diabetes.

While management of diabetes has been happening at Queens Hospital since the 1960s (Goodall and Pilbeam 1964), the diabetes clinic as it was at the time of fieldwork had been functioning since 2008. The organisation of the clinic, and diabetes management in public health facilities Malawi, were informed by the ‘successful’ implementation of the Direct Observation Therapy, short course (DOTs) for tuberculosis management and the delivery and monitoring of Antiretroviral Therapy (ART) (Allain, et al. 2011). For example, patients have regular clinic appointments at diabetes clinics at which they get medicine and attend education sessions. Staff training, including nurse specialists and the introduction of standardised management guidelines and protocols with funding from the World Diabetes Foundation led to an improvement in the quality of care (Allain, et al. 2017). According to Dr Bertha Ngwalo, the coordinator for the diabetes project at the College of Medicine, a clinician and a nurse were trained in diabetes foot care in Tanzania as part of the project. These were supposed to train other providers in the clinic. The diabetes clinic provides free tertiary level clinical diabetes services. There were about 2000 registered diabetes patients at Queens Hospital. While most of these patients were from Blantyre, some had been referred from district hospitals in the southern region to receive specialist advice on the management of complications of diabetes (Allain, et al. 2017). About 80 or more patients attended each diabetes clinic. ‘Stable’ patients were seen every quarter, which entail three appointments every year (Allain, et al. 2011). Patients who were ‘unstable’ or with high sugar level were seen more often.

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<sup>27</sup> <https://ameca.org.uk/directory/listing/queen-elizabeth-hospital-malawi> [Accessed 25/08/2019]

The diabetes clinic at Queens Hospital was conducted every Tuesday. Patients came as early as 6 am to have a blood sample taken in the laboratory. Patients were told to come to the hospital before eating anything in the morning because the blood samples were used to measure fasting blood glucose, which was the only measure of diabetes control



*Figure 2 Diabetes Education Session, Queens Hospital*

used at the clinic. As was previously reported by Cohen, et al. (2010) and Burgess, et al. (2017), there were no routine measurement of lipids, glycosylated haemoglobin<sup>28</sup> (HbA1c), and urine test sticks for microalbuminuria<sup>29</sup>. Collection of blood samples ends at 8 am. From the laboratory, patients went to the diabetes shelter where they attended diabetes education. Nurses or a diabetes educator (volunteer from the Diabetes Association of Malawi) usually did this. During the diabetes education sessions, a volunteer or clerk measured weight and blood pressure and recorded it in patients' health passports. During the diabetes education session, some patients would be having

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<sup>28</sup> Average blood glucose values over a period of between two to three months.

<sup>29</sup> Defined as either a concentration of 20–200 mg/l of albumin in a random urine sample, or 30–300 mg of albumin in a 24-hour urine collection. It is a marker of current, and predictor of future progressive, renal disease, especially in diabetes mellitus and in patients with hypertension (Plange-Rhule, Dreyer and Eastwood, 2013).

their breakfast: tea and brown bread sold by a volunteer from the Diabetes Association of Malawi or food that they had brought from home.

Diabetes education sessions usually last for about an hour and thirty minutes. After the education session, some patients who have ulcers will attend the diabetes foot care sessions run by one of the nurses, Sister Maria Mataka. Other patients sit outside on hospital grounds as they wait for the clinic in the afternoon. Around 12:00 noon, one of the clerks goes to the laboratory to collect results of the sugar measurements. These results were then brought to the Sisters' Office to categorise patients according to whether they would attend a consultation with a doctor/clinical officer or a nurse. Consultations start at 1:30 pm. During the clinic, patient consultations conducted by nurses and clinicians consist of an assessment of glycaemic and blood pressure control and overall health. After the medical review, patients that have been prescribed medicine go to the pharmacy to collect them if available free of charge. From the pharmacy, patients went back to the laboratory to book their next appointment. Usually, the clinic finishes after 4:00 pm.

In most instances, glibenclamide was available in good supply while metformin and insulin (Lente and soluble) were usually in smaller quantities. As such, patients were often given a portion of their prescribed medicines (Allain, et al. 2017). Such patients come again after a month (or when their supply has run out) to collect their remaining medicine. They are asked to come to collect their medicine at most three days before their supply runs out. Stock-outs of metformin and insulin were common such that patients were asked to buy them at local private pharmacies.

### 3.1.2. St Joseph's Mission Hospital, Chiradzulu

St. Joseph's Mission Hospital (locally known as Nguludi Hospital) is located in Nguludi, a rural area in Chiradzulu District. People in Nguludi area are mostly subsistence farmers, growing maize, pigeon peas, and beans. There are several ethnic groups around Nguludi area, including the Yao, Mang'anja and Lhomwe.

Nguludi Hospital is located next to St. Joseph's Roman Catholic Parish and St. Joseph's College of Nursing. It belongs to the Christian Health Association of Malawi (CHAM). A Roman Catholic Congregation, the Daughters of Wisdom Sisters, established the hospital

in 1953. Nguludi Hospital is a secondary care health facility with 190 beds. It has OPD and HIV services (outpatients), maternity and antenatal, wards (male, female and paediatric), a dental clinic, primary healthcare services, two large operating theatres, minor theatre for small procedures, X-Ray, pharmacy, laboratory, and ultrasound facilities<sup>30</sup>.



*Figure 3 Waiting room (left) and Table during diabetes clinic*

Nguludi Hospital operates on a ‘not-for-profit’ basis. Its primary funding comes from the government, which provides salary grants for all 200 employees. Funding from the government also covers 75% of the hospital’s total annual budget. The remaining 25% comes from patient user fees (20%) and donations (5%). Diabetes management is one of the services for which patients must pay. Patients pay for testing strips for blood sugar level testing and the medicine that they are prescribed. Patients do not pay for consultations.

At the time that I conducted fieldwork, the diabetes clinic at Nguludi Hospital had about 65 registered patients who come from surrounding villages but also from neighbouring districts: Blantyre, Mulanje and Thyolo. Usually, about half of those turned up for their appointments. The diabetes clinic is conducted on the first Tuesday of each month. The clinic starts at 6:00 am in the waiting room (Fig. 3 above) of the Outpatient Department (OPD). The nurses typically start arriving just after Six O’clock. Usually, there are two nurses and two nurse aides (patient attendants). At times, student nurses from Nguludi College of Nursing and Midwifery come to assist in the clinic as part of their training. When patients arrive, they are given their master cards –a hospital record of their

<sup>30</sup> <https://ameca.org.uk/directory/listing/st-josephs-hospital-malawi> [Accessed: 25/08/2019]

previous visits which include weight, sugar level and medicine. At the same time, a nurse or clinical officer conducts diabetes education sessions. On some occasions, a member of the Diabetes Association of Malawi is asked to do this. A nurse aide measures weight and blood pressure, moving along each row as patients move forward to get their fasting blood glucose measured by a nurse who sits in front of the room (Fig. 3 above). The nurse uses a glucometer to do these measurements. At times, the nurse comments on fasting blood glucose measurements results which everyone can overhear. Just before I completed my fieldwork in June 2017, the clinic started measuring height and BMI after one of the clinicians had attended a meeting organised by the College of Medicine Diabetes Project at which they were given a new weighing scale, blood pressure monitor and BMI wheels.

Soon after these measurements, patients wait for consultations in the corridor next to the OPD waiting room. Consultations are conducted in the first three rooms on one end of a long corridor which is in the middle of the OPD building. Outside each of these rooms, there are benches on either side of the door. This is where patients sit and wait for their consultations. Usually, three clinical officers conduct the consultations. Because few patients come, consultations are usually finalised by 8 am. After consultations, patients pay for the medicine at a small kiosk at the back of the waiting room. They then go to collect their medicine from the pharmacy which is located in the main building.

### 3.2. Negotiating access

Conducting fieldwork entailed negotiating access from different gatekeepers, including ethics boards, hospital administrators, guardians, clinicians/doctors, and nurses who run diabetes clinics. Before starting fieldwork, I sought and was granted ethical approvals by the Ethics Committee at Durham University's Anthropology Department and the National Health Science Research Committee (NHSRC) in Malawi (Number 16/8/1648). I had assumed that I would not have problems to start fieldwork, considering that I was doing fieldwork at 'home' and I was familiar with ethics approval application processes. However, despite my knowledge of the 'field' and processes, getting access to my field sites did not go ahead as I had expected.

It took about one and a half months to receive my approvals from both Durham University and the NHSRC in Malawi. However, it took another month before I could start fieldwork at the two hospitals. On the first day that I went to Nguludi Hospital to seek permission to start fieldwork, Sister Gloria,<sup>31</sup> the hospital administrator, was attending a meeting outside the country. I waited for a week before she got back. When I met her on 21<sup>st</sup> August 2016, our meeting was quite short. After I had explained what my research was about, and what it would involve, Sister Gloria said I was free to start visiting the diabetes clinic. She then asked her secretary to escort me to Mrs Thokozani Njewa, a senior nurse who was running the diabetes clinic alongside Tereza Malikebu, a clinical officer. Sister Gloria told the secretary to inform Mrs Njewa that *“I had already been to the Sister”* [Field notes, Nguludi Hospital, 21082016]. When she is not running the diabetes clinic, Mrs Njewa sits in the ART clinic, which is also located in the Outpatient Department Building. The ART clinic is one of the rooms along a long corridor that runs from one end to the other end in the Outpatient department. When we arrived, the secretary knocked, open the door and introduced me as *“the visitor from last week whom I told you about”* and said: *“he has just seen the administrator, who asked me to bring him to you”* [Field notes, Nguludi Hospital, 21082016]. Mrs Njewa was with some nursing students, and we were asked to wait outside. After the students had left, I was invited in, and Mrs Njewa started telling me about her background and the clinic in terms of how it is organised, where the patients come from, and the challenges that patients face considering that they have to pay for services. After agreeing that I would attend the next clinic, Mrs Njewa asked what my background was, by which she meant my education qualifications. I responded that I am a social scientist and that I do not have any medical training.

Perhaps because not many research projects were taking place at Nguludi Hospital compared to Queens Hospital, it was easier to get permission to start fieldwork. While I got verbal approval soon after explaining to the hospital administrator what my research was all about, I had an entirely different experience gaining access to Queens Hospital. I was asked to send a copy of my research proposal and ethics approvals forms from Durham University and the NHSRC to Dr Gregory Gondwe, Head of the Department of Medicine at Queens Hospital under which the diabetes clinic falls. He forwarded the

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<sup>31</sup> Sister Gloria is a member of the Roman Catholic Community of Sisters called the Daughters of Wisdom. At Nguludi Hospital, the word Sister is not used for nurses in general as is the case at Queens Hospital and other government hospitals in Malawi.

documents to Dr Loveness Ndalama, a consultant and lead clinician in the diabetes clinic. Dr. Ndalama responded with comments and questions on the project including that the number of patients that I had indicated for an interview could be increased from 40<sup>32</sup> to 80 and that my interview guide needed clarity to ensure that I do not collect data that do not address my objectives.

Dr Ndalama also recommended that I needed to attend several diabetes clinics so that I could familiarise myself with what happens in the clinic. She also questioned how I would ensure that I minimise disruption considering that *“the clinic is busy and many patients are in a hurry to be seen so they can collect medication before the pharmacy closes”* [Email from Dr Loveness Ndalama, 06092016]. She had two questions that highlighted our differences in research methodology. She asked for clarity on specific areas I would be looking at to understand patients’ experiences. She also asked about the standards that I would use to compare “good compliance” among patients, correct diabetes diet, adequate physical activity, and having a good understanding of diabetes. While one of my research questions was “How do patients experience diabetes?”, I did not have a research question or objective on measuring “good compliance” or understanding of diabetes. I responded by clarifying that I was not looking to understand whether there is “good compliance”, instead what and how patients manage (whether “good” or “bad compliance”). I also told her of the anthropological interest in understanding experiences and that it is not a vague term that is hard to ‘measure’. Dr Ndalama responded to invite me to start attending the diabetes clinic, which was supposed to start at 1:30 pm<sup>33</sup>.

After starting fieldwork in the diabetes clinics, I realised that even though I had been granted permission, I still had to negotiate my access to some areas. For example, one Tuesday afternoon, I had planned to attend consultations at Queens Hospital. When I got there, Dr Ndalama was not around, so I approached another doctor, Dr Yohane Nkoloma. Because different doctors turn up, I had not been introduced to Dr Nkoloma. I explained to him my research and showed him copies of the ethics approvals from NHSRC and

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<sup>32</sup> The NHSRC requires that applications for ethical approval should state the number of patients that will participate in the study. To address this requirement, I indicated that I would interview 40 patients, even though I knew the number of patients that would participate through interviews, conversations and observations would be more than 40.

<sup>33</sup> In practice, the clinic starts after results have come from the laboratory or doctors have arrived to start consultations, whichever is last.

Durham University. However, he still would not allow me to sit in during the consultation. He asked me to have my ethics approval letters endorsed by Dr Gregory Gondwe before I could get access to his consultations. After a week, I got the endorsement, and I was allowed to attend Dr Nkoloma's consultations. Despite having a letter endorsed by Dr Gondwe, my access to consultation rooms was not always guaranteed. Some doctors and clinicians were not 'comfortable' to have me in their consultation rooms. A young clinician at Nguludi Hospital refused to have me in his consultation room because he was 'new' and wanted me to sit with a more experienced clinician. At Queens Hospital, a white doctor did not allow me to observe during her consultations because she did not want the room to be overcrowded. She always had a translator during her consultations.

### 3.3. Research design

I conducted fieldwork from September 2016 to in July 2017. I followed this with a two-week visit in September 2017 to interview study participants based on gaps in data I had noted during analysis. My research was an ethnographic study of experiences of diabetes, its care and management practices in Malawi. I was interested in patients' perceptions of diabetes and its causes, how they experience it, its symptoms and complications, patients and health care providers' (including those outside formal health services) practices (related to diet, physical activity, and measuring blood level) of diabetes care and management.

Fieldwork was a combination of a hospital ethnography (Van der Geest and Finkler 2004) and 'traditional' ethnography in patients' homes and communities. I started fieldwork at the two health facilities because it was more practical and convenient to get diabetes patients within diabetes clinics compared to the community. Moreover, I was not only interested in patients' practices of diabetes management but also those by health care providers. From the hospital setting, I followed patients into other areas of their social life, including homes and workplaces. Most significantly, fieldwork extended to other practices of diabetes management, including 'herbal' clinics and religion.

### 3.4. Participants

Participants in this study included diabetes patients, their caregivers ('guardians'), formal health care workers involved in diabetes management, staff from Ministry of

Health non-communicable diseases unit, staff from non-governmental organisations involved in diabetes programs and other care providers from folk or 'traditional' sector. I recruited my participants through several pathways. I approached most patients during diabetes clinics and asked if they could take part in the study.

I was also referred to some participants by other patients and health care workers. Especially at the beginning of fieldwork and upon telling them what my research was about, patients and health care workers often suggested participants whom they thought would be "*interesting to talk to*". For example, when I was seeking permission from Sister Gloria, the hospital administrator at Nguludi Hospital, she informed me that there were several members of staff with diabetes who attend clinic. Mrs Njewa, the lead diabetes nurse from Nguludi Hospital, referred me to two of these staff members both of whom had type 2 diabetes: Mrs Jacqueline Mangani (a clerk) and Mrs Zion Chipofya (a nurse instructor at the nearby St. Joseph's Nursing College). Mrs Njewa told me that Mrs Zion Chipofya was one of the 'best' patients who had managed to lower her '*shuga*' such that she no longer needed taking medicine and was managing by having a strict diet. At Queens Hospital, Sister Mataka, the lead nurse in the diabetes clinic, referred me to Mrs Joyce Jenala (type 2 diabetes). Mrs Jenala introduced me to Mrs Anastasia Kadewere (type 2 diabetes, Queens Hospital) because she was one of the patients who had once stopped taking hospital medicine after a pastor from one of the Pentecostal churches had prayed for her. Mrs Jenala also referred me to George Nyasulu, a type 1 diabetes patient. I did not restrict myself to interviewing and observing participants that were considered 'best' or 'experienced' patients. I also approached and interviewed other patients during the diabetes education sessions or in the waiting room before consultations.

I identified participants who were providers of herbal medicines in three ways. Firstly, I was referred to some of them by patients from both Queens and Nguludi Hospitals who had used their products. For example, Mrs Monica Chisale (a type 2 diabetes patient from Nguludi Hospital) referred me to Mr Pempho Galimoto, a provider of herbal medicine who has written two books on it. Mrs Chisale showed me one of those books when I visited her at home in Bangwe Township. She also gave me Mr Galimoto's phone number. Secondly, I knew about other providers through the media. For example, Cryton Njoka, herbalist from Bayethe Naturals, had advertisements in newspapers and on television. I saw these advertisements and decided to go to his 'clinic' located near Queens Hospital

in Blantyre City. Thirdly, I came across some providers of herbal medicine as I was moving around. That is how I came to meet young women who went around townships selling 'juices' in small plastic bottles and Brown Chapola, a herbalist who usually sat at a park in Limbe town, Blantyre City.

Not all participants that I approached agreed to participate in the study. Only one female patient from Nguludi Hospital refused to take part. Recently diagnosed patients often refused to take part in the study, saying they did not know much about diabetes to answer my questions. They would then refer me to those patients that they perceived as 'more experienced', those that had lived with diabetes for longer. In such instances, I would tell the recently diagnosed patients that their experiences were also of interest for me and hence, I would still want to talk to them. While some of these would later agree to participate, a few insisted that they were not competent to answer

In this study, I used three research methods: interviews, participant observation, and review of documents. Use of each of these methods depended on the setting and participants. For example, informal conversations were often part of participant observation during diabetes education sessions. I now reflect on how I used each of these methods.

#### 3.4.1 Interviews

Diabetes patients, health care workers involved in routine diabetes care and patients' family members or 'caregivers' were interviewed as part of this study. I approached patients who took part in this study on clinic days at Queens and Nguludi Hospitals. At Queens, I spoke to patients about the study soon after the diabetes education while they were waiting for the consultations in the afternoon. I did this to ensure minimum disruption during the clinic. At Nguludi Hospital, either I approached patients before the start of the diabetes clinic or after they had collected medicine from the pharmacy. Some patients would sit in the hospital kitchen while others would rush home to have breakfast.

Altogether, I interviewed thirty-nine (39) diabetes patients (19 females, 20 males; 24 from Queens Hospital and 15 from Nguludi Hospital<sup>34</sup>) within an age range of 19 to 70 years. Among these patients, 24 had type 2 diabetes, while 7 had type 1 diabetes<sup>35</sup>. Most of the patients were interviewed at least twice. Interviews were conducted at patients' homes, at the diabetes clinic or their workplaces. Patient interviews focused on how patients had been managing diabetes from the time they were diagnosed to the present. Interviews addressed the following areas: perceptions of diabetes, its symptoms, and causes; experiences of living with diabetes, how it was diagnosed, how it is supposed to be managed, and how it is managed in practice and challenges they face in the process. While I had an interview guide, interviews were less formal and often proceeded as a chat. The duration of the interviews ranged from twenty-five minutes to one and a half hours. I also had, and overheard, many conversations about diabetes and its management among patients, or between patients and their 'caregivers' and between patients and health care workers. Conversations were mostly about how they were managing, challenges, what they thought about some of the messages on diabetes, and what they thought about diabetes. These conversations were written down as part of my field notes.

Some of these interviews were conducted with key informants, "people with recognised special expertise in a topic of interest to the researcher" (Schensul and LeCompte 2012:30). In this study, key informants were government officials, providers of herbal medicines and staff from non-governmental organisations with knowledge of diabetes and its management in Malawi. These included the Head of the NCDs Unit at the Ministry of Health, the District Health Officer for Blantyre, the Head of the NCDs at Queens Hospital, leaders of the Diabetes Association of Malawi, Jiya-Vannie Diabetes Foundation, the College of Medicine Diabetes project coordinators, medical doctors/clinicians and nurses. I interviewed ten of the key informants and had informal conversations 20 of them.

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<sup>34</sup> During fieldwork, four patients who I had first met at Nguludi Hospital transferred to Chiradzulu District Hospital, a government hospital located 40kms away. They could not afford to continue paying for their medicine.

<sup>35</sup> Eight (8) patients did not know their diabetes type. Their health passports also did not show their diabetes type.

### 3.4.2 Participant observation

Participant observation “involves going out and staying out, learning a new language (or a new dialect of a language you already know), and experiencing the lives of the people you are studying as much as you can.... establishing rapport and learning to act so that people go about their business as usual when you show up”(Bernard 2006:334). In most instances, people appeared to go about their business even when I was present. Patients during consultations with health care workers talked about their ‘problems’ in my presence, some of which could be considered sensitive. The same can also be said in diabetes education, where my presence did not appear to hinder what was taught, and patients asking questions. During participant observation, my participation was limited because I did not have diabetes and I was not caring for a diabetes patient. There was a limit as to how much I could share the experience of patients living with diabetes or their health care workers. I could not directly experience living with, and managing diabetes as patients or their guardians did. I could not feel the uncertainty that comes from not knowing whether ‘*shuga*’ had gone up or down. For these experiences, I relied on what my participants said.

I could only participate in particular settings. I participated in activities taking place in diabetes education sessions, foot care clinics, consultations and in patients’ homes. For example, during diabetes education sessions, I sat among patients and took notes. At times, nurses asked me to weigh patients, measure blood pressure or go to the Sister’s Office to collect blood pressure monitors or files. During foot care clinics, Sister Mataka would ask me to put on gloves and assist her as she was dressing foot ulcers. In their homes, patients shared their meals, and we ate together. At other times, I would escort patients as they went about running their errands. Most of the times, we would sit outside their homes and talk about diabetes and other topics that emerged.

On the other hand, there were many instances where I could only observe what was happening rather than participate in the activity. For example, during diabetes clinic consultations and in the wards, I only observed what was happening rather than participate. Occasionally, some doctors would send me on an errand – get laboratory forms, for example. In some instances, I was asked to leave the consultation room,

especially when doctors needed to conduct examinations that involved patients taking off their clothes.

Doing participant observation in the clinics had its challenges. Because of the number of patients at Queens Hospital and fieldwork taking place in multiple settings, it was difficult to follow the same patients in different consultations with medical doctors, clinicians, and nurses. At times, there were up to six medical doctors conducting consultations at Queens Hospital. It was not possible to tell in advance which doctor would see a particular patient. At Nguludi Hospital, on the other hand, it was possible to attend consultations with the same patients over time because there were few patients and often two or three clinicians seeing them. Another challenge had to do with taking notes during the clinics. This was possible in the consultation room but during diabetes education sessions. It was not possible to take notes without drawing attention to myself. Often, some patients would ask what I was doing, and I would inform them that I was student who was conducting research. Often that was a good starting point for an interview after the session. At times in clinic consultations, there were students from the College of Medicine or the Malawi College of Health Sciences. Like me, these students always had note pads and took notes during consultations. Where I could not take any notes, I often waited until the end of the activity, and I would sit down to write down as detailed notes as possible.

### 3.4.3 Documents and media

Government and some non-governmental organisations have produced leaflets and pamphlets about diabetes and its management. For example, in conjunction with the University of Malawi, College of Medicine, the Diabetes Association of Malawi has produced leaflets on “What is Diabetes”. At Nguludi Hospital, health care workers had a leaflet on an appropriate diet which they distributed to newly diagnosed diabetes patients. Providers of herbal medicines also had leaflets that show the ingredients of their medicines or the diseases that they “cure”.

Patients also shared with me their hospital records, including health passports and biochemistry results forms, where their sugar levels were recorded. These health passports also had recordings for weight, blood pressure, doctors’ notes, and prescribed medication. Patients showed me these records to, among other reasons, verify their diabetes type, or to show how they were doing.

The growing recognition of diabetes and its contribution to mortality and morbidity has seen increased media coverage of diabetes and activities around it. As such, I paid attention to what was written about diabetes in local newspapers. Many providers of herbal medicine and pastors/prophets from Pentecostal churches also advertised their healing practices in newspapers. They also host programmes on local television and radio stations. Some have uploaded these programmes on Facebook, YouTube and specific websites for their products. During these programmes, providers of herbal medicines introduce their medicines, diseases they were meant to 'cure', and where people could buy them. Some programmes also include testimonies from patients that have been 'cured' using their medicine.

### 3.5. Data management and analysis

I had three different sets of data: recorded and transcribed interviews and programs aired on local television and radio stations, field notes for participant observation and conversations, and printed documents (including newspaper articles, leaflets and advertisements) and photos. Data management involved naming files using anonymous identification numbers and pseudonyms, sorting and classifying data appropriately. It also involved organising the data according to participant types (patients, caregivers and health care workers) and facility from which they access services. A Microsoft Access database was created to organise the individual characteristics of all the participants.

With permissions from participants, interviews and discussions were recorded using a digital recorder. Soon after interviews, recordings of interviews were downloaded onto a laptop. The recordings were then removed from the recorders. As most of the interviews were conducted in the local language (Chichewa), I transcribed and translated them into English. I recruited a well-trained and experienced research assistant to assist with transcription and translation. I did this to reduce the amount of time I spent on transcriptions and to concentrate on the preliminary analysis of data, which informed further questions and direction of my research. I have worked with the research assistant in previous research projects, and I retrained her on ethical issues with an emphasis on the confidentiality of the data. To avoid losing data in translation, I had my research assistant transcribe the interviews verbatim and translate interviews into English. The documents she produced had both Chichewa and English. I went through each of these

interviews to ensure that the translations were capturing what the participants had said. In this process, I also anonymised all the interviews to ensure the confidentiality of the study participants. All the data were stored on my password-protected laptop. The interview recordings that my research assistant transcribed and translated were deleted as soon as she completed working on them.

Data analysis was an on-going process that started while in the field. Analysis of emerging issues informed new questions for research and participants to take part in the study, for example, herbalists. Data were analysed using NVivo 12. After uploading the interviews, I read them and starting open coding of the transcripts. This coding was informed by what I found interesting and relevant to my research questions. I created a coding framework from open coding of transcripts and informed by my interview guides and theoretical review of literature. During coding, I started creating annotations and memos, where I recorded what was emerging and how it related to my research questions — writing memos also meant thinking about each question and how it had been addressed and whether there was a need to seek clarification. I then included such questions in my subsequent interviews and observation sessions. Through creating memos, I also started coming up with themes of what the data was revealing. This process involved going back and forth between interviews, codes and the themes that were emergent and revising them.

### 3.6. Ensuring no harm: consent, benefits, and confidentiality

Conduct of this research was guided by the ethical standards stipulated by the Framework of Guidelines for Research in the Social Sciences and Humanities in Malawi (National Commission for Science and Technology 2011), Association of Social Anthropologists in the UK and the Commonwealth (2011) and other international ethical guidelines. I have already reflected on the fact that getting approval from ‘gatekeepers’ to access the ‘field’ was a continuously negotiated process. In this section, I consider the procedures I undertook to ensure that my study was not ‘harmful’ to the participants, especially patients and health care workers. I reflect on processes for getting consent, minimising/anticipating potential harm and ensuring privacy and confidentiality for my study participants.

All the participants were above 18 years of age and hence, could give consent on their own. Only one girl, Odetta Selemani (type 1 diabetes patient from Nguludi Hospital), was a 19-year-old secondary school student. Even though she was of age to give her own consent, interviews with Odetta were done in the presence of her mother, who was also her 'guardian'. Patients who agreed to participate signed a consent form, a copy of which I retained as part of records for this study. I gave a copy of the consent form to each of the participants who consented to keep for their records. Recruiting participants started with introducing the study aims and the implications for participation. Most importantly, I highlighted that I planned to meet them several times, preferably at their homes, workplaces or anywhere they would prefer. I had translated my information sheet which contained the details of the study and the informed consent form into the Chichewa, a language which all the participants spoke, and some could read. When asking them to participate, I emphasised that their participation in the study was voluntary, and they could stop it at any time. I also repeatedly told participants that I was not going to share what they say with the health care workers and their participation (or refusal to do so) would not have any impact on the services that they get at the hospital.

During the interviews and conversations, I was aware that telling stories of diagnosis and earlier experiences of diabetes would be linked to other aspects of life, which could cause distress for patients. Participants like Mrs Jenala and Mr Zimba told me stories about the loss of their partners as we talked about diabetes. Mrs Jenala also described how her life changed following the death of her husband, and how that meant managing diabetes became a challenge. Therefore, I had to ensure that participants were protected from such distress. As such, I often reminded study participants that they could stop the interview at any time if they needed to and that they were not obliged to answer all my questions. Interviews with patients also entailed accessing sensitive data about their diabetes and other diseases. For example, during interviews and conversations, some patients would show me their hospital records (health passports, laboratory forms) "*so that I could see for myself how they were doing*" [Mrs Malewezi, type 2 diabetes patient, 16092017]. These records included other sensitive information, including HIV status. I also had access to such sensitive information when patients and health care workers talked about it during interviews and consultations, respectively.

Prior to each interview, I sought permission to record. A unique number rather than the name of the participant was used to identify each interview recording. I stored all participants' personal data (including age, sex, type of diabetes, village) in a password-protected Microsoft Access Database. Links between participant, their unique identification numbers and pseudonyms were stored in this database. Throughout this thesis, I have used pseudonyms for all the participants, the location of their homes and workplaces to protect their privacy. However, I have not anonymised the two hospitals where I conducted fieldwork. Each of the two hospitals is unique. Queens Hospital is the only referral hospital in Blantyre and the only one with a large diabetes clinic in the Southern Region of Malawi. Nguludi Hospital is the only secondary level CHAM health facility in Chiradzulu. Therefore, hiding their names would have been pointless.

### 3.7. 'Patient', 'Doctor' or 'Student': (perceived) roles in the field

The vignette at the beginning of this chapter shows how, as I participated in a diabetes education session at Queens Hospital, a clinical officer thought I was a patient. Participant observation in the hospitals entailed listening and observing while sitting with diabetes patients in the waiting room or the diabetes shelter. In those settings, I looked like everyone else (except for my note pad). It is not surprising that the clinical officer in the opening vignette mistook me for a patient or a 'guardian' as it was the first time that we met. At both Nguludi and Queens Hospitals, not the same clinical officers and medical doctors conduct consultations during each diabetes clinic. Therefore, because I observed one clinician/doctor at a time during clinic consultations, some of them did not know my research or me. Hence, I always had to introduce myself (and my research) to clinicians that I was meeting for the first time and ask them permission to observe as they conducted consultations.

Partly because I had not been introduced to them, some patients and health care workers assumed that I was a doctor or a student doctor. Some patients thought I was a doctor because they had seen me in consultation rooms, in the Sister's Office at Queens Hospital or helping in measuring weight and blood pressure. For others, the assumption that I was a doctor could have come because most of the doctors were young, and I was often in their company. Moreover, at both Queens and Nguludi Hospitals, there were student

doctors/clinicians who would attend diabetes clinic consultations as part of their training.

Patients who assumed I was a (student) doctor often asked me about their disease and its management. For example, patients that were using insulin often asked whether they would revert to oral medication if they maintained 'good' sugar levels over time. Some patients would ask whether it was right for them to eat a particular food, highlighting uncertainty around diet. Some health care workers assumed that my interest in researching diabetes was because I had medical training. On several occasions, and despite having introduced myself as a social scientist, some clinicians from Nguludi Hospital still thought I was a medical doctor or had had medical training. They would think that I was evaluating their practice, and they would ask me if they were doing the 'right thing'.

I reflect on this because it could have influenced what patients were willing to tell me about how they were managing diabetes. As I will show, doctors often sharply reprimanded patients who were not "complying". Patients who thought that I was a doctor may not have been willing to tell me their digressions for fear of reprimanding. However, I realised that even though I sat with doctors during consultations, some patients were still willing to tell me about their digressions from how they ought to manage. One such instance occurred during a consultation by Dr Ndalama at Queens Hospital. One of the patients had a remarkably high sugar level. Dr Ndalama asked what has been happening; he responded, "*I should not lie. I ate rice yesterday*" [Fieldnotes, 06062017]. He was suggesting that it was just for that one time that he had eaten rice. However, when Dr Ndalama told him that he "*had reverted to his inappropriate eating habits*" [Fieldnotes, 06062017], he refused. A few minutes later, Dr Ndalama went out of the room, leaving the two of us. He then turned to me and said he had been eating 'Gramil'<sup>36</sup> and rice for many days because he had run out of *mgaiwa*<sup>37</sup>. However, when Dr Ndalama came back, he did admit this.

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<sup>36</sup>Gramil is a stiff porridge made from cooking a mixture of water and de-hulling and de-germing maize flour.

<sup>37</sup> *Mgaiwa* is a stiff porridge made from cooking a mixture of water and whole maize flour (as opposed to refined, fermented maize flour).

At the beginning of each interview or conversation, or when asked, I told patients and health care workers that I was a social science student with no medical training and that I wanted to learn about management of diabetes. As a student, I assumed the position of ignorance, and I was happy for participants to tell me as much as they could about their diabetes management practices. For example, because I was a student, Sister Mataka was happy to sit down with me to tell me ‘everything’ about diabetes. As a student, I could also sit with other medical students during participant observation of consultations. Taking notes during diabetes education sessions did not seem strange when I introduced myself to patients as a student. However, in other circumstances, it limited what people were willing to tell me. For example, when I told Dr Kambewa, a herbalist, that “*I wanted to learn about diabetes and the medicines used to manage it*”, he told me that it was a ‘secret’ considering that I may want to make my own medicines. An assistant at Hope Nutrition Services was suspicious of my interest in their medicine. At one point, she suggested that I wanted to take their medicine and sell them to Europeans or in Europe [*kwa azungu*]. These suspicions were not unfounded. For example, many companies and individuals were selling ‘juices’ claiming that it was Teras Juice. There were many herbal products on the market, such that each of these healers wanted to ‘protect’ their brand to maintain its profitability.

On the other hand, Mr Pempho Galimoto, another provider of herbal medicine, ‘trains’ others in herbal medicines. So, when I told him I wanted to learn about diabetes management, he told me that he offers lessons for two hours and charges K3,000 (£3). I paid him, and he invited me to his home to tell and show me his medicines for diabetes. For others, being a student raised expectations. For example, when I told Mrs Florida Kandulu, a type 2 diabetes patient from Nguludi Hospital, that I was a student in England, she said, “*When you go to the UK, find some white people...There are a lot of white people who help, tell them that there is a certain clinic which needs help. The drugs we are taking like tripride 2, I think they come from India*” [Interview, 14092018]. Other expectations were that once I finish conducting research, I should inform the government about the challenges that the patients are facing, especially in buying medicines at Nguludi Hospital while AIDS medicines were provided free of charge.

Each of the roles that I assumed (was perceived to assume) had different implications on how I proceeded with my research and how participants engaged with me. However, my

role as a Malawian researcher conducting fieldwork at 'home' had implications of what became my 'field'.

### 3.8. Reflections on doing fieldwork at 'home'

My PhD research can be classified as doing fieldwork (or anthropology) at 'home'. As a Malawian, I conducted fieldwork in my home country. I briefly lived in Blantyre City, and many of my relatives live there. I conclude this chapter by reflecting on how the fact that I was doing fieldwork in places that I am familiar with (and where I had several friends and relatives) influenced the conduct of my research and findings.

Munthali (2001), a Malawian medical anthropologist who conducted fieldwork in his home village in northern Malawi, noted that one of the problems for the anthropologist doing fieldwork at home are the assumptions that informants make that he/she knows the answers to the questions he is asking. He suggested that even though he is a Tumbuka who studied fellow Tumbuka people in northern Malawi, he was an 'outsider' and a marginal native which allowed him to "study anthropology at home objectively" (Munthali 2001:128). Strathern (1987) noted the implicit assumptions that are made for those conducting anthropology at home: that such ethnographers will achieve greater understanding than elsewhere as they will not surmount cultural and linguistic barriers. Similar to Munthali (2001), I was an 'outsider' in the 'world' of diabetes patients. However, I cannot claim, as he did, to have studied my participants 'objectively'. Moreover, even though I did not have linguistic barriers, I had other challenges as a 'native' which I reflect on below.

My experiences in conducting fieldwork at 'home' revealed the extent to which I was an 'outsider' in terms of experiences and management of diabetes. Being a Malawian doing ethnographic research in Malawi created unique opportunities and challenges which may not be experienced by a non-Malawian if they were to conduct the same research. Even though I knew the local language and was familiar with most of the places I had to go to during the research, the hospital was still a 'new' place. I had been to both Queens and Nguludi Hospitals but not at the diabetes clinics, and not in my role as a researcher. I was not familiar with what goes on in a diabetes clinic. Before I started fieldwork, I was not

familiar with the staff at the hospital. I also was not trained as a medical doctor or a nurse. Therefore, when I went to the diabetes clinic, I was an outsider.

Furthermore, because I did not have diabetes, I did not know what it entailed to experience symptoms like hypoglycaemia. I was not aware of what happens when sugar levels go up or down. As such, when I stepped into the diabetes clinic, or when I spoke to diabetes patients about their experiences, I was a stranger to these. These were 'new' places and experiences I had not known before. It would have been a different experience had it been that someone who had diabetes and had been a patient at Queens or Nguludi Hospitals was conducting fieldwork. To emphasise the fact that I was an outsider and ignorant (even though some thought I was a doctor), I repeatedly told participants that I was a student. Consequently, participants were willing to help me learn and understand their lived experiences and the practices of diabetes management

Diabetes is not confined to the clinics (biomedical and herbal) where I conducted research. It is also in other hospitals, wards, community and homes, including those of friends and relatives. During fieldwork, I was often in contact with friends and relatives, some of whom had diabetes or knew someone who had. Each time I mentioned that I was doing fieldwork on diabetes, friends and relatives would share information about their own or someone else's experiences of diabetes. I heard many stories about experiences of some of my relatives who had diabetes. I also observed some of these practices of managing diabetes. For example, at one of my niece's wedding, my uncle, who has diabetes had to go outside to his car to eat a sandwich which he always carries in case his sugar levels go down. When I visited his home a few weeks later, he told me about his experiences of diabetes symptoms prior to diagnosis and his use of an herbal drink that he felt was effective.

Doing fieldwork at 'home' also meant that it could be entangled in personal social relations. For example, at some point, my wife's grandfather was admitted to a private hospital in Blantyre City. It is the widespread practice that friends and relatives bring food for a patient who has been admitted even though hospitals provide food. This food is usually what the patient prefers or what people think the patient will eat without difficulty. On one such visit, my wife and I volunteered to bring the food. My wife's grandmother advised that we should not add too much salt and make sure that the *Nsima*

is made from *mgaiwa* (unfermented maize flour). She finished by saying “*As you know he has ‘shuga’*”. Until she said this, I did not know that he had diabetes. Usually, during such hospital visits, one asks how the patient is doing or what the problem is. In response, a guardian or the patients would state a disease or the symptoms the patient is experiencing. In this case, we had been told that he had been vomiting.

Learning that he had ‘*shuga*’, I started paying attention to what happened at the hospital. The other day, a young nurse came to do a glucose test while we were visiting. She concluded that his ‘*shuga*’ was “all right”. During my visits, I also learnt that prayers had been organised for him. On one occasion, our visit coincided with a pastor visit who came to pray for him. Most of the visitors often prayed at the end of their visits. I also learnt that the cause of his ailment had been attributed to a dispute over land with another member of his church. Sadly, my wife’s grandfather died after a few weeks. I reflect on my visits because it was difficult not to pay attention to what was happening (for example testing his sugar level) and what was being said about his sickness, considering that he had ‘*shuga*’.

Finally, when people knew that I was researching diabetes, they often wanted to ask me questions about its management. It was often difficult not to give advice based on what I had heard several times during diabetes education, for example, how to respond when someone has hypoglycaemia. I had not anticipated all these experiences when I started fieldwork, but they were important in my understanding of how people live with and experience diabetes at social events when they are admitted in hospitals, how people explain symptoms of diabetes, and what they do about them.

### 3.9. Conclusion

In this chapter, I have described the methodology that I used in conducting this research, highlighting the context, research design and methods, ethical issues and my roles, especially as a Malawian researcher doing research at ‘home’. I have shown that negotiating access and consent with gatekeepers and participants respectively were not a one-off activity; instead, it occurred throughout fieldwork. I have also shown the limits of participant observation because I did not have and was not caring for a diabetes

patient. I have also shown the ‘fluidity’ of the field whereby moments of (participant) observation can emerge in personal engagements.

The two hospitals where I conducted fieldwork do not reflect on all diabetes care activities in Malawi. The diabetes clinic at Queens Hospital has been running for a several years. It is run differently from other public hospitals where diabetes clinics have been set up. The patients who participated in the study were also unique set of patients. For example, I did not interview patients who access diabetes care from private hospitals. I also did not have participants who were no longer receiving care from biomedical facilities. Despite these limitations, most patients experience uncertainty due to diabetes and “experiment” as a means of addressing it. In the next chapter, I present my ethnographic findings of patients’ perceptions and understandings of diabetes and its causes.

## Chapter 4

### 'Shuga' and its 'causes': 'lifestyle', 'being born with it' and pollution

This chapter draws from interviews and conversations with diabetes patients, their 'guardians', health care providers in biomedical facilities, and providers of herbal medicines to explore meanings and perceptions of diabetes and its causes. I show how its local name (*shuga*) and patients' perceptions of diabetes reflect on how they understood its causation and hence have implications on its management. I describe the range of causes of diabetes that are similar to but not the same as biomedical causes, and types of diabetes that do not fit with biomedical ones. In doing this, I highlight the uncertainties within patients' ideas of diabetes causation and how these uncertainties influence how patients live with and manage it.

#### 4.1 'Shuga' or diabetes: *What's in a name?*

I start by considering the names for diabetes in the local language (Chichewa) because they reflect on its causes and appropriate management. The Chewa name and conceptualise diseases in five ways. Firstly, and similar to Susan Whyte's research in Uganda, diseases are named using "vernacular variations of English words and concomitant meanings" which suggests "the spread of biomedical disease categories into popular domains" Whyte (2012:66). For example, AIDS is locally known as *edzi*, while cancer and hypertension are known as *khansa* and *bipi*, respectively. Secondly, some diseases have "local", Chichewa names. For example, malaria is locally known as *malungo*; bilharzia is called *likodzo*, while epilepsy is *chifufu*. Thirdly, diseases are "specifically related, and often named after the body part that is afflicted with pain or dysfunction" (Morris and Msonthi 1996:111). Examples of these include stomach ache (*m'mimba*) and heart disease (*mtima*). Fourthly, diseases are conceptualised according to their aetiology: diseases that are deemed 'natural' or indirectly attributed to a supreme being, diseases from witchcraft or sorcery, and disease from the possession of spirits. Fifthly, there are 'social diseases' which constitute a distinct category and are conceptualised according to their aetiology involving moral transgression. These do not have a counterpart within biomedicine.

During interviews, conversations, diabetes education sessions and consultations, *'shuga'*, *nthenda ya/matenda a shuga* [sugar disease] and (vernacular variations in the pronunciation of) diabetes<sup>38</sup> were used interchangeably among patients, health care workers and their caregivers to refer to diabetes. *Shuga* is the Chichewa name for sugar. *'Shuga'* is used when talking about sweetness (kukoma<sup>39</sup> or kutsekemera) for example, something sweet is said to have *'shuga'* (*zakudya a shuga* = food that has sugar). *'Shuga'* can also mean glucose, for example, when people talk about *shuga wa mthupi* (sugar that is in the body). *Nthenda ya/matenda a shuga* means sugar disease(s). Providers of herbal medicines advertise that they have medicine for diabetes or sugar/*'shuga'*. During fieldwork, I often heard medical doctors and nurses ask patients: "How is your *shuga/sugar*"? (*'Shuga' ili bwanji?*). This question could imply an enquiry about *'shuga'* as diabetes (a disease entity) or sugar/glucose level (is it high or low) or both. In response, patients would say: *shuga* is all right (*'shuga' ili bwino*)<sup>40</sup> or *shuga* has gone up/down (*'shuga' yakwera/yatsika*). If the patient has a sugar level reading following a glucose test, he or she can respond "*Shuga* is at 100 [mg/dL] (*'Shuga' ili pa 100* [mg/dL])<sup>41</sup>.

Several decades ago, Brian Morris argued that among the Chewa<sup>42</sup> of Malawi, some diseases are considered in 'essentialist' terms, as 'entities' causing the state of ill-health for the body (Morris 1985). I suggest that *'shuga'* fits this category but also goes beyond it. When people say "*shuga yakwera*", they are referring to some disease entity. However, when they say "*shuga wakwera*", it is not the disease 'entity'; instead, they are referring to sugar as a product that is in the body causing dis-ease. Diabetes does not seem to fit very well with Morris' idea of diseases conceptualised in terms of the body parts that are afflicted. For if it were so, diabetes could have been called 'disease of the pancreas'. Diabetes also does not fit the idea of how diseases are manifested. As I will show below, some of the symptoms of diabetes are similar to those of other diseases. However, diabetes fits with the idea of linking its conceptualisation to causation (aetiology).

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<sup>38</sup> Some refer to diabetes as *vuto la shuga* (sugar problem).

<sup>39</sup> The word kukoma (sweet) can be used with both salt and sugar. One can "*ndiwo zikukoma mchere*" (The relish has a good flavour). One can also say "*Phala likukoma (sugar)*" (Porridge is sweet).

<sup>40</sup> *Bwino* also means good or fine.

<sup>41</sup> When people say "*shuga ili pa 100*" [*shuga* is at 100], "*shuga ili bwino*" [*Shuga* is all right or good] or *Shuga yakwera/yatsika*, [*Shuga* has one up/down] they are referring to diabetes as a disease entity. When they say "*Shuga wakwera/watsika*", they are referring to glucose or sugar in the body.

<sup>42</sup> The Chewa are mainly found in the central region of Malawi. The Chewa people speak a language called Chichewa. It is spoken in most parts of the country, especially the central and southern region.

*'Nthenda ya shuga'* [sugar disease] or just *'shuga'*, as it is locally known, has two related meanings. Firstly, it entails a disease involving a problem with sugar/glucose that is within the body. In this sense, patients often talked about their sugar being high/low, going up/down, or having much sugar in their body. Secondly, and like Morris' idea of naming disease according to aetiology, *nthenda ya shuga* could mean a disease that comes from sugar as a food product. In this sense, patients often attributed diabetes to "*eating a lot of sugar*".

In both instances, diabetes as *'shuga'* implicates excess sugar and diet in its causation and how it is experienced. This point is emphasised when patients are told to stop eating, or in diabetes causal narratives that implicate eating food with sugar. Unlike in Cameroon, where the terms for diabetes implicated both sugar and salt<sup>43</sup> (Awah, et al. 2009), the names of diabetes in Malawi suggest it is associated exclusively with excess sugar (*kutsekemera*)<sup>44</sup>. Therefore, the name for diabetes suggests its management, in this case, avoiding excess sugar (*zotsekemera*).

#### 4.2 What is *'shuga'*? Types of diabetes – Constructions of diabetes

*Shuga is not a disease. It is a condition. Those that are sick are in the wards. However, remember that sugar/'shuga' damages the body/organs in the body.*

[Sister Maria Mataka, Queens Hospital, 18102016]

Diabetes education sessions usually start with the question: What is diabetes or *'shuga'*? This question is meant to address one of the expectations held by health care workers for diabetes patients to know the causes, signs, and symptoms of diabetes, and how to manage it. The answer to the question 'What is *shuga*?' was often linked to both perceived types and causes of diabetes. For Sister Mataka, the lead nurse at the diabetes clinic at Queens Hospital, *'shuga'* is a 'condition' whereby one has a lot of sugar in their body. During a diabetes education session at Queens Hospital, she said, "*[o]ur main problem is that we have a lot of sugar in our blood. There is a need for the sugar to be in the*

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<sup>43</sup> In Malawi, the equivalent to this would be the word *kukoma*. Both sugar and salt are used with *kukoma*. However, when people talk about diabetes, they do not link it to *kukoma*. They link it to *kutsekemera*, which is associated with sugar only.

<sup>44</sup> Some of the food that patients are told not to eat are not very sweet, hence seemingly contradicting the idea that excess sugar causes/makes sugar levels to go up.

*appropriate/proper amount.*" [Field notes, Queens Hospital, 24012017]. During another education session, she took this idea further by saying that because there is a lot of sugar in the patients' blood, that sugar is now causing illness for the patient.

Mr Zimba, the diabetes educator from the Diabetes Association of Malawi, usually started diabetes education sessions by giving details of what happens when one eats and how food is then turned into sugar. He would then proceed to explain how the pancreas secretes insulin to lower the sugar level in the bloodstream. Using this line of teaching, he led on the types of diabetes: one that starts from childhood and another that starts when one is 35 years and older. During one session, he said:

The *shuga* that attacks children starts at birth when the pancreas I was talking about has problems or has a fault before birth. Because it is attacking children, it is called type 1 diabetes. Type 1 diabetes or sometimes called type 1 diabetes mellitus of which when a child or someone who fall under the underlined age is diagnosed, most of the times they are prescribed insulin right away. This person injects insulin throughout his or her lifetime .... For type 2 diabetes mellitus, it attacks adults or the elderly or those who are above 35 to those 40 and onwards. We call that type of diabetes as type 2 diabetes mellitus.

[Field notes, Queens Hospital, 27062017]

I also heard nurses use the distinction that type 1 diabetes affects people that are younger than 30 years. However, the American Diabetes Association has noted that "The traditional paradigms of type 2 diabetes occurring only in adults and type 1 diabetes only in children are no longer accurate, as both diseases occur in both age-groups" (American Diabetes Association 2017:S13).

Patients often classified diabetes in three ways: according to how they manage it, biomedical categories, and according to the signs and symptoms that they experienced at diagnosis or as they live with it. Mrs Vera Kumbani, a retired 64-year-old widow, was one of the patients that classified diabetes according to how she manages it. As we sat in her living room, I asked her whether she knew what type of diabetes she had. She responded: "*They said it [diabetes] is in three types. I cannot remember the other types very well. They*

*told me that others receive an injection [insulin], others get tablets and some who are put on a diet. As for me, I was put on tablets; it was not the injection one, according to the diagnosis"* [Interview, 26042017]. Mrs Kumbani, a patient at Queens Hospital, was not alone in construing diabetes in terms of how one is supposed to manage it. Some of the patients who 'knew' their diabetes type often used biomedical categories (type 1, type 2) in ways that were different from how these are conceptualised in medicine. For example, Mrs Florida Kandulu, a type 2 diabetes patient from Nguludi Hospital, combined a biomedical category and how it is supposed to be managed. When I asked her diabetes type, she responded, *"Mine is type 2 diabetes, and I am advised not to take too much sugar; and then there is another type of diabetes whereby you are advised to eat a lot of sugar"* [Interview, 07102016].

While Mrs Kandulu describes her diabetes in terms of eating or not eating sugar, Peter Jere does so by referring to medicine he is supposed to take. Mr Peter Jere, a type 2 diabetes patient and volunteer for the diabetes association, described it according to the medicine that he must take: *"I have the type 2 one; it is the one that requires tablets and not insulin. I do not inject myself"* [Interview, 19032017]. Mrs Linly Mbawala, another type 2 diabetes patient, described it as follows: *"They say that there is type 1, 2 and 3. Type 1 is for children who are born with a weak pancreas, and they must inject themselves [with insulin] for the rest of their lives. For us, it is type 2"* [Interview, 15052017]. Mrs Mbawala had been diagnosed with diabetes in 2007 at the age of 48 years. She had been using metformin until 2017 when she was started on insulin. By saying *"For us, it is type 2"*, Mrs Mbawala is saying that she was not born with/did not inherit diabetes; Instead, it started later in life and that she has not been using insulin since she was a child.

Contrary to Mr Jere's understanding, both type 1 and type 2 diabetes patients can all be on insulin. While type 1 diabetes patients start insulin at diagnosis, type 2 diabetes patients who always present with high sugar levels are switched from oral glycaemic tablets to insulin. Therefore, even though Mr Jere said he had diabetes that is managed by tablets, he could be put on insulin if his sugar levels were persistently high. It is also possible for a patient to be wrongly diagnosed as having type 2 diabetes and hence be prescribed oral tablets when in fact he or she has type 1 diabetes, like the case of Odetta Selemani (a type 1 diabetes patient from Nguludi) that I describe in Chapter 5. Insulin may also be administered to patients with type 2 diabetes to lower sugar levels in the

short term, especially if they have been admitted to a hospital with extremely high 'shuga'. On being discharged, the patient may resume managing diabetes using oral tablets. Therefore, the categories of diabetes that Mr Jere uses are not static. One can have 'shuga' that requires tablets. That does not mean that it cannot change to 'shuga' that requires insulin, suggesting that these definitions reflect on perceived 'severity' of the disease.

While both Mrs Mbawala and Mrs Kandulu used biomedical categories of diabetes, they still understood their diabetes with how it is (supposed to be) managed. Further to this, what Mrs Kandulu referred to as type 3 diabetes (which is managed using diet) was not gestational diabetes. Her description of "*another type of diabetes whereby you are advised to eat a lot of sugar*" does not fit any of the biomedical categories of diabetes. The only instance where diabetes patients are asked to take sugar is when they are experiencing hypoglycaemia (low sugar level). In addition, this can happen for both type 1 and type 2 diabetes.

Other patients described diabetes in terms of the symptoms that they experienced at diagnosis. While patients experience different symptoms, the one used for characterising diabetes was weight loss. For example, Mrs Sera Malewezi's description of how and when she was diagnosed with diabetes was as follows: "*What happened is that I had gained so much weight. I am saying this because there are two types of diabetes. The other type you lose so much weight while with the other you gain a lot. As for me, I gained a lot of weight, and I suffered a lot with my legs*" [Mrs Malewezi, type 2 diabetes patient, 17102016].

Related to the conceptualisation of diabetes based on symptoms experienced at diagnosis, some patients mentioned that they had 'high shuga' (as opposed to those that have 'low shuga'). One of the patients that stated that they have 'high shuga' was Mr Kondwani Mapwesera, a diabetes patient from Queens Hospital. He said that he had never experienced any symptoms of low 'shuga' (hypoglycaemia). I was talking to Mr. Kondwani Mapwesera about his experiences of symptoms when the sugar level is high or low. He mentioned that he feels dizzy and weak. When I asked whether those symptoms are for low or high 'shuga', he responded: "*For me, that is when it is high. Those with low 'shuga' also have their signs and symptoms.*" Later, he used the same construction when talking about his diet, mainly what he is supposed to eat: "*Banana is also good for those with low sugar levels in their blood because it is sweet. Bananas help them when the sugar in their*

*blood has gone low, but for us with elevated levels, we must eat bread, especially brown bread, and drink some water” [Interview, 20112016].*

It is interesting to note how patients decide that they have high or low *‘shuga’*. This decision is interesting because having low or high *‘shuga’* has implications on how they experience and manage it. In such formulations, numbers are significant. Most of the patients could recall the blood sugar level at diagnosis. Most of these numbers were for sugar levels above 200mg/dL, which patients acknowledged was remarkably high. Probably such numbers could be what informed their ideas that they had high *‘shuga’*. Apart from the idea that such a conceptualisation could be traced to the sugar level at diagnosis, it is also noticeable that during diabetes education, patients are informed about high and low *‘shuga’*, and the dangers that come with each of these. The idea of saying one has high or low *‘shuga’* could be linked to the symptoms that patients experienced at diagnosis or symptoms experienced most frequently. Patients that say they have high *‘shuga’* are those that often experience symptoms of raised sugar levels. I now turn to how patients describe causes of diabetes to show that sugar is implicated in those narratives.

#### 4.3 *‘Causes’ of diabetes*

During interviews with patients, I often asked about how diabetes started or what had caused their diabetes. As most of the participants had had diabetes for some time (ranging from 4 months to 15years), their ideas of what may have caused diabetes have been informed by several factors, including but not limited to diabetes education sessions. These narratives may also have changed over the years as the patients tried to make sense of their diabetes. My interest in these *‘causes’* is how they are perceived to cause diabetes, their similarities/differences from biomedical ideas, and the implications for patients’ practices of diabetes management.

Patients often attributed diabetes to *‘lifestyle’*, *‘diet’* *‘heredity’*, ageing, *‘chemicals’* or a combination of two or more of these. Within biomedicine, some of these are referred to as *‘risk factors’* for diabetes. According to the WHO (2016b), the causes of type 1 diabetes are unknown: it is attributed to interactions between genes and environmental factors, without elaborating what these factors are. The risk for type 2 diabetes is determined by genetic and metabolic factors, with the risk increased because of physical inactivity,

unhealthy diet, overweight and obesity, age, smoking, ethnicity, and family history of diabetes (World Health Organisation 2016b). Some of the factors that patients mentioned were not part of this biomedical repertoire for example ‘chemicals’ and ‘toxins’. However, even when patients mention biomedical causes, it is essential to consider how they explain them in ways that make sense within their experiences of diabetes. I now turn to patients’ narratives of diabetes causation.

#### 4.3.1 Unknown causes

Not all patients could mention what they thought had caused their diabetes. Mrs Sakina Mtema, a senior member of the Diabetes Association and a retired nurse, was one of the patients who said she did not know what had caused her diabetes. When I met her, she had been living with diabetes for 14 years. When I asked if she had an idea as to what had caused her diabetes, she responded: *“I do not recall. I do not know what caused it. It could be that it is diabetes with an unknown cause. However, I do not know what caused it”* [Interview, 25012017]. Mr Mosses Botomani, a 48-year-old businessperson who was diagnosed with diabetes in 2005 and patient at Queens Hospital, also did not know what had caused his diabetes. He said, *“It is just a disease; I do not know what the cause was. I just started having the symptoms; I just started urinating often. From the time we started [the interview], I would have gone to urinate several times”* [Interview, 15052017]. Similarly, Mr Isaac Stenala, a 69-year-old type 2 diabetes patient from Nguludi Hospital, said, *“I do not know what specifically caused shuga. I just realised I had been diagnosed with shuga”* [Interview, 09012017]. Both Mr Stenala and Mr Botomani said they did not have family members who had had diabetes before, seemingly eliminating the idea that they were born with it (‘genetics’). For Mr Botomani, the symptoms that he experienced were significant rather than knowing what the aetiology of diabetes was. For Mr Stenala, the diagnosis itself was significant. When Mr Botomani said, *“it is just a disease”*, he was suggesting that it is less important or not possible for one to know its cause.

Other patients suggested some causes of diabetes, albeit with little certainty. For example, Mrs Maureen Kwitanda, a type 2 diabetes patient from Nguludi Hospital, said she was told [at the hospital] that ‘shuga’ is a disease that starts on its own, that there are no factors that could be attributed to having caused it. When I probed as to what she thought causes ‘shuga’, she also said she did not know. However, she went on to talk about

the fact that when she was diagnosed with diabetes, she was fat and used to enjoy fast foods from local food stalls. Mr Solomon Sembereka, a type 2 diabetes patient from Nguludi Hospital, gave a similar response as follows: *“I do not know what caused diabetes in me ...it is just that during that time I was obese. I do not know, but it could be the cause considering they say fat people are regarded as being at risk of suffering from diabetes”* [Interview, 10032017]. During diabetes education sessions, “fat” patients were told to lose weight. They were also taught not to eat fast food as it was bad for their ‘shuga’.

By saying *“it is just a disease”*, *“it starts on its own”* and *“I just realised I had been diagnosed”*, patients were showing uncertainty about causes of diabetes and highlighting their diminished agency in that they were not to blame as they had no control over how it started. Patients’ perceptions that they did not have control over diabetes causation were also extended to management: that there was nothing they could do about their sugar levels. Even through Mrs Kwitanda and Mr Solomon Sembereka mentioned the cause of diabetes, they framed it as something they were told. For patients that said they ‘knew’ what caused their diabetes, it was attributed variously to ‘lifestyle’, food and diet, ‘heredity’, ageing, ‘chemicals’ and for some, a combination of these. I now turn to consider each of these causes.

#### 4.3.2 ‘Diet’ and ‘lifestyle’

Most of the patients’ and health care workers’ explanations of what caused diabetes were about food and exercise. Some refer to these as ‘lifestyle’. They mentioned food that they are not supposed to eat as advised during diabetes education and a lack of exercise as causes of diabetes. It is essential to note from the outset that during diabetes education sessions, diabetes educators describe these as causes of diabetes. For example, while acknowledging that type 2 diabetes may be inherited, Mr Zimba stresses that it is a result of our “bad behaviours”, highlighting the immorality of modernity as the cause of diabetes. He said:

It [type 2 diabetes] can also arise from our dieting behaviours such as improper use of drugs, the drinking of alcohol that affects our health,

eating foodstuffs with a lot of sugar and cooking oil<sup>45</sup>. These foodstuffs burden our pancreas in such a way that it is overloaded and as a result, it stops functioning. Due to this malfunction, the pancreas cannot release fluids that help in sugar breakdown to acceptable levels. Due to this problem, we are diagnosed with elevated levels of sugar in our body .... High sugar levels result from our bad behaviours such as smoking, heavy drinking of alcohol, eating oily and sugary foodstuffs and on top of that, no physical exercises conducted for healthy and stronger bodies. We do not exercise. That is all about type 2 diabetes.

[Field notes, Queens Hospital, 27062017]

Patients' descriptions of the causes of diabetes often borrowed from what is taught during diabetes education. One would be tempted to think that patients share a biomedical understanding of diabetes. Consider the story of Mr Sosten Kandewu, a 34-year-old type 1 diabetes patient from Nguludi Hospital, who was diagnosed with diabetes in 2013. He had migrated from his rural village in Chiradzulu to Mbayani, one of the slum areas of Blantyre city in 2012. He started working as an attendant in a maize mill. After being diagnosed with diabetes in 2013, he moved back to his home village in 2014 at his mother's insistence. Relocating to the village was meant to reduce the burden on his relations who would be assisting in caring for him. After narrating how he was diagnosed, I asked him what he thought had caused his '*shuga*', and he responded:

Before I left [the village], I was a very hard-working person. At that time, I was extremely hard working. ...When I went to Mbayani, I was mostly idle. ...I was working as an attendant in a maize mill, and that is not arduous work. ...It was mostly light work. When I was there, I also changed my diet. Here in the village, we often eat amaranth/pig weed/wild Spinach (*Bonongwe*) and blackjack. When we were in Mbayani, we could eat other things apart from *Nsima*; we also used to

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<sup>45</sup> Diabetes educators like Mr Zimba talked about cooking oil as 'causing' diabetes. Yet, it is not related to whether sugar levels go up or down. Inclusion of cooking oil and salt in diabetes education was for prevention of diseases like hypertension, for which diabetes patients are at 'risk'.

eat food with cooking oil and *kanyenya*<sup>46</sup>. That is what caused my *shuga*.

[Interview, 0402017]

In this account, Sosten's ideas of diabetes causation implicate the changes that came because of moving from a rural to an urban area. For him, diabetes was attributed to a change from a life in the village, characterised by 'hard work', eating pigweed weekly and blackjack<sup>47</sup> (*Bidens pilosa*), to life in the city characterised by 'light work', eating food with cooking oil and *kanyenya*. The life in the city is portrayed as sedentary and with a diversity of food choices. Reverend Daveson Kachulu, a provider of herbal medicines, also shared these ideas. He said, "*The body's system is no longer what it is supposed to be because of the fats that we are consuming, the cooking oil that we are using ....*" [Interview, 07042017].

Some patients associated diabetes with sugar, saying it was what had caused their diabetes. Just before Sosten said that his '*shuga*' had started after he had moved from the village to the city, I had asked him what he thought causes '*shuga*'. He said, "*I was also told that it might start because someone is consuming plenty of sugar, eating foods with plenty of fat, having tea with much sugar. All those can cause shuga disease*" [Interview, 0402017]. While Sosten said he was told that '*shuga*' starts from consuming much sugar, other patients specifically mentioned that they had diabetes because, at some point in their life, they enjoyed adding sugar to their food. One such patient was Mrs Victoria Singini, a 66-year-old type 2 diabetes patient from Queens Hospital. She said, "*I also never knew that sugar which has all along been taken as food could cause disease in our body. I was taken by surprise that the same sugar we used to eat is causing some of our body parts to be incapacitated*" [Interview, 17102016].

For other patients, '*shuga*' was caused by sugar through drinking soft drinks like Coca-Cola. Mrs Monica Chisale and Mr Cosmos Nakanga, type 2 diabetes patients from Nguludi Hospital, expressed similar ideas when they attributed diabetes to 'eating habits' and diet, respectively. When I asked what caused her diabetes, Mrs Chisale said, "*Eating habits. I*

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<sup>46</sup> Roasted or fried meat or fish sold in food stalls

<sup>47</sup> Blackjack is also known as farmers' friends, beggar's ticks, pitchforks, or stick-tights.

*loved my sugar too much. There was a time that I could not just stay without a Coke. I think I was becoming addicted to Coca-Cola. I think that is what triggered it. I think that is what triggered diabetes. I could not go an entire day without Coca-Cola. I could not”* [Interview, 01032017]. Mr Nakanga also implicated ‘diet’, explicitly mentioning Coca-Cola as one of the causes. He said, *“It was the diet that I was having at that time that caused it. I used to have margarine and food fried in cooking oil. I used to drink a lot of Coca-Cola; I could drink four bottles a day”* [Interview, 01022017]. For Mrs Kadewere, a type 2 diabetes patient from Queens Hospital, Coca-Cola and ice cream had caused her diabetes. She said, *“As for me, I used to take drinks like Coca-Cola, and during hot days, I could take about four bottles of coke in a day, and yet the sugar levels that are in Coca-Cola are extremely high. It contributes to shuga disease. Besides, I also liked ice cream very much back then, and there is a lot of sugar in ice cream”* [Interview, 07112016]. Later in the interview, she said, *“It [diabetes] can also happen if you are getting fat and you are eating anyhow. Some of the things that we are eating these days contribute to diseases. What you eat is what you become; one ends up with high sugar levels”* [Interview, 07112016]. By referring to *“things that we are eating these days”*, drinking Coca-Cola on hot days and liking ice cream, Mrs Kadewere not only implicated food as a cause for diabetes, but also ‘modernity’ itself.

The patients above implicated sugar in diabetes causation by stating that they consumed a lot of it. On the other hand, some patients were surprised that they had diabetes, even though they did not like consuming sugar. A good example is Mrs Maureen Kwitanda, a type 2 diabetes patient from Nguludi Hospital. We were talking about her experiences at diagnosis; whether she had suspected diabetes before diagnosis. She responded by describing what she was told about *shuga*. She said, *“I think they also said it means one has much sugar in the body. Nevertheless, I told them that I do not take tea<sup>48</sup> often, that I take very little. I also told them that I hardly use cooking oil. I only buy a little cooking oil”* [Interview, 05052017]. In this example, the ideas of diabetes causation do not fit with Mrs Kwitanda’s interpretation of her daily dietary practices, where she uses “little” cooking oil and does not often drink tea which is usually taken with sugar.

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<sup>48</sup>Most people in Malawi have three main meals: breakfast (usually tea (with bread, boiled cassava or sweet potatoes) or porridge (maize or rice), lunch (*Nsima* and relish (vegetables, beef, chicken, beans) and supper (the same as lunch). For most people, sugar is applied to tea and porridge that they eat for breakfast. They do not envisage any other ways in which sugar is ingested.

#### 4.3.3 “Chemicals” and “toxins” in food, water and medicines

I have shown in the previous section that during diabetes education, Mr Zimba referred to modernity and change as contributing to diabetes. I now turn to how some patients and providers of herbal medicine implicate ‘modernity’ in the causation of diabetes. In doing so, I also touch on another linkage between herbal medicines and biomedical practices: that the accumulation of medicines in the body causes or worsens diabetes. Some patients and providers of herbal medicine implicate “*food that we are eating these days*” as the cause for diabetes. For providers of herbal medicines and diabetes educators, “*the things that we are eating these days*” contain not just sugar but also ‘chemicals’, fertiliser or ‘toxins’ which cause diabetes and other non-communicable diseases, especially hypertension (*bipi* as they call it). During one diabetes education session, Mr Lucius Zimba said, “*We should eat vegetables that are not treated with fertiliser. We should eat vegetables that are grown using manure and not fertiliser. The fertiliser can enter our body after consumption, and it is destroying us*” [Field notes, Queens Hospital, 15102016].

Another example was Reverend Daveson Kachulu, founder of one of the Pentecostal churches in a populous township in Blantyre, who also runs an herbal medicine shop in Limbe town. When I visited the shop, he was waiting for a business partner with whom he was planning to open another shop in one of the townships. In his shop, he sells medicine from China called Tianshi. These include herbal tea, tablets, powders, toothpaste, and soap. I asked what he thought causes diabetes, and he responded:

These [hybrid chickens]<sup>49</sup> are injected with chemicals every day. Besides, because we are eating these every day, the body is no longer the system it used to be. ...You can agree with me that one who lives in the village is better off than us who are in towns. For us here, it starts with the water that we drink – it has Chlorine, bread has some chemicals added to it, cows are injected with chemicals every day. As we are eating/using these, we are also taking in these chemicals. Some chemicals remain in the body even after going to the toilet. ... We are

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<sup>49</sup> Hybrid chickens are locally called *nkhuku za chizungu* which means European chickens. These are contrasted from local chickens which are known as *nkhuku za chikuda* or *nkhuku za lokolo*. These chickens are vaccinated against various diseases and are feed which is meant to make them mature quickly.

not supposed to be eating certain food anyhow. Nowadays, we tend to take whatever others are doing and do the same. We do things without even knowing what that thing can cause/its effects. In rural areas, people are selective. In rural areas, people do not eat the chicks that we eat in town. They would say they are not mature enough. If you go to a shop, you will find baby chickens, and they are tiny. People are buying those and eating them. Those chickens are reared by being fed with chemicals; that means they have chemicals all over. We are not concerned about their effects on our bodies. Our concern is that we have found something to eat.

[Interview, 07042017]

Mr Pempho Galimoto, another provider of herbal medicine, further expressed the idea that people in rural areas are better off as they are not eating food eaten by those in towns and cities. For him, it is a “Western” diet that people in towns are eating, a diet that he refers to as not “Malawian”. He said,

You will notice that the diet, I mean the Malawian diet, is now becoming westernised. You will then notice that the diseases from Western Countries are now present in Malawi and they are afflicting people. ...What I mean is that now, we are not eating local food as Malawians used to eat years ago. You understand. The local foods are completely neglected...Local food that people used to eat like fruits that naturally grow in forests, natural vegetables like wild spinach [amaranth] and others. We used to eat that when we were in the village. It is only now, as older people, that we have known vegetables that we buy shops. Most of these are processed foods. This is what people are eating nowadays.

[Interview, 10032017]

Other providers of herbal medicines also expressed similar sentiments, including Brown Chapola, herbalist from Hope Herbal Clinic and Thokozani Stima, an assistant at Hope Nutrition Services. Their descriptions link modern ways of living (food and agricultural

production) and the emergence of many diseases, including diabetes. For example, Brown said:

Several things are happening these days for example, consider the food that we are eating. ...Some of the things [that cause these diseases] are the foods that we are eating these days – hybrid chickens [*nkhuku za ma jakisoni meaning chickens that are injected with 'chemicals'*] that only take a week, and they are ready for example. Some people are negligent/careless, and they eat the bones from such chickens. The bones may affect the bodies and cause some diseases.

[Interview, 27062017]

Similarly, Thokozani Stima, an assistant at Hope Nutrition Services (providers of herbal medicines), described the effects of the 'chemicals' which were blamed on 'Europeans'. She said:

Chemicals are destroying people's bodies. Chickens that are infused with chemicals are destroying people. Once these artificial [chemicals] enter the body, people are growing up extremely fast. That is why we have been given a life span of 40 years. In maize, we put fertiliser. There are also chemicals in vegetables and chickens. The Europeans have destroyed our country.

[Interview, 15062017]

Notice that Brown emphasised what is happening and the food that people are eating 'these days'. For Reverend Kachulu, the body is no longer the system "it used to be" and that those in the rural areas are "better off" and selective in what they eat. These ideas are also expressed by Sosten, who suggested that going to the city led to his diabetes because of the food and less strenuous work. In saying this, Reverend Kachulu, Brown and Sosten are implicating modernity: they are pointing to modern agricultural practices, especially 'chemicals' as contributing to diabetes. Some participants, like Pempho Galimoto, a herbalist, are implicating 'Western' or ways of life that are not Malawian. They

are implicating 'modernity' in ways different from biomedical ideas where diet from refined products is implicated.

Herbal medicine providers often said that people also take in "chemicals" through medicines for diabetes, blood pressure and AIDS. For example, Stavudine, one of the first regimens for AIDS treatment in Malawi, is known to increase the risk for diabetes (van Oosterhout, et al. 2012). Dr Banda from the Ministry of Health's NCDs unit expressed this as follows, "*If you look at these conditions – diabetes, hypertension – they are also common in people that are HIV positive. It is because of the drugs that they are taking, they contribute to diabetes and even hypertension*" [Interview, 29062017]. Here again, 'modernity' in terms of hospital medicine was being implicated in the causation or worsening diabetes. Participants were attributing diabetes to 'modern' medicine. Thokozani Stima, an assistant at Hope Nutrition Services, continued her views on 'chemicals' as follows: "*We discourage biomedical drugs<sup>50</sup>. You live in a European country [muli konko kwa azungu], they have damaged everything, including our land...we now know that the Europeans are bad. It is not right that one should be taking medicine for up to three years*" [Interview, 15062017].

Some patients also noted the problem of 'chemicals' in hospital medicine. Mrs Anastanzia Kadewere, a type 2 diabetes patient from Queens and also a 'born-again' Christian, put it this way: "*These medicines from the hospital are not bad, but I have noted that they are made of chemicals of which when taken for a long time, they end up coming with some side effects which are damaging to our bodies. Then you end up relying on medicine*" [Interview, 07112016]. Similarly, Mr Yohane Kachingwe, a partner to one of the patients, said, "*I think the reason is that there is an accumulation of medicine in the body. Imagine taking medicine for ten years. Do you think it is good in here [gestures towards the stomach]?"* [Interview, 04112016]. Accumulation of medicines in the body was also attributed to the use of 'modern' family planning methods. Earlier on in my interview with Brown (herbalist), he had mentioned that food was causing problems. Later in the interview, he attributed the accumulation of 'chemicals' to family planning methods that women are using, and which are sucked into male bodies during sexual intercourse. He said, "*Besides, these days, for women, there are family planning injections, if one has sex with them ..., one sucks some*

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<sup>50</sup> The participant used the word "*mankhwala achizungu*" which means European medicine.

*fluids ...Little by little, you are also sucking some of the power of that medicine. That then blocks blood vessels. Those that are married end up having sex with their wives only once, and at times, they will not even have sex at all the whole night” [Interview, 27062017].*

The idea that during sexual intercourse, men ‘suck fluids’ that also contain the ‘power’ of family planning medicines is not new. Bruun’s ethnographic study in a rural fishing village in Malawi reported perceptions that sex-related diseases are transmitted through sucking of blood from each other during sexual intercourse (Bruun 2002). For participants in my study, instead of blood which contains diseases (*‘bad blood’*), it was ‘chemicals’ which are transferred to men and cause ‘problems’ including diabetes and failure to have sex. Interestingly, failure to have sex is linked to, although different from, erectile dysfunction, one of the symptoms of diabetes which were of significant concern among some male participants (See also Cooper, et al. (2018)).

#### 4.3.4 Born with it, “heredity” or “genes”

There were two ideas of diabetes and “heredity”: those that said they had inherited it and those who did not know anyone from their family from whom they would have inherited it. Some patients said their diabetes was inherited, hence implicating social relations in diabetes causation. Variations of this were the patients who said that they were born with diabetes. Some patients had relatives who had had *‘shuga’*, and this was used to explain why they also had *‘shuga’*. For example, I asked Mrs Modesta Juma [MJ], a type 2 diabetes patient from Queens Hospital what she thought had caused her *‘shuga’*, and she responded by mentioning all the people that have had *‘shuga’* in her family:

MJN: What do you think caused *shuga*?

MJ: I do not know, but I heard that my mother passed away because of *shuga*, my father passed away because of *shuga*, my elder sister has *shuga* up to date, and my elder brother has *shuga*. Therefore, I think some other people told me that it must be hereditary.

[Patient, Interview, Queens Hospital]

Later in the interview, she also mentioned that people in her community talk about “heredity” as a cause of *‘shuga’*. I had asked her whether she talks about *‘shuga’* with her friends and neighbours. She responded: “*There are some people whom I have spoken to about ‘shuga’; others say ‘shuga’ is hereditary, and there is no way they can have it*” [Patient, Interview, Queens Hospital].

Similarly, Mrs Madalo Phiri, a type 2 diabetes patient from Nguludi Hospital, did not know what caused her *‘shuga’* but still attributed it to “heredity”. She said: “*Until now, I do not know how it started. I do not understand. There was a time that my father told me that his father died of shuga. I tend to think that could be it*” [Interview, 23032017]. In explaining what caused his *‘shuga’*, Mr Lifred Mwiyeriwa (type 1 diabetes patient, Queens Hospital) explained that his *‘shuga’* comes from parents. In the same description, he ruled out other potential causes: transmission through sex and blood. He also went on to add that one is born with *‘shuga’*. He said, “*shuga is a disease that comes from parents. Shuga is not transmitted through sex. It cannot be transmitted through blood. I have heard that one is born with shuga. ...It just comes*” [Interview, 20052017]. It is interesting to note that Mr Mwiyeriwa ruled out the transmission of *‘shuga’* through blood and sex. On the other hand, some participants initially thought that their diabetes had started because someone had infected them with it. Such understanding and framing resonate with messages around HIV and AIDS whereby transmission occurs through unprotected sex and blood.

There were some patients for whom attributing the cause of diabetes to “heredity” did not make sense. This was because they did not know any family member who had diabetes. For example, when Sosten was diagnosed with *‘shuga’*, he started wondering as to who may have infected him as he thought it was “*a disease that could be transmitted from one person to another*” [Interview, 04022017]. However, while Sosten was told that “*shuga is inherited from one's forefathers/clan ...*” and that “*there may have been someone in our clan who had shuga*”, he did not know anyone who had had diabetes in his family [Interview, 04022017].

Mr Solomon Sembereka, a type 2 diabetes patient who I first met at Nguludi Hospital but later transferred to Queens Hospital, had earlier said he did not know what caused his diabetes. He later said at the time he was diagnosed, he was fat. He then proceeded as follows: “*in our family, there is no one who has had diabetes*”. Mr Alinafe Mandere, a 58-

year-old type 2 diabetes patient from Queens Hospital said, *“Most people say that shuga started because they used to consume a lot of sugar. Others also say that it was inherited from my family, but I do not have any other family members that have diabetes, maybe when I was still a child. However, no one in my family has diabetes at all”* [Interview, 20032017]. For both Mr Solomon Sembereka and Mr Alinafe Mandere, they could not have ‘inherited’ diabetes from family members. When patients say they inherited diabetes, or they were born with it, they do not specify what causes the affliction. Patients acknowledged that diabetes was transmitted from parents to children through other means, and not blood as in HIV and AIDS.

#### 4.3.5 “Weak” or “disabled” pancreas, and ageing

For some participants, diabetes was a manifestation of ‘problems’ with the pancreas and its functioning. For children, it could be because they were born with a “disabled” or “weak” pancreas. During one diabetes education, Mr Zimba, the diabetes educator described type 1 diabetes as follows: *“the shuga that attacks children starts at birth when the pancreas I was talking about has problems or is disabled. We call it type 1 diabetes because it is attacking children”* [Diabetes education, Queens Hospital, 27062017]. According to Mrs Mbawala, a type 2 diabetes patient from Queens Hospital: *“Type 1 [diabetes] is for children who are born with a weak pancreas, and they are given an injection for the rest of their lives”* [Interview, 15052017]. For older people, Mrs Mbawala said the pancreas was getting “weak” because of old age. The argument was that the *“pancreas is a part in our body and if it is weak such that it cannot produce insulin, it becomes a problem”* or *“...for us elderly people, the pancreas gets weak. As a person is growing the body parts gets weaker as compared to when a person is young. They [bodies] do not work the same way. Therefore, one of the body parts that get weaker is that pancreas. It controls sugar”* (Linly Mbawala, Patient, Queens Hospital). For George Nyasulu, type 1 diabetes patient from Queens, the pancreas *“becomes weak and stops doing its job”* [Interview, 20052017]. Sister Mataka said it this way: *“the pancreas [is] getting weak, losing some of its power, or it has broken down”* [Field notes, Queens Hospital, 18102016] or that it stops working.

In short, the pancreas is said to not work ‘properly’ because of old age. For example, in my first interview with Peter Kambwiri, an ambulance driver and a type 2 diabetes

patient at Queens Hospital, I had asked him what he thought caused his diabetes, and he responded:

MJN: What do you think made you start suffering from diabetes?

PK: I cannot say the cause but since I have worked at the hospital for some time and I know there is type 1, 2 and 3. Based on how they described them, I think it started due to old age... They say that when you are aged more than 40yrs, your pancreas becomes weak and does not produce enough insulin. As such, you are not supposed to eat foodstuffs with too much sugar to control your glucose levels. Therefore, I think it came because of old age since I am now 51 years old. Apart from that, I cannot say the actual cause.

[Interview, 18102016]

In this regard, patients are using ideas of diabetes causality that are beyond the control and influence of the patients. Ideas that diabetes is a result of ageing and the pancreas getting weak with age suggest patients' attempts at normalising diabetes in old age, a finding which Broom and Whittaker (2004) have also noted in rural Australia. Broom and Whittaker (2004) further argue that normalisation is also invoked when patients discuss deviating from diabetes management practices as being 'normal' or as something that every patient does.. At least in terms of explaining diabetes as 'normal' process of ageing, such normalising is said to exonerate the patient from the moral responsibility of the cause of diabetes and poor health (Naemiratch and Manderson 2007).

However, some participants like Mrs Singini (type 2 diabetes patient, Queens Hospital) challenged theories of causation that attribute diabetes to old age, considering the increase in the number of young people who were being diagnosed with it. She accepted that diabetes was 'expected' for those that are old. However, she was puzzled with the increase in young people with diabetes. She said, "*these days, babies are being born with shuga; our young people are being found with shuga. Traditionally shuga and blood pressure have been considered as diseases for elderly people like me since our bodies have become weak*" [Interview, 17102016]. In this statement, she suggests that there is uncertainty as to what is causing *shuga*, considering that both young people and older people are getting it.

Mr Zimba seems to offer an explanation as to why young people are being diagnosed with *shuga*. His explanation combined ideas of how the pancreas works, 'modernity', lifestyle, and morality. He said:

Right now, diabetes is coming in a way that I can say it is because of our lifestyle. People like eating junk food and drinking beer that is not recommended such as *midoli*<sup>51</sup>. I always say we overload the pancreas such that it is unable to produce enough insulin; or that the pancreas is annihilated because of the effects of the *midoli* to the point where it stops working. Why do we have diabetes in adolescents? It is because our young people like junk foods such as chocolate, sweets, and other foods such as Frozy<sup>52</sup>, the famous drink which is very sweet. This means when they take these sugars from tea with white bread and Frozy, the pancreas reacts and says I am tired. It cannot produce more than it is expected. It stops functioning and as a result, a person starts suffering from type 2 diabetes. That is my understanding.

[Interview, 15062017]

Mr Zimba went on to suggest an explanation as to why even those in rural areas are also having diabetes, in contradiction to ideas by Pempho Galimoto and Reverend Kachulu (herbalists) who suggested that people in rural areas were not being affected by diabetes. He said:

...the situation is like that some of the things that we do in town, they have also gone to rural areas. If you go to Njolomole my home village, there is a lifestyle like that of Ndirande Township. You will find bars, fridges, *midoli*, *kachasu* [a locally distilled spirit] and local beer. When they are preparing it nowadays, they add certain herbs for example sisal [*Agave sisalana*] and some poisonous drugs to make the alcoholic drinks stronger. However, the herbs that are added are causing many problems. When they take those alcoholic drinks, they experience side

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<sup>51</sup> A generic name that referred to alcohol packaged in sachets. These were popular among young people as they were cheap but with a high alcohol content.

<sup>52</sup> This is a popular soft drink imported from Mozambique.

effects one of which is the damage to the pancreas. The pancreas was made to digest a healthy diet from childhood to adulthood, reducing blood sugars to a normal level. Now the pancreas is working on the sugar that has entered the body through these [alcoholic] drinks.

[Interview, 15062017]

#### 4.4 Conclusion

This chapter has considered patients' and health care workers' perception of diabetes, its types and causes. I showed that in Malawi, *'shuga'* and diabetes are used interchangeably. I have also shown how participants linked diabetes to sugar and sweetness, based on its local name (*shuga*) and how they talk about its causation. While a few patients mentioned that they did not know what caused their diabetes, most of them named causes that were linked to, but different from and 'wrong' in biomedical terms. During diabetes education, health care workers often talk about diet as the cause of diabetes. Patients and providers of herbal medicine also talk about diet through sugar (like biomedical providers) but also "chemicals" or "toxins" that are in food and water that are lodged in patients' bodies. These "chemicals", which are in the form of fertiliser and pesticides, are part of "modern" agricultural practices that are aimed at increasing outputs and profits.

Patients' ideas of diabetes causation were formulated retrospectively: looking back and reflecting to identify behaviours that fit the biomedical model of diabetes causation. They then eliminate those causes that they deemed not plausible. Patients may have been selective in the behaviours that they present as having caused diabetes. In a study that explored perception and understanding of type 2 diabetes causation, Lawton and others (2007) have shown that white (British) respondents in the UK tended to emphasise 'lifestyle choices' and their 'personal failings' as causes of type 2 diabetes. On the other hand, Pakistani and Indian respondents who had migrated to Britain tended to emphasise external factors in terms of living conditions and migration to Britain as being the causes of diabetes. In my study, participants also emphasised 'lifestyle choices' and 'personal failings' as the cause of their diabetes, which resonated with public health messages of living a healthy lifestyle, self-control and discipline (Lupton 1995). They moved beyond emphasising their failures by also blaming their diabetes on change.

In their discussion on the 'charm' of medicines, Van der Geest and Whyte (1989) argued that using metaphors and metonyms aids in perceiving and locating illness in a manner that is concrete, graspable and therefore, amenable to treatment. Using metaphors and metonyms, experiences that are obscure, elusive, and indefinite are likened to those that are more tangible. In many ways, diabetes is a 'new' disease in Malawi. There are no local language translations for insulin or pancreas (in one diabetes session, people struggled to name them in Chichewa. They resorted to using the English names). However, considering diabetes as being caused by the accumulation of sugar/'chemicals' in the body is a way of making diabetes have an "appearance of concreteness which makes it accessible for communication and therapeutic action" (Van der Geest and Whyte 1989:354). Referring to diabetes as '*shuga*' and implicating 'chemicals' in its causation implies different forms of management of diabetes. As '*shuga*' refers to both sugar and diabetes, management implies focussing on the managing consumption of sugar as the main component. In this case, as sugar is associated with sweetness, its management implies reducing the consumption of sweet foods, yet most foods (regardless of sweetness), can potentially raise sugar levels in the body.

That patients attribute diabetes to many causes highlights one of the uncertainties of diabetes. Patients attributed diabetes to many causes in the same or over several interviews. Interestingly, patients even managed to attribute to some behaviour that they thought had caused diabetes, for example, drinking a lot of Coca-Cola. Firstly, it is possible that the time that the patient was diagnosed, they had had diabetes for a while. As such, what patients refer to as 'causes' may have occurred after they already had diabetes, only that it was yet to be diagnosed. Hence, those may not be causes after all. Patients are convinced with these narratives as reflecting why they had diabetes. Secondly, when talking about these causes of diabetes, patients described themselves as "*eating anyhow*", "*addicted to Coca-Cola*" or "*eating something, yet there is plenty of sugar in it*". The language appears to be some form of self-blame for the fact that they have diabetes. It also has moral overtones to it.

Narratives of diseases causation often imply management. For example, diseases that are a result of broken social relations may require mending these relations as a means of dealing with the affliction (Morris and Msonthi 1996). That diabetes is attributed to diet is particularly important when one considers how patients manage it. Patients referred

to the sugar that is in food as causing diabetes. Cooking oil was also blamed as contributing to diabetes. Patients and providers of herbal medicines referred to 'chemicals' and 'toxins' that are in the food that cause diabetes and other non-communicable diseases. Vaughan, et al. (2018) reported similar findings in their study on changes in diet in Lilongwe city and Karonga district, located in the central and northern regions of Malawi, respectively. In their study, participants said 'chemicals' in the form of fertilisers and pesticides used in the production of food, especially vegetables were detrimental to health as they were poisoning them. Further, their participants mentioned that " 'speeding up' growth of foodstuffs (staple crops, vegetables and also livestock such as chickens) was artificial and unhealthy ", and linked to the rise of 'new diseases' of hypertension, type 2 diabetes and other conditions (Vaughan, et al. 2018:7).

Interestingly, according to patients and providers of herbal medicines, all these are attributed to food that people are eating nowadays, which is posited as different from the past but also rural areas. Vaughan, et al. (2018) have reported that in Malawi, sugar was less widely consumed in the past, and it was a feature of urban rather than rural diets. Ideas of contamination, exposure, and disease causation are not new. However, what is significant is that what is implicated here are "modern" methods of agriculture. While patients have been using sugar and cooking oil over the years, their availability and use have changed in 'modern' times. One can find these in small grocery stores in most villages but these are more readily available (and less expensive) in cities than rural areas. Modern agricultural methods that rely on fertilisers and medicines are blamed for causing diabetes. Rearing hybrid chickens, for example, requires the use of antimicrobials to prevent them from infections and, sometimes, to make them grow faster. These practices are assumed to highlight the greed of chicken farmers whose only desire is to make a profit without considering the effects of the medicines they use. These practices are implicated in diabetes causation. Drinking Coca-Cola every day, eating ice cream and margarine could be considered a form of 'modernity' that characterises life in the city, but which is dangerous and can bring diabetes to the body.

## Chapter 5

### Becoming “*munthu wa shuga*”: Certainties and uncertainties

At 8:00 am on every Tuesday morning, the diabetes shelter at Queens Hospital is usually packed with up to 90 people, mostly patients. A few of the patients come with ‘guardians’ (daughters, spouses, and sons). Patients sit on cement benches on either side of the room with an aisle in the middle. From the back of the room, Mrs Mboti, a diabetes patient and a volunteer for the Diabetes Association of Malawi, serves tea from a large, cylindrical metal boiler set on a small table. Next to the small table are three basins: one with loaves of brown bread and margarine, the other one has empty cups while the third basin has used cups and some water. In front of the shelter, there is a white metal pole. During the diabetes education session, an old white scale is placed next to it. There are also two doors in front: one door leads to a room that serves as an office for the Diabetes Association of Malawi (DAM) while the other one leads to a room that is used as storage for (old) furniture. Both rooms have doors leading to a corridor. In this corridor, there are three rooms: two are sometimes used for consultations. Sometimes, researchers from the College of Medicine sit in one of them collecting data among patients. Sister Maria Mataka uses the third room for diabetes foot care.

When I arrived at the diabetes shelter on 17 January 2017, Peter Jere, a volunteer for DAM, was measuring patients’ weight on the old white scale and recording it in their health passports. The process proceeded as follows: a patient walks forward towards the scale, removes their shoes or slippers, gives their health passport to Peter, and then steps on the scale. Peter asks them to straighten up and not lean against the metal pole, and then reads the weight from the scale. He records it in the patient’s health passport (date and weight in kilograms), and then gives it back. The patient then returns to their seat.

Later in the session, Peter announced that there would be a change in the organisation of the clinic in terms of booking for appointments. He stated that patients would be booking their appointments at the laboratory rather than in Room 1. There was some murmuring from the patients expressing disapproval. One of them, an elderly man, felt that the new arrangement meant he would have to walk more to get to the laboratory for booking the appointment. In response, Peter said, “*Please let us take [accept] what we are being told*”.

Some patients also complained that it was scorching in the shelter and that nurses were yet to arrive to take blood pressure and teach them about diabetes.

While Peter Jere was weighing patients, Mrs Mbota was serving tea and bread. The water in the boiler had been mixed with pasteurised milk manufactured by one of the local companies. The milk used was one of the few brands that diabetes patients were told they could drink. Tea was being served with brown bread to which Mrs Mbota was applying Blue Band margarine, the one with a light blue rather than dark blue lid. Patients were told that it was fat-free and hence recommended for them to eat albeit in modest amounts.

Mr Zimba, the diabetes educator from DAM walked into the shelter a few minutes before nine o'clock. He greeted the patients by saying "Happy new year" and then continued, "Have you eaten a lot of mangoes<sup>53</sup>?" At nine o'clock, Sister Maria Mataka walked into the shelter carrying two Blood Pressure (BP) Monitors. Usually, at least two nurses measure blood pressure. At times, one of the clerks helps in measuring blood pressure. However, on this day, Sister Mataka was alone, and she started using both BP monitors at the same time: putting one machine on one patient, and as it was reading, she would put the second machine on another patient. While Sister Mataka measured blood pressure, Mr Zimba started the diabetes education session by asking if there were any new patients. Two people raised their hands. Usually, he would have started by talking for an hour about what is diabetes, its types, causes, and management with emphasis on diet and taking medicine. After the talk, he would then invite patients to ask questions. On this day, he started by asking if they had any questions. Several patients raised their hands to ask questions, just like in a classroom.

One patient wanted to know why they were not told whether their sugar level was lower or higher compared to the previous month. Another patient said he had heard that a diabetes patient was not supposed to apply body lotion on his or her feet. He wanted to verify if that was true. A young woman, in her late twenties, asked whether someone who has diabetes could have a child. Another patient wanted to know the cut-off points for

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<sup>53</sup> Mr Zimba asks whether the patients have eaten many mangoes mango season. However, diabetes patients are not supposed to eat many mangoes. Therefore, Mr Zimba was asking whether patients had been complying with their diet.

high and low sugar level. Another patient asked whether a diabetes patient ought to take tea or coffee while another patient said he had heard that diabetes patients were supposed to take honey and cinnamon. He wanted to know if that was true. For the next hour, Mr Zimba responded to these questions while Sister Mataka was measuring blood pressure. After that, patients left the shelter to wait for the clinic at 1 pm.

Despite the differences in setting, there were many similarities in how diabetes education was provided at Queens and Nguludi Hospitals. At both facilities, as patients wait for consultations to start, patients often discussed their health and how they were managing diabetes, whether they had tried one herbal medicine or another or whether they could eat certain foods or not. In both facilities, diabetes education was framed as “*something that the patients already knew*” or “*something they already did*”. Health care workers emphasised that diabetes education was a form of revision of what patients knew and did as part of diabetes management. It was provided with a sense of authority that patients had to accept and do everything that was taught without questioning it. Having diabetes was also portrayed as bringing uncertainties, and through education, patients were told how to, and expected to manage them.

Therefore, diabetes education emphasised that to manage diabetes requires becoming a “moral” subject who was supposed to take on the responsibility of not just living with it but also doing something about diabetes, its symptoms, and complications to avoid death. In short, patients were supposed to learn uncertainties of diabetes: for example, when and why sugar levels go up and, most importantly, what to do about it. Diabetes education content was framed in certainty to facilitate management and ensure patients “complied” with what they were learning. For example, that not following instructions would lead to complications or death. To sum up, diabetes education posited both certainty and uncertainty; yet for patients, living with and experiencing diabetes was [mostly] characterised by uncertainties. In this chapter, my interest is how diabetes and its management are framed as a form of uncertainty within diabetes education and how patients are supposed to manage those uncertainties. This focus on uncertainty and diabetes draws attention to the management of disease as an on-going process of everyday life. Living with diabetes was as much about learning new practices and changing social relations and activities as it was about taking on a new identity or being ‘*munthu wa shuga*’ (a person who has *shuga*). During diabetes education, educators

emphasised what diabetes patients were supposed to do or not. For example, educators emphasised that patients should not do what they had been doing before their diagnosis. They emphasized that a diabetes patient should not/does not do those things but follows what they were told during diabetes education.

In this chapter, my focus is on how diabetes is framed and the implication of this framing for management among patients. This chapter will address three related issues: the creation of a '*munthu wa shuga*'- a 'new' form of "moral" subjectivity for diabetes management through diagnosis and diabetes education, the uncertainties in the experience of diabetes, and the implication of not following what they were taught. I show how diabetes patients learned about the various forms of uncertainties inherent in diabetes and its management through education sessions. In learning about these uncertainties and how to deal with them, patients were expected to assume particular moral subjectivities, in which health was their individual responsibility, and they were subjects of biomedical practice.

In the previous chapter, I explored how patients perceive diabetes in terms of types and causes. I argued that patients (re)produce accounts of diabetes causation that fit and make sense within their biographies and that these accounts borrow from biomedical and local conceptualisations of diabetes. Some of these ideas are drawn from several sources, including but not limited to discussions with others (patients, friends, 'guardians') and the media via radio, television, and newspapers that advertise medicines for diabetes. In this chapter, I use data from participant observation to highlight how diabetes education contributes to these understandings by highlighting uncertainties and how this informs the way patients manage diabetes, a topic that I explore in more detail in the next chapter. Paying attention to the messages, I will also show that diabetes education is informed by the context in which it is practised. I start by exploring how patients 'knew' that they had diabetes, what diabetes education is (the various forms it takes and aims), and its contents in terms of key messages. I conclude by reflecting on the implications of uncertainties and emergence of "*munthu wa shuga*".

## 5.1 Knowing diabetes through diagnosis

In this section, I explore patients' descriptions of how diabetes was diagnosed to highlight the uncertainties around it. In interviews and conversations with patients, I often asked patients how and when they "knew" they had diabetes. I start by narrating the story of Mrs Sera Malewezi, a 42-year-old primary school teacher with type 2 diabetes. I first met her at the diabetes clinic at Queens Hospital. Mrs Malewezi was diagnosed with diabetes in 2009. She told me that at that time of the diagnosis, she had gained much weight and was experiencing pain in the legs such that she struggled to walk.

In April of the same year, she started experiencing pain on one of her toes, "*as if there was a wound*". After a few days, her whole leg was swollen such that she could not walk. Mrs Malewezi then told her mother about her condition. No one suspected that it was diabetes. At that time, Mrs Malewezi's mother had diabetes, and she was using insulin. Her mother asked her to go to Lilongwe so they could visit an herbalist. Both Mrs Malewezi and her mother suspected that she had been bewitched. When they visited the herbalist, he told them that her enemies had "trapped" her by placing charms on a path through which she had passed<sup>54</sup>. If she had not walked on that path, she would not have had the affliction. The herbalist advised her to stay and receive treatment for about three weeks. However, she could not stay for long as she had to return to work. The herbalist applied some herbs and cut some marks on her legs. However, there was no improvement. On the fourth day, she left Lilongwe for Blantyre. On the way, she stopped in Ntcheu District to see her grandmother who suggested that she visit another herbalist from that area. She could not walk; as such, she had to be carried to the herbalist's home. The second herbalist also told her that she had stepped on some charms, only that they were not meant for her. According to Mrs Malewezi, the second herbalist even described everything she was feeling. She also got some herbs from him. When she got to Blantyre, she noted that there was some improvement for a while. However, the symptoms continued.

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<sup>54</sup> Among the Chewa, witches or sorcerers consciously harm others using magical substances (*mankhwala*) which are usually placed "under the eaves of a victim's house, or near the doorway, or they may be buried under a path along which" the victim is known to pass (Morris and Msonthi (1996:163)).

Mrs Malewezi said she had been to Queens Hospital on more than five occasions, and health care workers did not diagnose diabetes. Her problem with legs was attributed to fluids that were on her knees that needed to be removed. She was given medicine for that. However, there was no change as she gained more weight and struggled to walk. One of her uncles then started suspecting that she had acquired HIV because *“people say when one is HIV positive, they experience problems with legs”* [Interview, 17102016]. He arranged to take her to Chiradzulu District Hospital, a government health facility. At some point, Chiradzulu District Hospital was said to have excellent HIV services as the clinic was supported by an NGO called Médecins Sans Frontières (MSF). To avoid stigma around HIV, many people from Blantyre City would go to Chiradzulu District Hospital to get ARVs. It was for this reason that the uncle suggested that they go to Chiradzulu District Hospital. At the hospital, her uncle requested that they conduct a ‘full blood count’ *“to know what the real problem was”* [Interview, 17102016]. When the results came out, her uncle collected them and told her that she tested HIV negative but that her problem was that she had diabetes. At that time, her fasting blood glucose was at 490 [mg/dL]. Then she went to the doctor who confirmed that she had diabetes. The doctor then gave her some advice. Mrs Malewezi put it this way: *“...he gave me some advice to stop eating anything sweet, any food prepared with cooking oil; that I should only eat food with less salt and Nsima ya mgaiwa only”* [Interview, 17102016].

Mrs Malewezi’s narrative reflects several issues that emerge before, during and soon after a diabetes diagnosis. Firstly, she noted that her diagnosis was prompted by the experience of a symptom: swelling of her leg. She also emphasises that she had gone to the hospital several times, but diabetes was not diagnosed; instead, she was prescribed medicine for her swelling leg. Like Mrs Malewezi, most patients said that initially, they had not suspected that they had diabetes. In the introductory chapter, I noted that studies in Malawi show that a considerable proportion of people live with undiagnosed diabetes. Partly, this is because of lack of routine screening for non-communicable diseases and health systems that are burdened by infectious diseases (tuberculosis, malaria and HIV) (Gowshall and Taylor-Robinson 2018). It could also be because of the inherent characteristic of diabetes itself, primarily type 2. According to the International Diabetes Federation (2017), type 2 diabetes patients remain undiagnosed for many in the population because they may remain without symptoms for many years. Alternatively,

symptoms may not be severe “owing to the slow pace at which hyperglycaemia is worsening” (World Health Organisation 2019:6). For a long time until diagnosis, such patients will be exposed to hyperglycaemia that is high enough to cause pathological and functional changes yet “not severe enough for the patient to notice the classic diabetes symptoms” (American Diabetes Association 2017:S18). Consequently, such patients present with complications when they are diagnosed (World Health Organisation 2019).

Dr Loveness Ndalama, a consultant at Queens Hospital, told me that most patients do not know that they have diabetes when presenting at the hospital. There were four ways in which diabetes patients were diagnosed. Firstly, some patients presented at the clinic with diabetes emergencies resulting from extremely high or low sugar levels. Of these emergencies, Dr Ndalama said:

Of the many of the patients that come in, some are emergencies. They come in with diabetic emergencies because their sugar has been very high for a long time. I mentioned diabetic ketoacidosis<sup>55</sup>, it is an emergency which type ones come in with. Type 2 [diabetes patients] usually will come in as hyperglycaemic hyperosmolar syndrome, and they are also an emergency. ...We then admit them and given them insulin and monitor them very closely in the wards. When we discharge them, we will then refer them to the diabetic clinic, and they will start following up with us.

[Interview, 18012017]

In the introductory chapter, I gave the example of Mrs Jenala, a type 2 diabetes patient from Queens Hospital, who was taken to a hospital after collapsing while taking a shower. Another example was Mrs Florida Kandulu, a type 2 diabetes patient from Nguludi Hospital, who was taken to Nguludi Hospital after she had collapsed and “*went into a ‘coma’*” [Interview, 07102016].

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<sup>55</sup> Ketoacidosis refers to the building up of ketones in the body resulting from the body having run out of insulin. It mainly affects type 1 diabetes patients and can be life threatening if not spotted and treated quickly [<https://www.nhs.uk/conditions/diabetic-ketoacidosis/>].

Secondly, some patients present with a different problem. According to Dr Ndalama, *“Another group of patients are those that present with a completely different problem. While you are looking at that problem, you find out that their sugars are also high. Alternatively, you may also find out that they have a strong family history of diabetes, that they have relatives that also have diabetes”*. Examples of these included Mrs Vera Kumbani, a diabetes patient from Queens Hospital, who had sought medical help because the symptoms that she was experiencing were like those she had seen on diabetes posters that are sometimes posted on hospital walls. Mrs Mbawala (type 2 diabetes), another diabetes patient from Queens Hospitals, informed her husband when she noted that she was urinating frequently. Her husband told me that he had suspected diabetes because a colleague who had diabetes was experiencing similar symptoms. He asked his wife to go to the nearest health facility, which is a health centre. The health centre did not have a glucometer and Mrs Mbawala was referred to Queens Hospital, where she was diagnosed with diabetes.

Thirdly, there were those patients who presented with diabetes complications. One good example was Mr Mabangwe, who was diagnosed with diabetes upon being admitted to the medical ward at Queens Hospital for a wound that was not healing, one of the complications of diabetes. I first met him when I had gone with Sister Mataka in the Male Surgical Ward. At that time, he had been admitted for one week. One month later, I met him at the diabetes clinic. He had been discharged from the ward the previous week and had then started coming to the diabetes clinic to have his wound dressed by Sister Mataka. Dr Ndalama gave an example of another complication: stroke. She said: *“The other significant group of patients are those that come in with a complication. Someone comes in with a stroke, and that is the first time that you realise that they have diabetes, which is what predisposed them to have a stroke”* [Interview, 18012017].

Finally, there were those patients who, according to Dr Ndalama, *“volunteer and come for a routine check-up”* [Interview, 18012017]. However, such patients were a minority. That such patients were rare was apparent to me when I asked for a glucose test at one of the private pharmacies in Limbe Town, Blantyre. The pharmacist was surprised when I told her that I did not have diabetes and yet I had asked for a test. She told me, in agreement to what Dr Ndalama had said, that not many people who did not have diabetes came for such tests. This could be one of the explanations as to why most patients did not seek

medical help for diabetes until the day they were diagnosed. In a study among chronic disease patients in Malawi, Angwenyi, et al. (2018) reported that patients' delay to seek medical attention was attributed to unawareness of signs and symptoms of their condition. For Participants in my study, the delay was linked more often to how patients and their caregivers perceived the (severity of the) symptoms and proper treatment for them. Symptoms like frequent urination were not perceived as requiring a hospital visit. Another reason could be attributed to the similarity of symptoms of diabetes and other diseases. Researchers have noted that for type 1 diabetes, symptoms like fatigue, abdominal pains, and weight loss can be mistaken for AIDS or cerebral malaria, hence delaying diabetes diagnosis (Atun, et al. 2017). In my study, patients said they had experienced malaria-like symptoms before diagnosis of diabetes. Patients could have engaged in self-treatment of these symptoms. In the introduction, I showed that Mrs Jenala was initially diagnosed with malaria before a diabetes diagnosis. Some of the patients that presented with diabetes symptoms were likely treated for malaria. Before 2011 when rapid diagnostic tests were introduced, guidelines for the management of malaria required presumptive treatment of malaria where one presented with a fever (National Malaria Control Programme 2011).

The uncertainties of diagnosing diabetes in the context of limited resources are compounded by the fact that it is difficult to determine the different types of diabetes. In the introductory chapter, I referred to the International Diabetes Federation (2017) which noted that it might not be possible to determine the whether a patient has 1 type or type 2 diabetes and that doing so may require further tests or can become evident over time. It is essential to distinguish between type 1 and type diabetes because: *"The main reason you have to decide whether people are type 1 or type 2 is that for type 1, they need to be on insulin. They will not respond to diabetes tablets. If you are keeping someone who has type 1 diabetes on tablets, you are just lengthening the time that they are exposed to high sugar [levels] and getting complications from diabetes. That is the main thing for us that we must decide whether it is type 1 or type 2"* [Dr Ndalama, Interview, 18012017]. In Malawi, distinguishing between type 1 and type 2 diabetes is done using clinical symptoms. According to Dr Ndalama,

We usually go for the clinical symptoms and the clinical presentation of the patient. If it is a young patient, they are losing weight, and they need

a lot of insulin for their treatment, then they have type 1 diabetes. Type 2 tends to be older patients. In most books, they say that type 2 is usually obese people, but we see many type 2 patients who are not obese; however, they are usually older, and their presentations are different. Even the sort of complications that they get [are different]: for type 1 they get what we call diabetic ketoacidosis, which will not happen in patients who have type 2 diabetes. ...If you are in a well-resourced setting, you can do further tests to confirm that it type 1 [diabetes]. You can do blood tests for that, but we do not have that available here. ...We do not have that in this country. However, usually with clinical diagnosis, there are a few borderline cases; they are not old, and you think they have features of both, but that is not very often. Usually, it is quite easy to see that this is type 1, and this is type 2.

[Interview, 18012017]

The case of Odetta Selemani, a 19-year-old type 1 diabetes patient from Nguludi Hospital, exemplifies the uncertainties around determining diabetes types compounded by challenges in the referral system in Malawi. For four months after her diagnosis, Odetta was getting oral medications rather than insulin. She was diagnosed with diabetes on 8 August 2016 after presenting with a random blood sugar level of 504 mg/dL<sup>56</sup>. It was also recorded that she had lost weight, and there was no history of diabetes in her family. Her diagnosis was indicated as type 1, and she was prescribed insulin (10 units in the morning and 5 units in the evening). However, because her guardian could not afford to buy insulin at Nguludi Hospital, the clinician advised them to go to Chiradzulu District Hospital, where they were to get it free.

Two days later, she went to Chiradzulu, where her fasting blood sugar level was 269mg/dL. Instead of getting insulin as prescribed at Nguludi, she was prescribed glibenclamide (1 tablet every 12 hours) and metformin (2 tablets every 12 hours). She went back to Nguludi Hospital in October 2016, and her sugar level was 371mg/dL. Once again, she was prescribed insulin. However, she could still not afford it and went to

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<sup>56</sup> In Malawi, diabetes is diagnosed if one presents with a random blood sugar level above 200mg/dL.

Chiradzulu Hospital after a month. During that visit in November 2016, her fasting blood sugar level was 276 mg/dL. Strangely, the clinician recorded “*patient doing fine...observe diet.... continue with diabetes medication (glibenclamide and metformin)*” (Odetta’s Health Passport). She went back to Nguludi Hospital on 6 December 2016, presenting with a fasting blood sugar level of 376mg/dL and a weight of 33kgs. She got intravenous fluids for two hours, and her sugar level went down to 254mg/dL. After being discharged, the clinical officer who attended to her referred her again to Chiradzulu Hospital. This time, he recorded in her health passport and wrote a referral letter informing them that she was supposed to get insulin rather than oral medication. On 6<sup>th</sup> January 2017, after presenting with a fasting blood sugar level of 309mg/dL, Odetta received her first insulin dosage from Chiradzulu Hospital.

I have highlighted uncertainties that are inherent in knowing that one had, and the various types of diabetes. Other uncertainties emerge in diabetes education, a key component for diabetes management in biomedicine.

## 5.2 Diabetes education as “*reminding one another*”

After the diagnosis of diabetes, patients were taught what was expected of them as diabetes patients. However, these education sessions for ‘new’ patients were rare. Two reasons could explain the rarity of such sessions. Firstly, diagnosis was made in other departments of the hospital rather than the diabetes clinic itself. As such, most people who were attending the clinic have had diabetes for a while. Patients were diagnosed in the wards or the outpatient department after presenting with diabetes symptoms. Secondly, it could be because nurses did not conduct separate diabetes education for the new patients as they were often asked to attend an education session with the rest of the diabetes patients. At the beginning of diabetes education sessions that I attended, diabetes educators often asked if there were any new patients. In this case, ‘new’ patients referred to those that had been recently diagnosed with diabetes or those that are attending the clinic for the first time. Sister Maria Mataka usually asked, “*How many of us have come here for the first time?*” Usually, one or two people would raise their hands.

At Queens Hospital, such ‘new’ patients would be asked to be attentive as the diabetes educator was teaching, as there would be no separate session for them. On the other hand,

I observed two sessions where Mrs Njewa, a nurse at Nguludi Hospital was teaching a 'new' patient. During one such session, Mrs Njewa and the patient sat on a desk which was at the back of the OPD room so that she could have him registered. She asked the patient about his date of birth, where he came from, his phone number, his 'guardian', if there was any member of his family who had diabetes or high blood pressure. These details were filled on a blank master card for the patient, which was then stored in the diabetes clinic. On the next visit, the patient is given their master card so that he/she takes it to the consultation room where a clinician would record the patient's weight, fasting blood glucose level, dosage for the prescribed medicine and the next appointment date. After completing the registration, Mrs Njewa then started the education session for the 'new' patient by telling him that as a diabetes patient, he would have a 'special' diet. She informed him of a 'diabetes diet' leaflet that had details of what patients were to eat or not. On that day, the only copy of the 'diet' was in English, and Mrs Njewa promised to look for the Chichewa version and give the patient at his next appointment, a month later. At the end of the session, she said, "*It is usually difficult at the beginning when you are just starting. However, you will get used to it. You eat a little (mongolawa)*" [Field notes, 31012017].

After registration, one of the responsibilities for '*munthu wa shuga*' was to attend diabetes education sessions with other patients because not doing so meant treatment would not work. To emphasise this responsibility of the patient, Sister Mataka often highlighted the importance of attending diabetes education by saying: "*taking medicine without counselling would not lead to lowering the sugar [level]*" [Field notes, Queens Hospital, 24012017]. Mr Lucius Zimba, the diabetes educator, also used to make the same point by stating: "*The best medicines that you get are the advice and education sessions that you are given*" [Field notes, Queens Hospital, 27062017]. Both Sister Mataka and Mr Zimba stressed the importance of diabetes education, equating it to the medicine that the patients must take without skipping. They must take medicine for the rest of their lives. Just like medicine, patients should always attend the diabetes education session and should never skip it. At both clinics, attending the education was also of practical importance as it is geared towards treatment through measurement of blood pressure, weight, and blood glucose (Nguludi Hospital). These measurements were used during the clinic to determine whether the patient is managing well but also how much medicine

they should get. As Mr Zimba put it, doctors used weight and blood pressure to decide the dosage to be prescribed to the patient. In a way, these remarks also affirmed the centrality of biomedical practices in the management of diabetes: one needs diabetes education and the medicine that is provided within biomedical facilities.

The aim of diabetes education was to teach patients and their 'guardians' how to take care of themselves as diabetes patients. During education sessions, diabetes educators talked about: why patients come to the clinic, what is diabetes, types of diabetes, signs and symptoms of low and high 'shuga', how to care for feet, diet – what, when and how to eat and what not to be eaten, complications of diabetes and what to do if one experiences such complications. Most of the sessions that I attended were said to reinforce diabetes education that had been provided over the time that patients had had diabetes. At Queens Hospital, some patients have been attending the diabetes clinic, and education sessions, for more than ten years. Mr Zimba, the diabetes educator, often referred to such patients as "akabwerekwere". 'Kabwerekwere' means repeat offender or jailbird. By calling them 'kabwerekwere', Mr Zimba suggests that they had been to the clinic before and hence already knew what was taught.

To underscore that the education was about reinforcing what the patients had already been taught, diabetes educators often emphasised that they were not teaching patients new things but reminding one another of what they [patients] already knew and had been doing. However, even though some of the patients have been attending the clinic for a while, they did not recall what was taught by, among other things, failing to correctly mention the foods that they were supposed to eat or not. To such responses, diabetes educators will often ask, "Have I ever taught that?" Nurses also noted that some patients had *shuga* that was not well managed. For example, at the beginning of a diabetes education session, Mrs Njewa, a nurse from Nguludi Hospital, said: "Let us remind one another about how we eat". She continued: "For most of us, *shuga/sugar* is being well managed, but there are a few whose *shuga* is not being well managed" [Field notes, Nguludi Hospital, 31012017]. On another day, Mrs Mkamanga, another nurse from Nguludi Hospital, started the education session in the following manner: "As usual, we are going to remind one another. What are we supposed to eat in the morning?" [Field notes, 09062017]. Later in the session, she said, "We are helping/assisting one another and not teaching *per se*". At Queens Hospital, the diabetes educators usually said patients already

knew what they were teaching, and that all they were doing was to remind each other about these things. They emphasised that the diabetes education sessions were for revision of what patients knew and did every day. Most importantly, though, they targeted new patients.

By framing diabetes education as something that patients were already doing, diabetes educators were highlighting the pragmatic nature of what they taught. They were, in a way, trying to distance it from theoretical understandings of diabetes, what people in Malawi often call *zammabuku* (originating from books/reading). This is often said to emphasise that something is practical and of proven workability as it is from experience rather than 'theory'. One could also state that by saying it is what patients do, diabetes educators were inadvertently assuming that the patients had been managing diabetes according to what they were taught during diabetes education sessions. Despite the education session being framed as "reminding one another", I noted above that some patients did not have 'good' knowledge and others were said to have *shuga* which was "not being well managed". Among other things, patients "experiment" with food and medicine. Questions reveal uncertainties of food that patients are supposed to eat, which drives "experimenting".

### 5.3 Uncertainties in diabetes education

Sister Mataka: We should follow all the instructions that we have gotten today.

Patient: There are many instructions, but we still need to follow them.

[Field notes, Queens Hospital, 24012017]

The conversation above occurred at the end of a diabetes education session at Queens Hospital. It is difficult for patients to follow all the instructions that they get because there are many of them. Most significantly, having multiple instructions is one of the many uncertainties that patients have to live with and manage. It was perhaps when patients were told what to do that the uncertainties in diabetes education were much clearer. To prevent or to manage consequences of low or high sugar level, or the uncertainties that come with '*shuga*', patients were told to follow some 'instructions' that they learn during the diabetes education sessions. Patients are expected to accept that they have diabetes

and the requirements and expectations that come with that. They are expected to accept that because of diabetes, they must take medicine for the rest of their life and that they will change their lifestyle to fit the requirements of having diabetes. Patients must accept that biomedical practices are the [only] way of dealing with diabetes and that they must follow all its requirements. For example, patients are told that they are done with their past food habits and lifestyle. Sister Maria Mataka often said, *"We are done with fruit juices...We should not eat as we used to eat before"* [Field notes, Queens Hospital, 24012017]. She usually says the same thing about sweet foods, cooking oil, and other 'prohibited foods'. The diabetes educators acknowledge that even though diabetes patients should not eat certain foods, there are always cravings, and hence, they suggest ways of addressing these. One patient asked about the use of sweeteners and Mrs Zion Njewa, the diabetes nurse from Nguludi Hospital said, *"They [sweeteners] are not sweet. They are only meant to address your craving for something sweet"* [Field notes, Nguludi Hospital, 31012017]. The message is that diabetes patients were new beings/people; as such, they were supposed to engage in 'new' practices, different from their practices before diagnosis.

### 5.3.1 '*Shuga*' is diet, diet is 'medicine', medicine is 'life'

In the diabetes education sessions that I attended, most of the time was devoted to talking about food and diet. Diabetes educators talked about food in two ways. Firstly, food was said to be the primary treatment for diabetes. Sister Mataka usually said, *"shuga is diet"* [Field notes, Queens Hospital, 18102016]. Saying *"shuga is diet"* means that for patients to manage diabetes, they must pay attention to the food they eat. Sugar levels go up or down depending on what and how one eats. Mr Zimba expressed it as follows: *"The medicine for this type of diabetes, we start with diet; when we talk of diet, we mean proper eating of nutritious food"* [Field notes, Queens Hospital, 27062017]. Secondly, food becomes medicine when one's sugar level goes extremely low. For example, having asked patients about the symptoms that they experience when '*shuga*' is low, Golden Mposa, a clinical officer at Nguludi Hospital said, *"I hope we have captured what our friends have said. I am not saying that taking sweets should be a habit. Taking sweets act as medicine for low sugar level. Brown sugar also works the same as sweets. When you feel these signs, take brown sugar, and place it under the tongue. This is the only time we can use sugar. Are we together?"* [Field notes, Nguludi Hospital, 02052017]

By saying that “*taking sweets should not be a habit*” and that “[*t*]his is the only time we can use sugar”, Golden Mposa is emphasising a distinction made within diabetes education sessions among food patients should eat, the food they can eat, and food that they should avoid. Some foods are prohibited/inappropriate foods and those that people can (not should) or ‘are allowed’ to eat and those that they should eat. When talking about diet during diabetes education, nurses often started by asking patients to mention the foods that they are supposed to eat or “*to make a menu for the day*” [Field notes, Nguludi Hospital, 06092016]. At Queens Hospital, usually, the question is “*What should we eat in the morning?*” followed by “*What are we supposed to eat at 12[noon]*”, and then “*What should we eat around 3 pm*” and finally, “*What should we eat in the evening*”. At Nguludi Hospital, one of the clinical officers put it this way:

Right now, we must tell each other how to prepare our breakfast when it comes to diet. Can one amongst us take us through on how to prepare breakfast because I understand that for some of us; it is our first time to be here and a reminder to others who have never heard about it. Besides, I will request another person who will take us through the preparation of lunch. I need a volunteer on this. How do we prepare our breakfast? Yes, tell us, young woman.

[Field notes, Nguludi Hospital, 02052017]

Patients often asked about whether they could eat a particular food and in what amounts. Consider the following example at Nguludi Hospital, where several patients asked whether they should be eating gourd<sup>57</sup>, avocados, milk, pineapple, or *thobwa*<sup>58</sup> [Field notes, Nguludi Hospital, 31012017]. Firstly, diabetes patients were told that they must not eat food that has sugar. In other words, diabetes patients were not supposed to eat “sweet things”. When asked what they were supposed to eat, a patient responded: “*We are restricted/prohibited from eating very sweet things*” [Field notes, Queens Hospital, 13122016]. Sister Mataka put it this way: “*You can eat brown bread, boiled Irish potatoes, cake/bread from unprocessed maize flour but it should not have any sugar. You can also eat*

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<sup>57</sup> These belong to the same plant family as pumpkins. However, gourds are smaller and have a softer shell when cooked.

<sup>58</sup> *Thobwa* is a drink made from maize flour and millet.

*Soya.*” [Field notes, Queens Hospital, 18102016]. Secondly, patients were also told that they should not eat food with fat or use cooking oil<sup>59</sup>. The quote from Sister Mataka above ends with the following: “*I have not mentioned fritters or chips because these contain a lot of fats.*”

On another day, Mr Zimba said, “*what you must know is that you should eat food that is low in fat, starch, and sugar*” [Field notes, Queens Hospital, 27062017]. When he said they should eat food with low starch, he meant that diabetes patients should not eat *Nsima* and porridge made from refined maize flour. Patients were told to eat *Nsima* made from whole grain maize flour (*mgaiwa*)<sup>60</sup>. The example below from Nguludi Hospital highlights the reasons for doing so. At the start of a diabetes session, Mrs Thokozani Njewa asked patients why they were supposed to eat *Nsima* made from wholemeal maize flour. One of the patients, Mr Sosola, a type 2 diabetes patient from Nguludi Hospital, responded: “*Because Nsima from fermented maize flour contains much starch while Nsima from wholemeal flour has very little starch*” [Field notes, Nguludi Hospital, 31012017]. *Nsima* that has a lot of starch and less fibre and vitamins was said to rapidly increase the level of sugar, hence the need to avoid it. Another patient, Mr Nakanga, a type 2 diabetes patient from Nguludi Hospital, gave a more practical explanation: “*Nsima from wholemeal flour is more satisfying*” [Field notes, Nguludi Hospital, 31012017]. By saying *Nsima* from wholemeal is more “satisfying”, Mr Nakanga meant that that one would get a full stomach quickly and it will take longer to get hungry again. The practicality of Mr Nakanga’s point lies in the fact that one of the symptoms of diabetes is frequent hunger, and that *munthu wa shuga* is not supposed to feel hungry.

Mr Nakanga’s statement leads directly to another issue in the diabetes clinic: the amount of food that diabetes patients were supposed to eat. At Nguludi Hospital, Mrs Sekeni, a nurse, emphasises that diabetes patients need to “*eat carefully/with care*” and “*eat [certain things] but only once a week*” [Field notes, Nguludi Hospital, 31012017]. The emphasis here is twofold: the patient should eat carefully or with care and that, the patient should not eat these foods often. Sister Mataka states, “*A diabetes patient ...should*

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<sup>59</sup> Inclusion of cooking oil and salt in diabetes education was for prevention of diseases like hypertension, for which diabetes patients are at ‘risk’.

<sup>60</sup> While whole grain maize also contains starch, it is recommended for diabetes patients because it also contains fiber, minerals and vitamins. As such, it takes longer to digest hence resulting in gradual increase of sugar level (<https://www.hsph.harvard.edu/nutritionsource/carbohydrates/carbohydrates-and-blood-sugar/>).

*not get hungry*” [Field notes, Queens Hospital, 18102016]. However, there is a potential contradiction which may imply uncertainty. While diabetes educators often said that a diabetes patient was not supposed to get hungry, eating carefully also implied that all food must be taken in moderation as a diabetes patient is not supposed to get full. This quote from Sister Mataka emphasises this position: “*A diabetes patient is not supposed to get full. He or she is not supposed to get hungry. He/she should be in between the two (pakatikati)*” [Field notes, Queens Hospital, 13122016].

According to the National Nutrition Guidelines for Malawi, diabetes patients must eat boiled or roasted food rather than fried food, and a lot of fibre (unrefined food products) such as whole-grain cereal, legumes, root crops, fruits, and vegetables. They must use less gravy and fats, and eat regularly with defined timetable, frequently but in modest amount. They must also have a clear, timely, and regular pattern of eating, working and exercise and sleep.

Apart from the amount of food, patients are also supposed to eat food that is prepared within the homes rather than buying already prepared foods. The rationale for doing so is because “*other people may not have prepared the food with the diabetes patient in mind*”. For example, patients are told that they can eat porridge made from Soya beans, but they must prepare it themselves rather than use soya flour available in grocery stores or that distributed in hospitals as part of nutrition rehabilitation programmes. Sister Mataka put it as follows: “*Alternatively, you can have soya porridge but make sure that you have made it yourself – and not buying from grocery stores*” [Field notes, Queens Hospital, 13122016]. Sister Mataka encourages patients to use homemade soya because there are specific amounts that should be mixed to make flour: two basins of maize mixed with one basin of soya beans. Once again, the patients must pay attention to amounts and levels that are appropriate. They must do so to ensure that ‘*shuga*’ does not go up.

Other than diet, diabetes education also emphasises the symptoms of low and high ‘*shuga*’. Diabetes patients are expected to know types of diabetes, symptoms of diabetes and most importantly, what they must do when sugar levels are low or high. The reason for emphasising that patients must know about signs and symptoms of diabetes was that they must do something about it because of the uncertainty that pervades diabetes. According to Sister Mataka, “*Shuga can go up [or go low] without the patient knowing.*

*Therefore, one needs to know the symptoms of high and low shuga*” [Field notes, Queens Hospital, 18102016]. There is also the uncertainty of deciding whether symptoms that patients experience mean that ‘*shuga*’ is low or high as some patients have difficulties differentiating the two. A similar finding was reported in a study among adolescent boys with type 1 diabetes at Queens and Mzuzu hospitals in Malawi where 48% of the patients had difficulties differentiating signs and symptoms of hyperglycaemia and hypoglycaemia (Phiri, et al. 2017).

When diabetes educators said ‘*shuga*’ is diet, they were emphasising one aspect of management. Diabetes education literature highlights that management is about lifestyle which includes diet, physical activity, and maintaining a ‘healthy’ body weight (International Diabetes Federation 2017). By emphasising diet, patients may concentrate on it at the expense of other aspects of management, hence leading to poor glycaemic control. Further to this, adopting a ‘healthy’ lifestyle implies a change from how they have been living.

### 5.3.2 Uncertain target

During the clinic, numbers were used to determine ‘*shuga yabwino*’ [A ‘good *shuga*’ or ‘good’ sugar level]. A ‘normal’ sugar level was said to range from 70mg/dL to 126mg/dL. There is a variation between health facilities and among staff regarding the higher cut-off point as some put it at 130mg/dL<sup>61</sup>. However, what was considered a ‘good’ sugar level or ‘good *shuga*’ varied in the clinics. It was not always within this ‘normal’ range. At Queens Hospital, nurses conducted consultations with patients that had a ‘good *shuga*’ or those that did not have any ‘problems’. These excluded patients with type 1 diabetes, those that were using insulin, or those whose sugar level was extremely high or low, and patients who had a high blood pressure measurement. Doctors saw such patients. However, the cut-off points used to determine who was seen by doctors or nurses tended to vary. Sometimes, nurses had consultations with patients whose sugar levels are below 150 mg/dL. At times, the cut-off point was raised to 200 mg/dL. These cut off points depended on several factors, among them the availability of doctors to conduct

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<sup>61</sup> On a Biochemistry Request and Report Form (what is referred to as ‘results’) at Queens Hospital, the reference range for glucose is 70 – 130mg/dL. A ‘Laboratory Form’ from Nguludi Hospital shows that a ‘normal’ Fasting Blood Sugar is between 70 – 115mg/dL. For Random Blood Sugar, the ‘normal’ range is 70 – 198mg/dL.

consultations. Consider the following exchange that I observed in the Sister's Office as Sister Mataka and two clerks were sorting the 'results':

Clerk 1: This one is at 111. It is all right (*yabwinobwino*). I am not sure if the patient uses insulin (*ngati ali ozibaya*). Most of the patients have improved.

Clerk 2: These are up to 178, the normal ones

Sister Mataka: This one is 359. This is for the doctors.

[Field notes, Queens Hospital, 27092017]

In this instance, both 111mg/dL and 178mg/dL were classified as 'good *shuga*'. That meant patients with such results had a sugar level that was "all right" and hence had a consultation by a nurse. Therefore, the availability of medical doctors influenced the definition of what was considered a 'good *shuga*'. Patients who were told that their '*shuga*' was "all right" did not know that it was because doctors were not available, and the threshold for being seen by a doctor had been raised. For such patients, being told that their *shuga* "was all right" was 'proof' that they had been managing their diabetes correctly, even when they had been "non-complying".

During one a diabetes clinic at Nguludi Hospital, a patient had a fasting sugar level of 130mg/dL. The nurse who conducted the test said, "*That is a good sugar [level] for someone who has diabetes*" [Field notes, Nguludi Hospital, 06122016]. Compare this to what Dr Loveness Ndalama, a consultant at Queens Hospital, said to a patient during one of her consultation sessions. Before this appointment, the patient had a sugar level of about 360 mg/dL. On this clinic day, the sugar level was 200mg/dL, and the patient was happy with that because it had gone down. However, Dr Ndalama was not pleased. She said, "*As long as it is above 120[mg/dL], organs in your body are getting damaged. It does not matter that it was at 360 [mg/dL] and it has now gone to 200 [mg/dL]. You must aim for shuga below 120 [mg/dL]*" [Field notes, Queens Hospital, 20062017]. On another day, I asked Dr Ndalama at what level one should be concerned with their sugar, and she responded by saying: "*Anything above 200 is worrying*" [Fieldnotes, 06062017]. During a consultation at Queens Hospital, a nurse gave the following advice to a patient: "*This one*

is 155 [mg/dL]. It should not go beyond that. You need to follow a diet” [Field notes, 27092016]. Patients must ensure that their sugar level is below these targets, and from above, one can note that there is no single target number.

Targets were not only set in terms of sugar level; they were also set for other aspects that were needed for diabetes management, including weight and blood pressure. In a clinic consultation with Katalina Mkwamba (a patient at Nguludi Hospital), Golden Mposa noted that her weight was “*high for a diabetes patient*”. He asked, “*Have you been doing exercises?*” and she responded, “*No*”. Golden then admonished her that she was supposed to be doing exercises. She looked down shyly and did not say anything. Golden continued to ask, “*What prevents you from doing physical exercises?*” Again, she did not respond; she just looked down shyly. Golden then said, “*Your weight should not be 68kgs again when you come for the next appointment. Is that clear*” and she nodded in agreement [Field notes, Nguludi Hospital, 31012017]. That was her target. The instruction, which was given verbally, was not recorded in the patient’s health passport. On her next appointment, Katalina may not meet Golden Mposa. She might meet another clinical officer who may not know the target that Golden had set for her.

In the Malawi context, targets in terms of sugar level and weight were shrouded in uncertainty. In this chapter, I use the idea of a ‘good *shuga*’ rather than ‘normal’ or ‘good’ sugar level. ‘Good *shuga*’ and the multiplicity of its meanings conveys the uncertainty of these targets as its meanings vary. It may include a sugar level that is within or goes beyond what is considered ‘normal’ sugar level in biomedicine. It was what patients strived for and also what informed how they were supposed to manage. ‘Good *shuga*’ varies, because not only is it within a range, but also because patients were given a target of coming back with a sugar level that was neither high nor low. Patients were aiming for a ‘balance’. However, this was also a source of uncertainty. Without a glucometer, how does the patient know that they are within the range, that they are balancing?

The idea of consultation by nurses is one of the improvisations that is done in response to a lack of staff. While international diabetes management guidelines recommend that a doctor must see a diabetes patient at least once a year, some of the patients may not be seen at all. If the patient’s sugar level is always ‘good’, they are likely to continue to be seen by nurses for the whole year. The consultation by nurses is usually short. Often, they

will repeat the previous prescription and schedule another appointment after three months.

#### 5.4 Contradictions and uncertainties

There were some differences in diabetes messages, some of which even contradicted each other. Messages and ideas about diabetes varied among diabetes educators and health service providers. For example, at Queens Hospital, I noticed that there were differences between what Sister Mataka and Mr Zimba taught on how much diabetes patients were supposed to eat, Sister Mataka always emphasised that patients had to make sure they did not get full. She used to say:

We should eat *Nsima* carefully. We should not eat as we used to eat before. A diabetes patient is not supposed to get full. He/she is not supposed to feel hungry. He just must be in between.

[Diabetes education session, 24012017]

George Nyasulu, a type 1 diabetes patient from Queens Hospital, seemed to echo what Sister Mataka used to teach. He said he was advised that he: “*should not eat up to the extent that your stomach is full, and you are uncomfortable*” [Interview, 14092017].

On the other hand, Mr Zimba did not agree with such advice. For him, and that is what he taught, patients should be allowed to eat until they are full. He viewed the idea of balancing between not getting hungry and not getting full as challenging but also impossible for patients to put in practice. In an interview at his home, he gave me a rationale for telling patients to eat until they are full. He said:

[In other countries], food content is measured while here we do not. That is why I always say eat *Nsima* to get satisfied not following the instructions. I say you can eat because if you say your measurement is first, then you can kill that person. Even to me if you say so, you are killing me because I may wake up at midnight [hungry], which is not good. I should eat to get satisfied. I should not over-eat but I should eat the amount that I eat every day and which my intestines are used

to that. That is why I say eat until you are satisfied because we do not measure the food content. When I am covering those things, I am doing that because I am looking at the life of the person. Are we together?

[Interview, 15062017]

There were also other areas in which Sister Mataka and Mr Zimba did not agree on what diabetes patients ought to do. For Sister Mataka, alcohol was forbidden. Diabetes patients were not supposed to drink it at all, at one point referring to it as “poison”. On the other hand, an exchange between Mr Zimba and a patient during a diabetes education session, alcohol was allowed albeit not excessive drinking. The exchange was as follows:

Patient: What about beer, how many bottles?

Mr Zimba: Take one bottle of beer per day.

Patient: What [alcohol] percentage?

Mr Zimba: I do not know the percentage. Take one can of beer. However, we do not encourage the taking of beer. We say no to that because of the problem with beer; you start with one bottle, then two, three, four up to the extent of saying you cannot stop taking beer.

[Diabetes education session, 23052017]

Diabetes patients were also aware of these contradictions and they expressed these during interviews and the questions that they posed during diabetes education sessions. During my interview with Mrs Florida Kandulu, a type 2 diabetes patient from Nguludi Hospital, she said: *“Some people say that you can also eat boiled beef but others are against that idea saying boiling the meat doesn’t drain all the fats so I do not know which is which. That is what happens when you interact with different doctors, but the main point is you should not eat food with too much fat”* [Interview, 07102016]. Mrs Victoria Singini, a type 2 diabetes patient from Queens Hospital, also noted the same challenge. However, she was mainly concerned about different messages that different diabetes educators often

taught. She expressed these apparent contradictions in the messages by inviting me to attend the diabetes education sessions and notice it for myself. She said:

We also get different messages from those who teach us. On the same topic, we are usually taught differently especially when there are two educators. If you can have time, try to go and attend a lesson there this week and then when you will come back for the same lesson the following week; you will see that, this other person is giving out totally different information to what was being taught by another person the past week. You can be told that, you are only supposed to add only one spoon of cooking oil to your relish; but the other person will tell you not to use any cooking oil but instead will say, just boil your relish. Therefore, it really becomes a big challenge for a patient to choose which instruction to follow.

[Interview, 17102016]

For Mrs Singini, these contradictions went further to the availability of herbal medicines in the clinic which had different, and sometimes, conflicting instructions to hospital medicines. She said: *“At the [diabetes] clinic, they tell us not to stop taking hospital medicine. Yet, at the [same] hospital, they also sell to us another type of medicine which is made in the form of a juice. This type of medicine is made from a mixture of fruits and is being sold in Limbe. We buy a bottle at MK10,000.00. There are instructions that we follow on how to take this medicine. The medicine is also sold at the hospital”* [Interview, 17102016]. The contradiction expressed by Mrs Singini relates to differences between providers of biomedical and herbal medicines. While she focusses on differences in instructions between the two providers, other differences were in terms of claims made about their medicines. Many herbal providers claimed that their medicine “cured” diabetes while biomedical health care workers insisted that diabetes had no cure [I addressed these in Chapter 7]. For patients there were also other sources of information including other patients and the media which often provided different and at times contradictory ideas about diabetes. However, the critical point is that some of these contradictions may require patients to address them.

## 5.5 The immorality of “non-compliance” / “experimentation”

The ideas (and ideals) that patients should not “experiment” and that they should follow everything that they are taught at the clinic were repeated several times during diabetes education. These were based on two ‘certainties’: that sugar levels would go up if patients did not follow what they were taught and the emergence of complications (amputations, stroke, hypertension etc.) and death. Health care workers used examples of what happened with patients who did not follow what they had been taught. During diabetes education at Queens Hospital, Sister Maria Mataka often said to patients: “*We need to discipline our lives, considering the problem that we have*” [Field notes, Queens Hospital, 24012017]. She usually told two stories of why patients should follow everything they were told and not “experiment”.

The first story was of a woman who ignored advice on eating fruits before going to bed. During one education session, Sister Mataka was describing what patients should be eating at various times of the day. She said patients were supposed to eat fruits around 10 a.m. and “*around 3, 4*” in the afternoon. One female patient asked whether eating cucumber would pose a risk of raising ‘*shuga*’. Sister Mataka responded, “*You need to discipline yourself. Do not eat plenty of it because if you do, you will be admitted. If you try to experiment, to increase a little, you will be admitted. Everything should be eaten carefully. One cucumber is enough!*” [Field notes, Queens Hospital, 24012017]. She then continued to tell the patients that fruits were part of their treatment and that before going to bed, they should ensure to eat fruit. In saying this, she highlights the uncertainty of *shuga* but also the consequences of not doing as the patient is told. She said,

Just before you go to bed, eat some fruit. You should never run out of fruits in your households. Consider fruits as part of your treatment. Take it as treatment. So, make sure you take a fruit just before you sleep. Why do you think we ask you to take fruit before sleeping? This is because *shuga* can go down while you are asleep. Remember, low *shuga* is very dangerous. You can die in your sleep. Last year, in February 2016, a woman died because she did not eat a fruit [before going to sleep]. *Shuga* is unpredictable; it can do up or down if we are

not careful. It can go down while you are asleep. If you have eaten fruit, it will raise the sugar level.

[Field notes, Queens Hospital, 24012017]

The second story was about another woman who, despite being told to wear shoes at all times, went around her house barefoot. Unfortunately, she stepped on a piece of broken glass and suffered a big cut. She delayed going to the hospital as she thought it would heal on its own. However, the cut kept getting bigger, and she went to the hospital after a week. Sister Mataka dressed her wound and recommended her to come again after a week to have it cleaned. She also got a prescription for a particular antibiotic for '*anthu a shuga*' [people with '*shuga*']. At that time, the hospital pharmacy did not have the antibiotic, and she was asked to buy it at a private pharmacy. She did not. When she came back after a week, the wound was so bad such that Sister Mataka felt that it was beyond her expertise and referred her to one of the surgeons who recommended that they amputate her. She did not want to be amputated and decided to seek medical care in South Africa. According to Sister Mataka, she died while in South Africa.

One of the critical themes of diabetes education is that patients are supposed to follow everything that they are told in the diabetes education session without questioning it because it is for their 'good'. It is also the moral thing to do. With regard to the advice that they give, Dr Ndalama once told me that, "*... as a doctor, I can write all I want, I can say all I want, but if the patient does not take it upon themselves to do the right things, and make the right changes in their lives, it is challenging to help*" [Interview, 18012017]. Mr Zimba emphasises that "*If we tell you that you must do in such a way, you must understand and follow that*" [Field notes, Queens Hospital, 27062017]. For Sister Mataka, diabetes only causes problems if patients are not "complying" with what they have been taught. She said, "*Shuga does not cause problems if one is following those rules*" [Field notes, Queens Hospital, 25042017]. Later, she continued: "*A diabetes patient should not feel hungry because low shuga kills extremely fast. That can happen at any time if we do not follow the rules/instructions*". In this statement, Sister Mataka was highlighting that diabetes complications only emerge because a patient has not followed the "rules" about managing '*shuga*' that they learn at the clinic. Moreover, she was emphasising that if sugar levels go

up or down, the patient was to blame as it is his or her responsibility to make sure they do not.

This idea was also reiterated in diabetes consultations during which patients with an extremely high or low sugar level were asked what they have been doing for their '*shuga*' to go up or down respectively. At the end of a consultation, health care workers would tell the patient what they thought about their '*shuga*' and, most importantly, what they were to do next. Based on their assessment of how the patient was managing, health care workers either changed or maintained the dosage for the patient. In rare instances, patients were told to stop taking medicine and adhere to a 'diabetic diet' as a means of controlling '*shuga*'. This final part of the consultation included some advice, and in some cases, warning against and the implications of having high or low sugar level (depending on what the patient has presented with). At the end of a clinic consultation with a 52-year-old male patient who had presented with a high sugar level, Dr Ndalama said, "*Your shuga is not being well managed. The problem you are experiencing on the feet is because some of your body organs are being damaged. Do you know what level your sugar is supposed to be? The results are showing that your shuga is not being well managed*" [Field notes, Queens Hospital, 24012017].

Patients were supposed to care or control themselves by following all instructions to avoid complications. Doctors expected patients to do this by accepting that they had diabetes and that it cannot be 'cured', accepting that like HIV and AIDS patients, they will take medicines for the rest of their lives. It was the patients' (and caregivers' if available) responsibility to ensure that they exercise, take medicine on time and correctly, or eat well/carefully. Mphatso Lemani, a type 1 diabetes patient from Queens Hospital, clearly described the patient that health care workers expect. Apparently, over time, he had become that patient. He said:

I have now learnt/I now understand my body. I do things on my own. It is different from when I was young, and I needed someone to take care of me. I now know what I am supposed to do, and what I am not supposed to do. I have learnt *shuga*... [in terms of] knowing the symptoms that sugar has gone up and hence I should not go anywhere, I should just stay home. Initially, they had to tell me that I should not

eat certain foods. Right now, I know that I should not be childish, or I might die.

[Interview, 09042017]

Finally, diabetes and the bodies that it affects are unpredictable – it is an uncertain disease. *'Shuga'* can go up or go low at any time. Uncertainty also emerges in the availability of diabetes medicines as stock-outs are frequent. Therefore, patients and their 'guardians' must be prepared for such uncertainties. They cannot know when their sugar level is going to get low, but they must be prepared when such an eventuality happens – having a small packet of sugar wherever they go or a sweet, telling others (especially family members) about their condition and what they can potentially do, or eating a fruit before going to bed.

Diabetes educators (nurses and volunteers) emphasised that patients must be accompanied by 'guardians' when attending the clinic and that these should also know diabetes, its symptoms and what they ought to do at home in terms of what patients eat. Besides, of importance is that 'guardians' also must know what to do when the patient's sugar level has gone down as this is dangerous. Few patients come with their 'guardians' or caregivers to the diabetes clinic. While the patients are encouraged to come with their caregivers or 'guardians', I observed instances when, because of lack of space in the area where education sessions are conducted, 'guardians' were asked to sit outside.

## 5.6 Conclusion: Uncertainties and subjectivity in diabetes

Diabetes education was meant for patients to assume 'responsibility' for managing diabetes, but also a pathway for treatment. Some of the content of diabetes education, for example the emphasis on not eating fats, was not for management of diabetes itself, rather it was meant to prevent other non-communicable diseases especially hypertension. However, when presented in diabetes education, patients were told not to eat fats to ensure that their sugar level did not go up. Diabetes education was about certainties and uncertainties that emerge because of having diabetes and how patients ought to manage them. Patients were taught about signs and symptoms of low and high *'shuga'*, symptoms that emerge if sugar levels went up or down. They were also taught that sugar levels rise if they ate inappropriate foods and go very low if they took medicine

without eating. These were communicated with certainty to make sure patients follow them. At the end of diabetes education sessions, patients were expected to 'know' what was right or wrong in terms of food and their behaviour. By presenting what patients were supposed to do as either right or wrong, morality was invoked in diabetes education. They were expected to know the potential ramifications of not following this: complications and death. They were supposed to do the "right" thing by ensuring that they followed what they had been taught to prevent complications and death.

Patients also learned about uncertainties that having diabetes entails. There were uncertainties in their bodily experiences but also in their social environment. Patients were told of the uncertainty as to when signs and symptoms will appear. This sort of uncertainty is slightly different from what Susan Whyte described in *Questioning Misfortune* (Whyte 1997). She described uncertainties that emerge as outcomes of misfortunes such as poverty, infertility, and disease, and in practices such as divination which are meant to deal with these misfortunes. What was described in diabetes education was not uncertainty as an outcome of an event but as part of the experience of diabetes. For example, in experiencing diabetes, a patient is uncertain as to when these symptoms will appear.

The other uncertainty related to bodily experience is related to attaining "good *shuga*" which, as I have shown, may vary depending on various circumstances including availability of doctors. Patients' practices towards achieving a 'good' sugar level were not guaranteed to succeed as evidenced by patients who complain that even though they had been 'complying', their sugar level still went up. On the uncertainty of a 'good *shuga*' as a target, Mol (2008:19) has a similar idea when she suggests that "In chronic diseases health is beyond reach, and it has been replaced by the ideal of a 'good life'. However, what counts as a 'good life' is neither clear nor fixed. Aiming for a long and happy life might sound nice, but it is often necessary to juggle between 'long' and 'happy'".

Patients also faced uncertainty about access to medicine. In Malawi, patients get free services (including medicine) from government-owned health facilities like Queens Hospital. In most government facilities, the stock out of medicine was a common challenge. There was uncertainty considering that patients were not sure when medicines will run out of the government facilities. During stock out of medicine, patients

were asked to buy from local pharmacies. For most patients, medicine was expensive, more so for those that were using insulin. Even patients who were accessing services at Nguludi Hospital where they had to pay for their medicine also faced uncertainties in the availability of medicine and testing strips. While Nguludi Hospital provided testing strips, this was not guaranteed, and patients had resorted to buying their strips.

To manage the uncertainties in diabetes and its management entailed action on the part of the patient. The intention in diabetes education was to produce '*munthu wa shuga*' who knew their disease, symptoms that emerge and knew what to do about it. Patients had to change to a new one that followed diabetes education advice. This new person was supposed to accept that they were different from those that were 'normal'. In this case, "normality" was binary: those that did not have diabetes were 'normal' while diabetes patients were not 'normal'. The expected transformation was akin to the religious conversion from a sinner to a 'born-again', in which the old person was gone, and a new one had emerged (cf. Robins 2006). This transformation was what Sister Mataka was referring to when she said: "*you are done with sugar food*". The education session was meant to fashion '*munthu wa shuga*': one who 'knews' *shuga*, one who was responsible for their health; one who was responsible and moral to do something about their health out of self-interest to avoid the emergence of symptoms/complications or the doctor's admonition for high sugar level. They were supposed to take care of themselves and not self-harm by eating foods that was forbidden. This new subject was one that followed all the advice received from diabetes education without question. This new subject was responsible and made sure that their sugar level was neither low nor high. This 'new subject' attended clinic appointments without fail. The emphasis on individual control, self-discipline and responsibility led to moral overtones in which failure to "comply" by following a "diabetes diet" or regularly exercising were blamed on the individual as if they are independent of their social and historical context which ultimately influences management (Borovoy and Hine 2008).

For patients within the diabetes clinic, their main goal was to prevent uncertainties or to be ready when they occurred. However, diabetes education recognised that it was not possible to eliminate these uncertainties. As such, patients had to be sure when the symptoms appear and what they were. They had to be sure of what they needed to do when such symptoms appeared. However, as noted by Phiri, et al. (2017), while

identifying a symptom of hyperglycaemia or hypoglycaemia was deemed easy because patients experience them when blood sugar level goes down, patients still needed to develop a skill over time to identify them. That was why a diabetes patient needed diabetes education. Using diabetes education, patients made sense of uncertainty by constructing a narrative that made sense within their life experience by using biomedical and other ideas about disease. Such a narrative fit neoliberal ideas of personhood and was often fraught with self-blame, responsibility and a moral imperative to do something about diabetes. It was within this responsibility and morality that patients tried out anything that was said to alleviate, remove or manage this uncertainty (cure diabetes), including using herbal medicines and religion. Patients were “responsible” for making sure that they followed everything that they had been taught as a means of avoiding diabetes complications. Considering that “experimenting” was said to result in diabetes complications and death, it follows that only a patient who does not care about himself or herself would do to it. *Munthu wa shuga* would do what was “right” by making sure that these symptoms did not emerge. However, in practice and in spite of the messages in diabetes education, patients “experimented”. This is what I show in the next chapter.

## Chapter 6

### “Experimenting” as diabetes management

What are the practices of diabetes management that were made possible considering patients’ perceptions of diabetes, and what was taught in diabetes education? I address this question in this chapter by focussing on how “*munthu wa shuga*” takes on diabetes management practices in everyday life. Most research on diabetes management practices shows that patients do not follow the advice that they are given in biomedical health facilities, which is referred to as “non-compliance” in biomedicine. In this chapter, I explore such practices in terms of the use of food and biomedical drugs. I describe some of these forms of “non-compliance” as “experimentation”, a strategy to deal with uncertainties that characterise diabetes and its management. I highlight how these practices are individual patients’ “experiments” on and with (in) their bodies. These experiments were driven by two ideas that were stressed in diabetes education: “*the body speaks*” and “*be your own doctor*”. I show that both patients and health care workers improvise various practices of diabetes management in response to the uncertainties that exist in the context within which it is managed. I show that contrary to perceptions mostly held by biomedical practitioners, the so-called “non-compliance” was not a result of patients’ “irresponsible behaviour” or lack of acceptance as doctors often said, but instead it was a form of taking care of themselves, part of being moral patients. In doing so, I also highlight some of the challenges that patients face in managing diabetes in Malawi.

In making these arguments, I contribute to studies that have explored “non-compliance” and morality in diabetes management. In public health, being “moral” patients entail following the dictates of biomedicine (Lupton 1995). On the other hand, in anthropology, Broom and Whittaker (2004) showed the “moral” dimensions in the narratives of diabetes patients in south-eastern Australia, which acknowledge, but also distance the patients from, discredited identities for example being mistaken for a drug addict because one is injecting insulin. Diabetes patients positioned themselves as ‘children’ to diminish their agency but also to posit themselves as blameless whenever they failed to control diabetes. Broom and Whittaker (2004) further noted that some patients described the failure to control as “normal” while others concealed transgressions. By highlighting their diminished agency and normalising their behaviour, these patients maintained their

morality while engaging in behaviour that was deemed “non-compliant” by health care providers. In Thailand, Naemiratch and Manderson (2006) explored the reasons why diabetes patients’ practices of managing diabetes involved adjusting advice that is given by doctors. They argued that ideas of control and adherence resonate and are consistent with Buddhist philosophy and Thai norms. They show that doctors, using an authoritative ‘voice’, required patients to stop certain behaviours that are inconsistent with biomedical management of diabetes. They argue that the doctors’ authoritative nature contradicted the Thai value of “being free, neither taking charge nor being subject to others’ authority” (Naemiratch and Manderson 2006).

In contrast to the position of Broom and Whittaker (2004), participants in my study maintained their agency in the quest of being moral and responsible patients. While participants in my study adjusted doctors’ advice on management (what I refer to as “experimenting”), they did so not as a challenge but acceptance of the doctors’ authority. I start the chapter by exploring the experience of symptoms through the idiom *‘the body speaks’*. Health care workers use this idiom to ensure that *‘munthu wa shuga’* pays attention to diabetes symptoms so that their sugar level does not go extremely high or low. Patients were told to *‘be their own doctors’* as a strategy to deal with those symptoms. Patients went beyond the intended use of these ideas by “experimenting” with food and medicine as they strive for a *‘good shuga’*.

### 6.1 *‘Thupi limanena’ The body speaks*

One afternoon, Mrs Joyce Jenala, a type 2 diabetes patient and volunteer for the diabetes association, was distributing “results” for patients in Room 1 at Queens Hospital. She was reading out names for patients and giving them their ‘results’ and instruction as to whether they were to be seen by a nurse or a doctor. As she was doing so, she read one of the patients’ names wrongly. She did it three times, and no one stood to get the ‘result’. When that happens, the usual assumption is that the patient is not in the waiting room as they have gone into town to run some errands. When she read it the fourth time, one of the patients stood and asked to see the ‘result’. It turned out that Mrs Jenala had not read it correctly. As the patient left with her ‘result’, Mrs Jenala apologised and said: *“Eye problems are shuga”* [*Masowo nde shugazo*]. By this, she meant that diabetes manifests itself in terms of eye problems. Therefore, she was not to blame for her failure to read the

name correctly. This is one of the ways that patients describe symptoms and complications of diabetes. These descriptions highlight two things: the social disruption that comes because of diabetes and the experience of its symptoms, and the many ways in which the *'body speaks'*.

I first learnt about the idiom *'the body speaks'* in relation to diabetes during education sessions. It was repeated in my interviews with patients when talking about their experience of symptoms. However, its usage is not limited to diabetes. During the peak of the AIDS epidemic in Malawi, it was used for someone who had contracted the virus and then the signs, like losing weight, had started showing. This example, a quote from an HIV counsellor during a 2004 study on Voluntary Counselling and Testing in Malawi, illustrates this usage: "*The body speaks'*, so when the person does not have HIV or has got it, they (people observing) can tell from the way the person walks or looks. Maybe they are reactive or not, depending on the way the body has spoken" (Yoder and Matinga 2004:43 emphasis added). In day-to-day parlance, people use the idiom *'body speaks'* to suggest that they can tell how one is doing in life even if the person does not say it or tries to hide it. In both usages, something that has happened to the body is deduced from how the body is being perceived or experienced. Those experiencing symptoms of diabetes, and their caregivers can tell when *'the body speaks'*.

As used in diabetes education, the idiom was being used to warn patients that if they do not eat as they were advised, the body will *'speak/tell'*, and the health care workers will *'know'*. In this case, even if patients were to try to hide that they have been managing poorly, the body will expose them. The idiom was also used to tell patients that they needed to pay attention to the body so that they can *'hear'* the body when it *'speaks'* and so act on what the body had *'spoken'*. This usage entails that when symptoms and complications emerge, the patient has no excuse for not doing anything because the body will have "spoken" and they did not listen and do something about. It was meant to highlight the symptoms of low and high *'shuga'*. Among patients, *'the body speaks'* was also described as a *"feeling in their body"* or *"how the body is behaving"*.

When does the *'body speak'*? According to diabetes educators, the *"body speaks"* when sugar levels are extremely low or high. Sister Mataka said: *"It will not just go down; it will give you a warning. The signs for low sugar blurred vision, feeling hungry and*

*shaking/shivering mean that the body is speaking/telling, it is giving a warning*" [Fieldnotes, Queens Hospital, 24052017]. One instance when the "body speaks" is "When you make a mistake [Field notes, Queens Hospital, 24012017]. An example of such a mistake is about not taking medicine at the same every day. Sister Mataka said: "In the evening, again we start by taking medicine [before we eat]. We should not forget this ritual. If you took your medicine at 6 am, you need to take the other dosage 12 hours later. The body speaks that you have made a mistake" [Field notes, Queens Hospital, 13122016]. At another diabetes education session, she said talked about mistakes involving eating or drinking inappropriate food or drinks. She said: "When it comes to shuga if one makes a mistake in terms of diet, that is it. If you took Fanta yesterday, today it [the body] will tell." [Field notes, Queens Hospital, 25042017]. Dr Bertha Ngwalo, the coordinator for one of the diabetes projects at the College of Medicine, referred to it as carelessness. She was telling me about patients knowing when their sugar level is up or down. She said: "That is why it is important to ask how the patient has been. The experienced patients actually know when their blood sugar is high, even before you measure it. They know; they can feel it. You ask them in a clever way if they have been well. The ones that are honest will tell you that at some point, I was not feeling well but I know why – it is because I was careless" [Interview, 15072017]

Mrs Jenala told me how this happens in practice while we were talking in Room 1 at Queen Elizabeth Central Hospital. It was just before half-past two and the room was almost empty, as the doctors had already had consultations with most of the patients. As we were talking, she took out a bottle of fruit juice from her bag. I asked if that was her 'lunch'. She said, "Yes, around lunch, I feel weak, I then take SOBO [a locally-manufactured orange soft drink]" (Conversation, 08112016). During diabetes education, patients are told not to drink SOBO. However, they can take it in the event when they experience hypoglycaemia – low blood sugar levels. Therefore, when she said, "I feel weak", she was justifying why she was taking a 'prohibited' drink. I asked what she was experiencing, and she said, "Actually, I am currently experiencing both [hunger and weakness]. The body speaks, I feel so weak when this happens" [Conversation, 08112016]. She continued to say she then starts feeling headache, shivering, and that she feels weak. Mrs Jenala's description includes when and how "the body speaks". It 'speaks' to her when she has missed lunch – as she had on that day. "Munthu wa shuga" is not supposed to miss lunch.

Mr Gervasio Kenani, a type 2 diabetes patient from Queens Hospital, also said he experiences the *'body speaking'* when he has not eaten for a 'long time'. He said, "Sometimes when you have not eaten for a long time, it starts with the mouth. You start feeling bitter in the mouth, that feeling where one is very hungry. That is what one feels, and then you start feeling weakness in your joints. That happens to me when I have stayed for an exceedingly long time without eating" [Interview, 26062017]. Later in the same interview, he had said that even though he is a 'born-again' Christian, he does not engage in fasting that involves not eating the entire day. He said:

In my case, I cannot manage to do the type of fasting where one does not eat anything from 4 am until the evening. I take some water [in between]. I may not eat anything but at least take some water. ...For me, that is always ok, but I do not go beyond three o'clock [in the afternoon] because, by then, my whole body will have already started *speaking* that I am too weak. It means that the sugar level has gone low because even though my *shuga* is the high one, it goes down if you have not eaten.

[Interview, 26062017]

Other than not eating, some participants said that *'the body speaks'* when one has eaten a large amount of food, or they have eaten the 'wrong' food or taken a 'wrong' drink. By 'wrong' food or drink, patients are referring to food or drinks that have much sugar and can cause *'shuga'* to go up. Mrs Linly Mbawala, a type 2 diabetes patient from Queens Hospital, put it this way: "When you eat plenty of food, your body tells you; and those will make you urinate excessively" [Interview, 15052017]. On the other hand, Mr Kondwani Mapwesera (KM), a diabetes patient also from Queens Hospital, notes two things that make *'the body speak'* to him: not taking medication and eating foods that have 'plenty of sugar'. He recalled a time when he travelled to his home village and took a drink that made him sick. He said:

KM: If I miss taking my medication, something happens, or when I eat some other foodstuff, I get sick, for example, last time when I went to my home village...

MJN: Is that the time we spoke [on the phone]?

KM: Yes, that time. That time I took a drink called Frozy<sup>62</sup>. I do not take any soft drink except Coke Diet. However, this time, I took Frozy drink, not knowing that I was adding too much sugar in my body. Moreover, Frozy also has some acid, which is terrible for me, which made my BP go high again. I could feel that something was not ok until I came back home, and my wife told me that I looked sick. ...It made me very weak, but now I have adequately recovered.

[Interview, 20112016]

*'The body speaks'* depending on the amount of medicine they have taken. Diabetes educators often said that *'shuga'* goes low because of not eating or if one has had an overdose. For example, Mr Zimba said, *"Other reasons might be that you have not eaten or have taken more than prescribed drugs because you forgot that you took the drugs before. These two reduce the levels to unexpected. Then you start shivering"* [Field notes, Queens Hospital, 27062017]. My conversation with Mr Kondwani Mapwesera above started with him talking about what happened when he had missed taking his medication. It was a similar experience to when he has eaten certain foods or taken certain drinks, in this case, a beverage called Frozy. A remarkable aspect of Mr Mapwesera's response was that even his wife could tell that he was looking sick. In this instance, when the body spoke, it was apparent to the patient but also to those around him (cf Mol and Law 2004). During another interview, he said, *"... also the body speaks [when you feel] very weak, know that it has gone up. For example, for all the work I have done today, I am not feeling weak"* [Interview, 18032017]. In other instances, *'shuga'* can go low when one injects insulin or takes diabetes medicine without eating, as highlighted in the following quote: *"We take medicine first before eating. We then wait for thirty minutes before eating. If there is no food, we should not inject ourselves nor take our medicine. The insulin will wipe out all the sugar if we do not eat"* [Field notes, Queens Hospital, 13122016].

If *'shuga'* goes low or high, there are several signs and symptoms that patients experience. Sister Mataka once told patients: *"You must know if shuga is high or low and do something*

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<sup>62</sup> This is a popular soft drink imported from Mozambique.

*about it. It will not just go down; it will give you a warning*” [Field notes, Queens Hospital, 25042017]. When I asked patients how they know that their *shuga* is up, most of them said they *“feel it in our bodies”* [Field notes, Queens Hospital, 24012017]. Similarly, when Sister Thokozani Njewa, nurse at Nguludi Hospital, noted that a patient’s sugar level had increased compared to the previous months reading, she asked: *“Your shuga has gone up, and it is exceptionally high. Did you feel in your body that the shuga has gone up?”* [Field notes, Nguludi Hospital, 06122016].

On the other hand, low *‘shuga’*, according to Mrs Ziona Njewa, causes blurred vision, feeling weak, dryness of the mouth, dizziness, and seating and *“fast beating of the heart so that it should get all the available sugar”* [Field notes, Nguludi Hospital, 31012017]. If the patients or those around him or her do nothing, the patient then collapses. One of the patients said how low *‘shuga’* progresses to death:

Educator: What are the signs of low *shuga*?

Patient 1: Strange hunger

Patient 2: Hunger leads to shivering and then blurred vision, then sweating and finally, death.

[Field notes, Queens Hospital, 24012017]

*‘The body speaks’* through the experience of symptoms. Symptoms arise at a certain level of sugar. However, one cannot know when symptoms will come. *Shuga* is precarious. Over time, the body may get used to diabetes and its signs/medicines – this diminishes the extent to which *‘the body speaks’*. It is the patients’ and their caregivers’ responsibility to pay more attention to ‘hear’ when it ‘speaks’. Overall, dealing with those symptoms requires what diabetes educators called *“being your own doctor”* and *“experimenting”*.

## 6.2 *“Only when something is wrong” – improvising the glucometer*

As I have shown above, *‘the body speaks’* through symptoms like headache, shivering and feeling weak. However, there may be some uncertainty when *‘the body speaks’* as patients may also experience these symptoms on their own or because of other diseases. These symptoms are not specific to diabetes. For example, symptoms for malaria include

headache, shivering and feeling weak or bodily pains. Therefore, when “*the body speaks*”, patients may experience uncertainty whether it is because of diabetes, malaria or other diseases which have similar symptoms. Such uncertainty may be less noticeable for someone that has had diabetes for a long time because he or she loses ‘sensitivity’. Dr Loveness Ndalama, a consultant at Queens Hospital, said, “*Besides, for patients who have had diabetes for a while [there is another problem]. If it is a new patient or if it is you and your sugar [level] goes low, you will feel sick; you will feel specific symptoms that show that your sugar [level] is low. However, for patients that have been on treatment for a long time, sometimes they lose that sensitivity to knowing that their shuga is too low*” [Interview, 18012017]. Now, that is dangerous as it may lead to death. Patients always must avoid it. Therefore, it may be necessary to ascertain whether the body is ‘speaking’ because of ‘shuga’ or not. At times, it may be that one needs to know if the body is ‘speaking’ at all. Self-monitoring technologies are encouraged for diabetes patients to help clear this uncertainty. In the section below, I explore the use of glucometers as part of diabetes management among patients.

In a country where almost 75% of the population earn less than \$1.25 [£0.95] per day (United Nations No date.), a glucometer is an expensive gadget for most Malawian diabetes patients. Glucometers cost at least K12,000 (£12). It is not surprising that among my participants, only ten had a glucometer. Some, for example Mrs Florida Kandulu, a type 2 diabetes patient, had bought their glucometers from a pharmaceutical company that sold them at a reduced-price during the commemoration of the World Diabetes Day. Mr Alinafe Mandere’s (type 2 diabetes patient, Queens hospital) glucometer was a gift from his boss. Mphatso Lemani (type 1 diabetes patient, Queens Hospital) got his glucometer from a medical doctor from the College of Medicine.

I usually asked patients who had glucometers when they tested themselves and how often they did so. Responses to these two questions revealed several improvisations in the use of glucometers. In most cases, patients said they used their glucometers to test themselves when they were not feeling “all right”. A good example is the response I got from Mrs Sakina Mtema, a 72-year-old diabetes patient and retired nurse, as to how often she tests herself. She responded: “*I cannot tell you how often I test myself. I test when I notice that shuga is giving me problems*” [Interview, 25012017]. When I asked how she knows that ‘shuga’ is giving her problems, she said, “*...when I notice that I have a headache,*

*I test myself and then drink plenty of water... When it is low, I struggle to walk. My legs are shaky. I feel pain in my heart, and then I know that something is wrong."* Similarly, Mr Kondwani Mapwesera also tests himself when he feels that "something is wrong". However, he also tests himself when he has done something that can potentially raise his 'shuga'. He said, "As for me, when I feel that I have eaten a lot, so I must reduce the uptake of food and then the following day I test myself and find out that it is okay. That is how I monitor it" [Interview, 18032017]. Among my patients, using a glucometer was meant to confirm bodily feelings and experiences when 'the body speaks'.

Part of the reason that patients only test when something was observably wrong is that testing strips were not affordable for most patients that had glucometers. Testing strips cost as much as K5,000. By not testing often, patients were ensuring that the testing strips last as long as possible. I had asked Mr Mapwesera about how often he tested himself, and he responded by highlighting that he tests depending "on how I am feeling at that particular time. Then there are these [testing strips] which are expensive" [Interview, 20112016]. For Mrs Joyce Jenala, it was not only the cost of the testing strips but also the stress of testing that made her only test occasionally. She said:

I use it when I have suspected that something is wrong. It is stressful and expensive to use a glucometer daily. Therefore, I do not use it regularly. [I only use it] only when something has gone wrong. I may experience the signs of malaria when the sugar level has gone up. At times, I may have a fever or have body pains, and when I go to the hospital, they [test and find that] malaria [test] is negative. Upon requesting for a sugar test, they find it high.

[Interview, 08112016]

In this quote, Mrs Jenala notes that she does not test herself often because of the cost of testing strips and the stress of testing herself. In the last part of her response, she highlights another reason for testing. Using a glucometer is a means of dealing with the uncertainty of the symptoms that she experiences. Based on the result, she can confirm that the symptoms are a result of raised sugar level or another disease, for example, malaria. Mrs Victoria Singini, a type 2 diabetes patient, sees the futility of testing every

day because of the uncertainty around sugar levels. She said, “[*I test myself*] when I feel that I am not feeling okay. I do this because I can check it today and find that it is normal, but when I check the following day, then it shows some changes that it is rising” [Interview, 17102016].

Some patients have also used their glucometers to test others. For example, Mrs Jenala has one of those glucometers that store readings for previous tests. On one occasion, she showed me how her previous sugar level measurements had been fluctuating. At that time, some of the readings that were stored in the glucometer were not hers as she had tested others on two different occasions. She said:

Of course, the first three readings are not mine. At a graduation ceremony, a woman collapsed, and I was wondering what had happened. Therefore, I asked her if I could check her sugar [level] because that is what may cause someone to collapse as she did. When I measured, it was 89 [mg/dL]. This other one is for another woman whom I met at the market.

[Interview, 16092017]

Mr Lucius Zimba also tests some people that come to his home. He said, “[*There are some people who come here for blood sugar test. I test them, and for others, I find it very high. So, I advise them to go to Queens [Hospital] for medication or to change their diets*]” [Interview, 15062017].

Patients and health care workers also improvise the use of glucometers, devices which are intended for use by individual patients for self-monitoring. At Nguludi Hospital, a glucometer is used for measuring fasting blood glucose for patients who attend the diabetes clinic. While there is a laboratory that does other tests for sugar level, glucometer readings are used for diabetes patients because it is less expensive. Several private clinics and pharmacies offer blood sugar level tests using glucometers at K1,000 (£1). Some of my participants told me that they had been tested at these facilities. Mrs Florida Kandulu, a type 2 diabetes patient, went to a private clinic to test her sugar level because she had missed her appointment at Nguludi Hospital. Mphatso Lemani, a type 1 diabetes patient from Queens Hospital told me that he goes to a local private clinic to test

his sugar level when he is not “feeling well”. Most private pharmacies and clinics use glucometers to do these tests.

During diabetes education, patients who did not have (access to) a glucometer were asked to make other improvisations if they wanted to tell if their sugar level was low or high. According to Mr Zimba, the diabetes educator, one of the ways to determine is by noting the amount of urine and/or the number of times they urinate at night. Mr Zimba made further suggestions as follows:

If you do not have a machine to test your sugar level, simply get your urine, put it in your mouth, and taste it... [Do] not [use] somebody’s urine but yours. If it tastes sweet, then your sugar level is high. ...If you see plenty of foam in your urine, [it means] your sugar level is high. If you urinate on the ground and notice that ants start going towards where you urinated, know that your sugar level is high; That sugar which causes your sugar level to be high is thick; So is your urine. You can even feel it with your hands.

[Diabetes Education Session, 23052017]

Two participants in the study – Mrs Joyce Jenala and Mr Kondwani Mapwesera – tested themselves in my presence when I had visited their homes. I had visited Mrs Jenala’s home on a Saturday morning around 10 am. She had injected insulin that morning but said she would be “*all right*” because she had not had breakfast. By “*all right*”, she meant she would not experience symptoms of low ‘*shuga*’. She had been showing me her previous sugar levels on the glucometer when she said, “*In the morning, soon after waking up [Mammawa, kudzuka kumenekuku]. Two or three days before, it has measured 91 [mg/dL], and then on another day, it was 308 [mg/dL]. On another day, I was 80 [mg/dL]. Like that. For today, I had not eaten anything since I woke up. Let us check and see [She goes on to start measuring]*” [Interview, 16092017]. After checking, the reading was at 141 [mg/dL]. Once again highlighting why she does not test often, she said, “*I measure sparingly because of the strips. I do not frequently measure because Codefree [glucometer testing strips] are expensive. For example, I have run out of my testing strip now. This is the remaining one ...*” [Interview, 16092017]. Earlier in the interview, she had said the

Codefree glucometer could use any brand of testing strips. Therefore, when she said she had run out of testing strips for Codefree, I asked why she did not use the ones for SD CHECK. She said she could use them, but the glucometer gives a different reading. It was at that point she when said, *“Let me show you”*, as she went on to take out the testing strips. She continued to say:

Mrs JJ: The machine comes with some [testing strips]. It comes with some, but they are different from these. ...You see it is at 141 [mg/dL]. It is at that level because since I woke up, I have taken some sweets several times. If I had measured as soon as I woke up, it could have been less than 100 [mg/dL]. Now let me remove this strip and put the one for SD CHECK. Remember the other one read 141 [mg/dL]. It will read differently. .... You see, it reads differently.

MJN: Oh! Now which one is correct? Which one do you usually use?

Mrs JJ: I gave away my SD check machine. However, if I am not very sure about myself, I get assurance about the reading once I use both. In this case, I would say I am at 172 [mg/dL].

[Interview, 16092017]

She continued to say that is what happens when using different brands of testing strips. I asked which one she considers correct, and she responded that she considers SD CHECK more accurate compared to Codefree.

In high-income countries, blood sugar monitoring using glucometers is an essential aspect of diabetes management. Diabetes patients use glucometers to keep track of their sugar level fluctuations. Doctors use data from glucometer measurements to inform the patients' treatment using the. Together with other measurements like glycosylated haemoglobin (HbA1c), doctors determine whether patients have been managing diabetes as advised. Patients are not expected to record their glucometer readings every day and present them during diabetes clinic consultations. Mol (2008:49) has noted that “[t]echnologies do more than is expected of them” and they change expectations. My study participants had improvised the use of glucometers by testing other patients. In

doing so, the glucometer was no longer a technology for individual self-testing for monitoring; it was used as part of group surveillance.

Moreover, patients who had glucometers did not use them regularly. Contrast this use of glucometer to what Guell's study among Turkish Berliners in Germany who used their glucometers "enthusiastically and daily to test their blood sugars" despite the monitoring being quite a costly exercise (Guell 2012:526). For participants in my study, having a glucometer did not allow for more frequent measurements, as noted by Mol (2008). Cost of testing strips prevents regular measurement. Similar findings have been reported in Uganda, where patients who owned a glucometer do not monitor their blood sugar every day (Liggins and Beisel 2017).

More interestingly, patients who have glucometers test as a means of affirming what they are feeling. For these patients, it is not enough to experience the symptoms. There is uncertainty as regards their bodily feelings. In a way, they are either not sure about what the *'body is speaking'*, or they are not sure if they can *'hear'* the body correctly. What they do next, and whether they do anything at all, depends on the test result. When the glucometer reading is 'normal', patients do nothing about it. In that case, the patient may disregard the bodily feelings that prompted the testing. However, if the glucometer reading is high, the patient then goes ahead with actions that are meant to lower *'shuga'*, as Mrs Jenala (Mrs JJ) stated below:

Mrs JJ: I have learnt/understood my body. For example, right now, I am feeling noticeably light. I am not complaining about anything. However, as the day progresses, I may start feeling a headache, or I am feeling pain in the bloodstream. The pain one would feel as when they have malaria. Because I have *shuga*, the first thing I think about when I am experiencing such pain is that *shuga* has gone up. I will then decide to measure it right away. If the *shuga* is high, I know I am feeling this way because the sugar level is high. If I have measured around 3 or 4 [pm] and I find that it is high, I reflect/think about what I have been eating during the day, that what I have eaten has made my *shuga* to reach this point. Therefore, for me to have a good sleep, let me take the ten units that I was supposed to take in the evening now and take plenty of water. There was a day I woke up, and

it was around 400 [mg/dL]. I then injected 25 units and started taking some water. I measured again around 11[in the morning] and it was at 360 [mg/dL], a difference of 40 [mg/dL]. I continued taking water

MJN: Did you not eat anything?

Mrs JJ: I ate but with apprehension/angst. I kept on taking water, and by 4 pm, I was at 280 [mg/dL]. With the evening injection, I woke up the next morning, and I was at 101[mg/dL]. That is what happens.

[Interview, 16092017]

The body on its own may not *'speak'* clearly and the glucometer aids in clarifying what the body is saying. As has been noted by Beisel and Liggins (2017), this puts the burden on patients to interpret numbers and decide on what action to do, if there is need. The 'burden' that they refer to is part of the "experimentation" that is done in diabetes management. In the example above, Mrs Jenala's actions include taking her evening dose earlier than she usually does and taking plenty of water. She also must measure periodically to see if it is indeed going down. The act of measuring could be a response to uncertainty. Measuring could be considered taking responsibility for their illness, to make sure that they know the course of action that they must do.

On the other hand, deciding to take medicine earlier or altering the dosage may be considered as "non-compliance" and "experimentation". It may be considered as "non-compliance" because patients are not supposed to make changes to their dosage. It is health care workers who are supposed to decide how many tablets they take or how much insulin they inject. The responsibility of the patient is to make sure they follow this. I consider it as "experimentation" because the patient is doing that to see what will happen with the hope that *'shuga'* will go low to the proper amount. There is a possibility that the insulin can lower the sugar level to an undesirable level, below what is 'normal'. Here, we also see the need for a glucometer: so that the patient knows whether by taking an insulin injection earlier or taking plenty of water, they are indeed lowering their *'shuga'*.

### 6.3 Trying as “experimenting”: ‘*being your doctor.*’

During diabetes education, one of the main points that diabetes educators always told patients was: “*You are your own doctor*” (Dokotala ndiwe mwini). Patients also ought to know specific symptoms, especially those that come because of low blood sugar levels because “*low shuga kills*”, and patients (and ‘guardians’) must know what they ought to do if such symptoms occur. Because patients know that the “*body speaks*”, they (can) “experiment” with food and medication as part of managing diabetes. When “experimenting”, patients want to ascertain if it (food or medication) raises/lowers *shuga*. Based on what they find, they can continue using it or not. Mr Zimba, the diabetes educator, described the processes of “experimenting” retrospectively following an increase in sugar level:

Then you start recalling that after you ate this amount of fruits, took a bottle of Coke, and ate *Nsima* made from fermented flour with beef or pork in the evening, my blood sugar has risen. You then reflect on those things that after I ate this on such a day, it was not good. You say if I eat this, nothing happens and I am all right. In doing so, you can prescribe your diet.

[Interview, 15062017]

Most of what patients “experimented” with were things that others had already “experimented” with and had deemed efficacious. In this regard, for one to decide to “experiment” with a new medication for example, it was usually the testimony of others who had already tried it that was important. Mrs Kandulu talked of knowing someone who had ‘tried’ tripride 2. I witnessed the importance of those testimonies on the morning of 31 January 2017. I was talking to Mr Cosmos Nakanga, a type 2 diabetes patient, outside the OPD waiting room at Nguludi Hospital. He was telling me how his ‘*shuga*’ had gone down from 253mg/dL to 203mg/dL because of a drug called tripride 2, which he intended to buy again. As we were talking, Mr James Mwalwanda, a type 2 diabetes patient, overheard us as he was passing, and he stopped to ask Mr Nakanga where he could get this medicine. He said he had also overheard people talking about how ‘good’ this medicine was. Three months later, I asked Mr Mwalwanda if he had managed

to get tripride 2. At that time, he was using metformin. He told me he had asked the clinician whether he could take metformin together with tripride 2. The clinician had told him that ‘research’ was still going on regarding tripride 2. Mr Mwalwanda then concluded by saying: “*So that time I could not buy because the response was not positive. If they answered me properly, then I would have tried to buy and start using it and see if my shuga will go down, and my libido is improving*” [Conversation, 25052017]. The point I am highlighting here is the importance of testimonies in driving other patients to “experiment”.

Another form of “experimentation” with medicine involved reducing or increasing the amount of medicine. Mr Cosmos Nakanga deliberately increased his prescribed dosage from taking glibenclamide and metformin once to twice in a day. He had increased his dose when he had gone to the “field”. By going to the “field”, Mr Nakanga meant that he had gone to work outside his duty station, and this required spending some days and nights away from home. His work involves transcribing school textbooks from print to braille. He had travelled from Blantyre, where he is based, to distribute braille books in various schools in the central region of Malawi. When I met him at his office in 2017, he had just returned from Salima, a district found about 400Km from Blantyre City, where he had spent three weeks. Because of that, he had missed his appointment at the clinic. While also in the ‘field’, it was difficult for him to get ‘diabetic’ diets. He said:

I was not doing exercises; the diet was difficult such that even the meal itself was not what I am supposed to eat. There was no *mgaiwa* porridge, and I was forcing myself to take porridge made from rice and no groundnut flour added. I used to take tea or porridge but not made from *mgaiwa*. I did not have a choice. Therefore, based on the situation, I decided to take that dosage. ...I was using plan B to prevent my condition from worsening. ...I increased the dose.

[Interview, 15092017]

I asked him if he was going to maintain the high dose, now that he was back from the ‘field’. He responded by saying that would depend on what his ‘shuga’ would be at the next clinic visit. This was a tactical strategy for Mr Nakanga. It is also an “experiment”

because he wants to ascertain whether to maintain a high dose or not.

Patients also “experimented” with diet by trying foods that they are not ‘supposed’ to eat. In the previous chapter, I showed some of the contradictions that patients in terms of messages about management of diabetes, especially diet. Mrs Modesta Juma, a type 2 diabetes patient from Queens Hospital, experienced the uncertainty emanating from such contradictions regarding whether she could eat *white Nsima*. She said: “... I heard [on the radio], someone from Lilongwe or Chancellor College said they had researched [and found that] people should eat white Nsima” [Interview, 25052017]. Mrs Modesta Juma “experimented” by trying maize flour that was ‘prohibited’. She said: “And I said I would do research on myself; I should see how it will come out”. The results of her ‘experiment’ were that she noted that her ‘*shuga*’ did not go up, she concluded that she could use the prohibited flour, while ‘controlling’ her eating. She said:

...I tried it, but I did not see that my sugar levels were high, it was stable and even now, I can eat [*Nsima* made from] the white [maize] flour, but I control my eating. ...But when I ate *mgaiwa* very much, I gain a lot of weight than when eating white *Nsima*. I am stable when eating white *Nsima*, I am 72 [kgs] or 73 [kgs] but when I use *mgaiwa* I gain to eighty-something [kgs] and I also saw that there is a lot of starch in *mgaiwa*. ... However, I control myself when it comes to food and sugar. I use sweeteners, not the regular sugar that other people use. Besides, I take porridge every morning; in the evening, I have put myself on a diet.

[Interview, 25052017]

The examples of “experimenting” shown above are ‘single’ “experiments” with medicine and food. Their aim was to inform decision making on how to go about managing diabetes: if it (medicines and food) works (does not raise ‘*shuga*’), the patient will continue using it as part of diabetes management. If others can give testimony that it works, the patient can take it to try it and use it as part of their management. However, one of the challenges is that there may be several things that are being tried at the same time such that it may be because of the uncertainty as to how to attribute the change to one

specific thing. This was well exemplified in the “experiments” by Mrs Sera Malewezi, a type 2 diabetes patient from Queens Hospital.

Several of Mrs Malewezi’s “experiments” unfolded at the same time. Like Mr Nakanga, she also “experimented” by altering the dosage in terms of the number of tablets she was taking. In an interview at her home in September 2017, she had been “experimenting” since February 2017. She had been prescribed two tablets of glibenclamide and two tablets of metformin twice a day. At the time of our meeting, she had changed the number of tablets she was supposed to take and the timing. She had decided to start taking one tablet of metformin and one tablet of glibenclamide once a day. She said, *“I only take in the evening instead of two [of each] in the morning and two in the evening. I am testing/trying myself to observe [what will happen]”* [Interview, 16092017]. Her “experimenting” was also gradual. She said, *“It was like I was taking four tablets in the morning and four tablets in the evening. Then I changed, and I was only taking four tablets at once, in the evening. Now I have stopped taking four, and I am only taking two [in the evening]”* [Interview, 16092017].

Mrs Malewezi’s “experiment” was not only about medicine. Throughout the “experimenting”, she noted that at one point, ‘shuga’ had gone up. She attributed that to use of sweeteners. She then stopped adding sweeteners to her tea. She felt that her “experimenting” was going on successfully. When I asked how her ‘shuga’ was on her previous appointment, she said, *“The other time it was around one hundred fifty-something. The other time it was one hundred and sixty-something. It then went up to 187 [mg/dL]. It has always been around 100 [mg/dL]. This is also in addition to the exercises that I have been doing”* [Interviews, 16092017]. She was also planning to restart doing exercises which she had stopped around June 2017 since she had moved to a new place. In her “experiment”, she had added new variables (sweeteners and doing exercises) that she wanted to “observe”. She said, *“Since I moved here in June, I stopped. However, I am planning to start next Monday again. I will be doing it outside the house. I am planning to observe what will happen when I go for the appointment in October considering that I have stopped taking the two tablets, stopped taking sweeteners and [restarted doing] exercise. I want to observe these three things”* [Interview, 16092017].

Mrs Malewezi’s “experiment” involved three “variables”: reduction in the number of

medicines, stopping taking sweeteners and restarting the exercises. In our first interview, she had said that she used to jog at a football ground next to the school where she was teaching. Her house then was located within the perimeter of the school. When I revisited her, she had moved from the schoolhouse to a privately rented one outside the school premises. It took about 10 minutes to walk to school. She stopped jogging around the school football ground after moving to the new house.

The “experiment” with sweeteners had started two months before our interview. When I asked Mrs Malewezi why had started taking sweeteners, she responded: “*I wanted to observe, to confirm whether they raise shuga. Now I have confirmed that they indeed raise shuga*” [Interview, 16092017]. On her next diabetes clinic appointment, her ‘shuga’ had gone up from 187mg/dL to 300mg/dL. She attributed this increase to the sweeteners, and the doctor advised her to stop taking them. Having confirmed that they indeed raise ‘shuga’, the objective of the current “experiment” was to see if indeed sugar levels would go down.

#### 6.4 “Non-compliance” is neither resistance nor irresponsibility

When health care workers talk about patients that are not “complying”, they imply they are deliberately doing something the patients know they are not supposed to do. They are not submitting to requirements of biomedicine. When I asked clinicians about why patients do not follow what they are told, the response was that it was because of lack of education, lack of acceptance and not taking responsibility. I asked Golden Mposa, a clinical officer at Nguludi Hospital, why patients do not follow what they are told, and he responded:

It is about acceptance and responsibility towards diet. Most of them would want to continue eating as they used to do before a diabetes diagnosis. If they travel for a 2-day trip, most of the food that they will find along the way is fast foods. They can persevere for a while, but afterwards, they give up and continue to eat [what they are not supposed to eat]. The other thing has to do with the responsibility of the family members.

[Interview, 31012017]

He finished by saying that “non-compliance” was common, even among those that were “educated”. When I asked Dr Ndalama, the lead clinician for diabetes at Queens Hospital, about the challenges of diabetes management, she responded:

The other thing for me, with the Malawian patient and the Malawian culture, is awareness and being aggressive about illness and sickness. For me, that is a big thing because when you explain to people, they do not seem to appreciate at all. They do not seem to connect that because of this; this is what is going to happen. ...I think education for us is an important thing. It is an important thing. People need to learn and understand. Once people understand, it is quite natural for them to collaborate with you, and hence get a better outcome.

[Interview, 18012017]

For Dr Ndalama, patients were not taking it upon themselves to do the “right things” despite what they were told in the clinic. In this vein, and as Golden Mposa said above, patients were seen as not “responsible”; as such, they needed more “education”. The moral undertones to these statements are unmistakable: that patients were not doing the “right things”; that they were not active enough for their illness; that they were not making the right changes in their life; and that they only persevered for a short while and then went back to eat what they were not supposed to.

There are several reasons as to why patients may not “comply” with what they have been taught in biomedical facilities. Firstly, there are costs of travel to the clinic, medicine, and food. To travel to the hospital to attend the clinic is also a financial cost, especially for those that live very far from the hospital. For some patients that work, spending the entire day at the clinic is usually hard as some employers are not willing to let them go. Patients from Nguludi Hospital must buy medicine, and for those that do not have money, they may go without medicine for a while until they find the money to buy it.

Patients said that buying food that they are told to eat costs money, which most of them did not have. In their study on dietary changes in Malawi, Vaughan, et al. (2018:4) reported that their informants contrast the past and the present which they describe as a time when “food depends on money”. One of my study participants, Mr Gervasio Kenani,

a type 2 diabetes patient from Queens Hospital, also noted the costs for getting food, problems of eating the same food all the time and food that does fill the stomach. He said:

You know what, even though they say that the food that we are supposed to eat is easy to find [cheap], that is not entirely true because everything needs money. You cannot say you will always be having bread; you will not get full. Moreover, you cannot be taking porridge the whole time; as such, there are times that I eat sweet potatoes.

For Mrs Kadewere, another type 2 diabetes patient from Queens Hospital, the specific food that she is expected to eat (brown rice and olive oil) was expensive. She put it this way: *“You are forced to stop eating fire [a brand of rice] no matter how much you liked it. You are only allowed to be taking brown rice, but then, who can afford to buy brown rice. Very few people can afford to buy brown rice. ...We get advised to be using olive oil when cooking, but how many of us can afford olive oil”* [Anastansia Kadewere, type 2 diabetes, Queens Hospital]. Because “food depends on having money”, patients may find themselves in a situation where they eat whatever is available (Vaughan, et al. 2018). Such food may not be what is right for a diabetes patient, hence contribute to raising blood sugar levels.

Some patients also felt that they are expected to eat food that is different from what they usually eat. One good example was eating food with no salt or tea with no sugar. When I asked Mrs Malewezi, how much her life had changed as a result of diabetes, she said, *“My life became so difficult since I stopped drinking tea with sugar, I was only eating relish with less salt something which I was not used to”* [Mrs Sera Malewezi, type 2 diabetes, 17202016]. Reflecting on these restrictions on a diet, Mrs Linly Mbawala’s husband retorted:

Mr Mbawala: I feel like AIDS is better [than diabetes].

MJN: Why?

Mr Mbawala: Because in HIV and AIDS, when it comes to food, you eat how you want to, whether, with fat, you eat. However, this one, you are not supposed to use cooking oil in your food or overeat but eat the right

amount, you must use each right amount like eggs, you must eat one egg, and you should go beyond. [There are] so many rules!

[Interview, 15052017]

Another patient put the idea differently. In a conversation that I overheard during a diabetes education session at Queens Hospital, an elderly female patient was complaining to Mrs Sera Malewezi that she is prohibited from eating “good/nice” food that she has never had in her life. She said, *“I grew up in poverty. I never had access to milk. Now I have all the milk and Cremora [coffee creamer], and I am told I should not eat those. AIDS is better because you can eat everything. With diabetes, you are prohibited from eating many things”* [Field note, Queens Hospital, 11042017].

In other instances, patients find themselves eating food that they are not supposed to. For example, they may eat meals that are meant for people that do not have diabetes within homes. Mrs Sera Malewezi lives with her husband and two children who do not have diabetes. She does not want to prepare two separate meals (one for herself and one for her husband). She thinks that would be time-consuming. Other than that, she also thinks that preparing a ‘diabetes diet’ is too involving. She said, *“It is not that I was told not to eat meat, but when you want to prepare it, you must boil it first. If you see some oil in the water, you must dispose of the water and boil it again until the oil is gone. I feel like that is too involving”* [Interview, 17102016]. At the same time, she does not want to ‘punish’ those that do not have diabetes by making them eat food without cooking oil. Therefore, she says this is what happens:

The relish is still prepared with cooking oil but not too much oil since not all of us in the house have diabetes, so it cannot be relish prepared totally without cooking oil. I do that because of my children, so we add a little cooking oil and a little salt. I like vegetables and beans most. I do not like meat.

[Interview, 17102016]

At times, “non-compliance” may be unintentional. For two months after diagnosis, George Nyasulu (type 1 diabetes patient from Queens Hospital) was injecting less than the

prescribed insulin. For George, this was not intentional. George said, “*The time I could not see, the doctor instructed my brother on how to inject me but [when we got home], he was not using the correct dosage. The time the sugar level was high I went to the hospital and they asked on how we administer insulin after I explained he said we have been under dosing and that was the reason the sugar level [had] shot [up]*” [Interview, 14092017]. George had lost his sight around the time when he was diagnosed with diabetes in 2016. He was diagnosed with diabetes at the eye hospital at Queens after one of the doctors ordered a diabetes test after noticing that his situation was not improving.

For Mr Lucius Zimba (LZ), “non-compliance” involved taking “breaks” from medicine for two reasons: firstly, he said he experienced other symptoms when he took medicine. Secondly, and more strategically, he wanted to ensure that medicine works better when he restarts. I first heard him talking about it on 13<sup>th</sup> June 2016, just before he started a diabetes education session at Queens Hospital. I was seated among the patients who were sitting in front of the diabetes shelter when he came over and started talking to two female patients. He told patients who were in front of the diabetes shelter that he sometimes stops taking his medicine for a while as a strategy to ensure that the medicine works better when he restarts taking them. He said:

LZ: Now, you will not find any medicine at home. It is just that I know that at this moment, I must take my medicine. Now, I am urinating all right at night. I have enough strength for me to jog/run. If I check my urine, it is not making any foam.

P: Is it the same medicine we are taking?

LZ: Yes, it is the same one.

P: Please be open.

P2: He is a big man, well connected.

[Field notes, Queens Hospital, 13062017]

Diabetes patients are supposed to take medicine every day for the rest of their lives. It is with that in mind that Mr Zimba alludes to that fact that they will not find medicine at his

house. Because there are no medicines at his house, it means he is not taking any at present. The two patients above seem like they were convinced that as an educator, Mr Zimba knew more (secrets) about managing diabetes that other patients did not know. An alternative interpretation is that the patients were thinking that because of his position, he has much better access to much better medicine that allows him to say that he was not taking any medicine at that point. In both interpretations, the patients are surprised that he is admitting not following what is said in diabetes education. They are surprised considering how they are often reprimanded if they do the same but also the consequences of not following diabetes education.

In an interview at his home, Mr Zimba said he was not taking his medicine because he experiences symptoms when he is taking them. He said:

... as I am talking now, this is my third week; I have not been taking medicine. What happens is that I can [still] have an erection, although I do not have a wife. I feel energetic, and I drive my car without feeling dizzy or sleepy when driving unless I am just sitting, the body would want to rest. I feel I am healthy, but if I take drugs, more especially if I add HCTZ [Hydrochlorothiazide for Blood Pressure] and metformin, I frequently urinate during the night instead of going out once [to urinate] as I am doing now... Previously I felt that when I was taking the drugs, my feet would burn. Now that I have stopped [taking the drugs], my feet are no longer burning. I am not encouraging you to stop taking drugs, continue taking. I always say that you are your doctor.

[Interview, 15062017]

When I went to his home two days later, I sought clarification on the idea of stopping taking medicine for a while. He does not like talking about it at the clinic because he did not want to be perceived as contradicting doctors. In saying this, Mr Zimba is acknowledging that what he is doing is something that doctors would not recommend. He would be reprimanded if doctors were to know that he has been doing that or if they knew he was telling patients that.

He then admitted that he has been alternating between taking medicine and then stopping for a while. He said, “*Right now because I am used, I have stopped taking them. I will stop for the next six months unless I start experiencing some signs*” [Interview, 15062017]. By saying, “*he is used*”, Mr Zimba meant that he had ‘experimented’ with it and he knew it works. That is why he was doing it again.

## 6.5 Conclusion: uncertainty and “experimentation”

This chapter has been about practices of diabetes management: what patients do as part of the management of diabetes. It has not exhausted all practices but has focused on the use of medicines and diet. This chapter highlights two themes: improvisation and “experimentation”. For those that can afford or have received a glucometer, they use it to deal with this uncertainty. Two things are happening when they do so. Firstly, because some patients cannot afford to buy testing strips and test themselves every day, they use the glucometer sparingly to save the strips for when they need them. Julie Livingston (2012) has shown argued that despite biomedicine being a global system of practices and knowledge, it is highlight contextualised with patients, nurses, doctors and relatives tailoring practices to suit their specific situations. In using the glucometer to suit their situation of limited access to testing strips, it [the glucometer] is no longer a technology for monitoring ‘*shuga*’. It is improvised and transformed to become an instrument for ascertaining the experienced symptoms. With that, and this is the second thing that is happening, the reading from a glucometer is foregrounded at the expense of an individual’s experience of their body. The number that is shown on the glucometer after testing is considered a true reflection of how they are and shows what they are supposed to do. Those that do not have a glucometer, and they constitute the majority of the patients, must act on symptoms without having to clear the uncertainty whether it is diabetes or another disease that is causing the symptoms that they are experiencing.

From diabetes education sessions, the ideas that ‘*the body speaks*’ and “*you are your own doctor*” are meant to make patients ‘responsible’ for their disease – that when they experience some symptoms, they must do something about them. What is not talked about in education sessions, and which patients experience in living with diabetes is the uncertainty experienced when these symptoms emerge. In research on diabetes in anthropology, the theme of “non-compliance” has been addressed in using different

analytical lenses. For example, Little, et al. (2017) have shown that “non-compliance” through patients’ refusal to obey doctors’ orders can be used as a means of regaining their autonomy and control. Some patients in the study by Little and others (2017) in India refrained from taking biomedical drugs because their diabetes was not “acting up”. In my study, patients like Mr Zimba also experienced symptoms that they attributed to diabetes and blood pressure medicines. Others like Cooper, et al. (2018) report that diabetes and its medication were perceived to cause ‘weakening’ and physiological damage to the body and sexual organs.

Similarly, Mr Zimba also stopped taking medicine. However, his aim was that that would allow ‘*cleansing of his body*’ and when he would take medicines afterwards, they would be more potent. Indeed, others like Mr Nakanga (type 2 diabetes patient) increased the dosage to make sure that the symptoms do not emerge. The forms of “non-compliance” that are observed in this study were not about being irresponsible or autonomy from clinicians. Instead, they were thought-out practices that were in response to patients’ experience of symptoms. For the patients, they aimed to make sure that they do not experience the symptoms and altering doses worked for some of them like Mr Nakanga. It was not a sign of irresponsibility among the patient when they engaged in such “non-compliance”.

A similar consideration can be made when it comes to patients’ practices, which I refer to as “experiments”. Guell’s idea of “bio-tactics” in diabetes management highlights patients’ deliberate actions and practices that are aimed at making illness and ill bodies liveable (Guell, 2009). However, for my study participants, the ultimate aim was more than making bodies liveable. Presenting at the diabetes clinic with a ‘good *shuga*’ and making diabetes management possible were critical drivers of these “experiments”. Patients were making diabetes management possible by generating knowledge of what works or not. If we consider an individual who takes in an act for example eating food with the aim seeing what will happen, he or she is “experimenting”, trying to see what happens so that they determine their next course of action. That action could be continuing or stopping eating that food. That will depend on the “experiment”.

The patient wants to make the illness more liveable. However, the immediate aim of the practice is “*to see what happens*”. Loosely, such an act could be considered as having an

independent variable (eating something prohibited), dependent variable (sugar level), and observation (blood glucose test at next appointment at the clinic or experience of symptoms). Ultimately, patients want to find what will make their bodies more liveable as Guell (2009) suggests. What patients were concerned about and observing was whether what they are experimenting with (for example food) resulted in an increase in 'shuga' or not, and hence whether they should be using it. These, I acknowledge, are not pure "experiments" as many variables may influence the dependent variable (sugar level or experience of symptoms). While "experiments" in biomedical sciences are conducted in 'controlled' environments, this is not the case for the patients. What matters for the patients is that they know how they will determine the success or failure of the "experiment". Besides, this is informed by diabetes education. Messages in diabetes education seem to suggest that 'shuga' will go up there and then as soon as a patient eats something prohibited and that the patient will notice it [*the body will speak*]. If these do not occur – if the patient does not 'hear' *the body speak*, these are considered successful "experiments" - a justification that they can do it. That one can eat that food without any problem. As Dr Ndalama said, it may be slowly damaging organs and complications will emerge later in life.

In the next chapter, I consider other forms of what is referred to as "non-compliance" by paying attention to the use of herbal medicine and the rationale behind it and considering prayer and religion in diabetes management.

## Chapter 7

### Complex therapeutic landscapes of diabetes management

Thus far, I have described how patients learn to become *'munthu wa shuga'* and engage in practices of management informed by biomedicine, which involve “experimentation” and improvisation in response to uncertainties. For biomedical providers, diabetes management must be done using medicines and diet as they prescribe. However, in response to questions on how they were managing diabetes, some patients showed that their management practices were not limited to biomedical drugs and food. They had ‘tried’ practices and medicines outside biomedicine. These include the use of herbal medicines and religion through prayer and faith. Patients’ use, experience, and understanding of these practices form what Melissa Leach refers to as “therapeutic landscapes”. According to Leach, et al. (2008:2158), therapeutic landscapes are “the field of available forms of health provision as experienced, understood and constructed through practice by the populations that live with them”. Hampshire and others (2011: 703) note the increasing complexity of ‘pluralistic medical fields’ in contemporary Africa “giving rise to newly emerging health systems and therapeutic landscapes that incorporate not just ‘local herbal and hospital medicines’, but a vast array of healing options...”. In Malawi, this vast array of healing options includes homemade, locally made and imported herbal medicines, and religious practices in Pentecostal churches. In this chapter, I focus on these healing options because all my study participants had used them at some point, but also their increasing popularity as evident from local discourses in the media. I use the notion of therapeutic landscapes as it highlights not only the plurality of medical practices available but also how patients use these practices interdependently and as part of on-going every day “experimentation”.

Leach has argued that there is often a tendency to consider herbal/traditional and biomedical practices as distinct and not related/linked (Leach, et al. 2008). Hampshire and Owusu (2013:257) highlighted this interrelatedness by showing that ‘traditional’ healers “adopt, adapt, and modify versions of diverse therapeutic traditions and techniques in novel and creative ways”. In Tanzania, Marsland (2007) used the notion of “intentional hybridity” to show that “traditional healers” contested and challenged perceived dualism which characterised their practice as ‘traditional’ while biomedicine

as 'modern'. This hybridity is shown by healers who aspired to adapt the knowledge and techniques of biomedicine while also maintaining their expertise in dealing with diseases associated with witchcraft. In my research, providers of herbal medicines did not frame diabetes in supernatural terms, often highlighting the role of "diet" in its aetiology and treatment. As part of healing, they gave treatment instructions that were like those I heard during diabetes education and clinic consultations within biomedical facilities. Providers of herbal medicines also attempted to legitimise their practice by emphasising its 'efficacy', safety and 'research' basis.

Based on data from participant observation and interviews with providers of herbal medicines and patients, I explore the therapeutic landscapes "within which people negotiate to maintain [the] health ... [in this case a good '*shuga*'] and to respond to any particular illness episodes [i.e. an increase in sugar level], as it intersects with people's particular social relations and solidarities" (Leach, et al. 2008:2159). For diabetes patients in my study, the therapeutic landscape was a complex interaction of herbal medicine, religion, and biomedical practices. Patients were driven by the proliferation and professionalization of herbal medicines and Pentecostal churches, claims of 'efficacy' by herbal medicine providers and pastors, and testimonies by other users. Like "experimentation" with drugs and food, which I explored earlier, use of herbal medicines and prayers were also a response to the uncertainty of diabetes and its management, and they create other uncertainties that perpetuate their usage.

I start this chapter by showing the proliferation of "professionalised" herbal practitioners, their claims and rationale and how they are used in practice. In the next section, I consider how religion features in diabetes management through ideas of faith, prayer, grace, and miracles. These two practices are considered in different sections to highlight their uniqueness and rationale. However, in practice, they are used at the same time and are interconnected.

## 7.1 Herbal medicines in diabetes management

### 7.1.1 The proliferation, 'professionalisation' and appeal of herbal medicines

When considering why patients use herbal medicine, I start by reflecting on the proliferation and increasing professionalisation of herbal medicine, which account for the

appeal and legitimacy as an option which patients could 'try'. Researching in Malawi in the early 1980s, Brian Morris (1986; 2011) noted plurality and diversity of healers (locally known as *sing'anga*), consisting of distinct systems, etiological emphases, and therapeutic roles and strategies. Morris identified three types of healers: folk healers, doctor-diviners and spirit mediums. Folk healers or herbalists offer consultations and dispense plant medicines for empirical treatment of a variety of ailments and personal problems rather than ascertaining underlying causes (Morris 2011). These healers deal with ailments and personal problems including lack of good fortune in business or family affairs, impotence in men, venereal diseases, stomach ailments, and rheumatism. Doctor-diviners, the second category that Morris identified, have undergone training as a diviner and herbalist "after experiencing a divine 'call', either through a dream or a traumatic illness... [and they] "act as mediums for spirits from whom they derive their divinatory powers". (Morris 2011:250). Aetiology of disease is attributed to sorcery and witchcraft. These healers treat ailments at two levels: symptom level to heal a bodily ailment, and at causation level, the body is protected from further harm. The third group of healers are those involved in 'cults of affliction' where therapy is associated with spirit mediums. According to Morris (2011), aetiology for these healers is less about bodily malfunction or witchcraft, but rather possession by witch spirits or spirits of alien origin. Therapy is in the form of communal ritual involving possession, exorcism, and purification rites.

"New" and "professionalised" providers of herbal medicine have emerged over the last ten years as part of the therapeutic landscape in Malawi. These differ from the categories that Morris identified in terms of the diseases they claim to deal with, claims of legitimacy and appeal, and how and where they operate. As Dr Ndalama, a consultant at Queens Hospital, noted, "*almost at every shopping mall, you find a herbal shop*" [Interview, 18012017]. Herbal medicine shops have been set up in most parts of the cities, including more impoverished townships. During fieldwork, I saw several advertisements on walls of buildings (See Figure 7), signposts and newspaper classified advertisements which listed several diseases, including cancer, hypertension, and sugar/diabetes/'*shuga*' for which providers of herbal medicines claim they have a "cure". A recent phenomenon has been the selling of herbal medicine in pharmacies, supermarkets, and grocery stores. In biomedical pharmacies, herbal medicines share spaces with biomedical drugs. In supermarkets and grocery stores, herbal medicines sit next to everyday products like tea

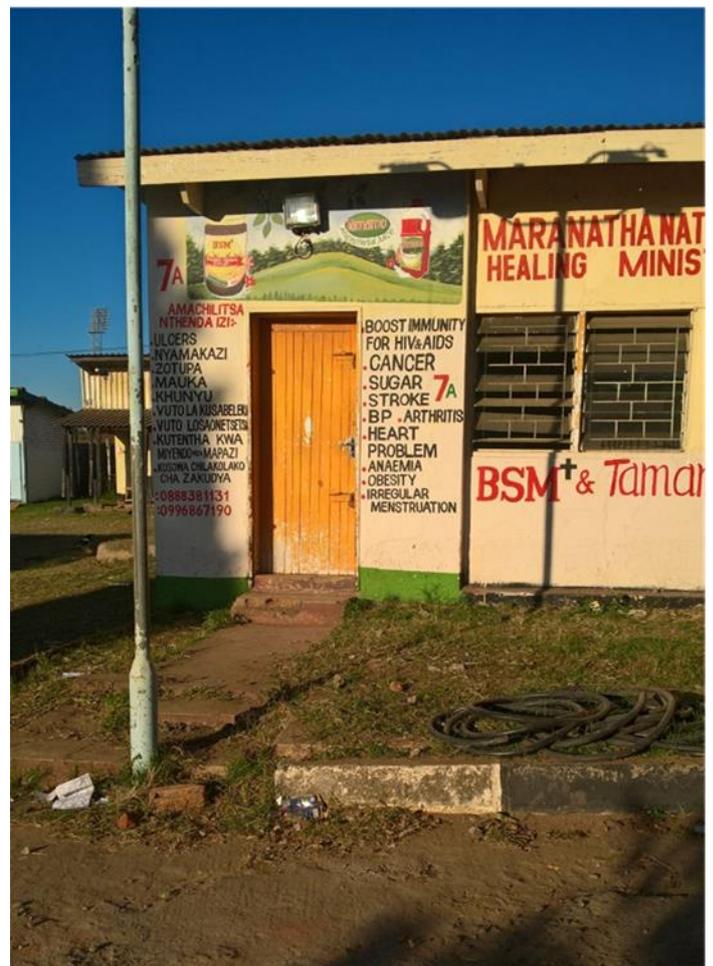


Figure 4 Herbal Medicine Sellers

and coffee. These herbal medicines also come in various forms including tablets (like those of biomedicines), powders, liquids, and packaging (plastic sachets, plastic bottles with each healers' branding). The packaging also includes the expiry date and a list of ingredients.

Herbal medicines have also found their way into waiting rooms of diabetes clinics in biomedical facilities. Patients and health care providers sometimes sell or share herbal medicine within biomedical facilities. During diabetes education sessions at Queens Hospital, Peter Jere, a type 2 diabetes patient and a volunteer for the Diabetes Association of Malawi, was selling herbal medicine that he claimed could '*cleanse the body*' and lower blood pressure. During one such session, he said: "*This is Molasse<sup>63</sup>,*" he says, "*It helps in cleansing the body and lowering BP [Blood Pressure]*". Patients also share stories of the

<sup>63</sup> Molasses are a by-product of sugar-refining process.

effectiveness of herbal medicines that they are using or have tried before. At times, patients share or sell herbal medicines amongst themselves while attending the diabetes clinic.

The “professionalisation” of “modern” herbalists was evident in that they claimed to base their practice and the efficacy of their medicine on ‘research’, training and books. By claiming that their practice is from training and books, these healers were distancing themselves from conceptions of the ‘traditional’ herbalist who usually had no formal training. The appeal of new herbal medicines is that they are said to be of ‘proven efficacy’. This efficacy was attributed to the characteristics of the medicine, the process of making them, and the expert knowledge of the providers who often highlight the superiority of their practices and medicines as compared to others that are available on the market. Providers of herbal medicines often emphasised that their practices were based on ‘research’ and ‘training’. Some said that they had undergone training or learnt about various curative plants from books. In a television advertisement for Bayethe Naturals, Cryton Njoka starts by saying: *“to make these products, Bayethe Naturals has researched for sixteen years. Everything I said here has, what in English is called laboratory backing. Everything I said here, there is nothing that will come back to me, we have tested everything for sixteen years”* [Times TV Programme, also available on You Tube (2018)]. According to Cryton, ‘research’ for these medicines started in 2001 and that it is still going on.

Tracy Nkhoma, the proprietor of Hope Nutrition Services, told me that she was a trained nutritionist who made various medicines in tablet form. Tracy started Hope Nutrition Services because she wanted to put into practice what she had learned and civic educate people with different ailments. She noted how provision of herbal medicine was a ‘standard’ practice in other countries like Kenya and Malaysia. It was in these countries that she had learned more about use of herbal medicines and machines for detecting illness. Reverend Kachulu said he was ‘trained’ by Tianshi, a Chinese company that manufactures and sells herbal medicines through agents. He was trained in Malawi while other agents before him went to China for the training. He uses a worn-out book that he received as part of this training. He refers to the book as *“my light/lamp in which everything about diabetes has been well explained”* [Interview, 07042017]. On the other

hand, Dr Kambewa, an herbalist, said he had learnt his practice from books that he bought while in Zimbabwe and Kenya. He said:

The first book that introduced me to start making this is called *Back to Eden*. Jethro Kloss from the United States wrote the book. I bought this one from Nairobi in Kenya. ...As I continued with research, I found other books like *Health Plants, Healing Wonders of Plants*, and other books like *Activated Charcoal* and others.

[Interview, 21022017]

‘Trained’ providers of herbal medicine also show their professionalisation by highlighting that government bodies regulate and approve their practices. They highlight the ‘safety’ of their medicines by claiming that they have been ‘tested and approved’ by the Malawi Bureau of Standards<sup>64</sup> and the Pharmacy, Medicines and Poisons Board<sup>65</sup>. For example, Brown Chapola, herbalist from Hope Herbal Clinic said he had “*documents from [Pharmacy, Medicines and] Poisons Board showing that they tested the medicine thoroughly*” [Interview, 27062017]. On the other hand, Reverend Kachulu emphasised that because his herbal medicines were from China and Egypt, they were ‘safer’ than locally made medicines “*as they have been tested*”. The origin of the medicines was also meant to highlight that they are superior in quality and more effective than locally made medicines. He said:

On the other hand, these medicines have been tested. The Malawi Bureau of Standards approved these medicines and hence we can sell them. That is the difference. ...I do not know if the government approved those things. On the other hand, anyone can buy our medicines without any problems. The Malawi Bureau of Standards has tested and approved them. Anyone can buy/use without any [side] effects. We sell them with confidence, knowing that they were

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<sup>64</sup> The Malawi Bureau of Standards (MBS) is a statutory organization with a mandate to promote metrology, standardization, and quality assurance of commodities and of the manufacture, production, processing or treatment thereof.

<sup>65</sup> The Pharmacy, Medicines and Poisons Board is Malawi’s national drug regulatory authority which promotes availability and use of safe, efficacious, good quality medicines and medical devices in Malawi.

approved. On the other hand, I do not know if the people that are making those things have ever been to the Malawi Bureau of Standards to have them certified.

[Interview, 07042017]

In a way, highlighting that these medicines had been “tested” and “approved” was meant to put them on a par with biomedical drugs which was regulated and underwent thorough testing and approval. However, it is interesting to note that institutions like the Pharmacy, Medicines, and Poisons Board (PMPB) approved these medicines as food supplements rather than medicines that were meant to cure diseases like diabetes. For example, on 16<sup>th</sup> June 2017, the PMPB released a press statement which stated that they had noted the herbal products advertisements which make unsubstantiated claims that they treat, heal, cure and prevent diseases and ailments. The Board further stated that it recognises herbal products as dietary and nutritional supplements with no medicinal effects. It said that these herbal products did not have clinical benefits and that the claims were not supported by scientific evidence [Pharmacy, Medicines and Poisons Board, Press Release, Daily Times Newspaper, 16062017].

Providers of herbal medicines highlighted the safety of their medicines by saying they were made from food and plants. Dr Kambewa, the proprietor of The Herbal Clinic, said: *“The books also show which plants are meant to be a treatment for what diseases or that if one processes a specific fruit, it will be a remedy for this or that disease. We use fruits to make most of what is on the shelves; it is not only plants/trees”* [Interview, 21022017]. Similarly, in a Television advertisement, Bayethe Naturals was introduced as *“a Malawian company that makes various medicines from foodstuffs in what is referred to as Nutri Therapy”* [Bayethe Naturals Television Advert]. Saying medicines are made from foodstuffs alludes to one of the characteristics of herbal medicines that make them appeal to patients: that they are ‘safe’ as they are made from foodstuffs or they are (like) food and ‘natural’ as inferred from the ingredients. Hence, these medicines are not harmful and do not have ‘side effects’. For other healers, medicines are given names of food, to highlight that they are not harmful. Mr Jeremiah Wanda from Maranatha Natural Healing Ministries said diabetes patients were given a ‘juice’ that has broccoli, Brussels sprouts. According to Mr Wanda, *“these are vegetables. However, by nature, they help insulin to*

*work, for the pancreas to work well*” [Interview, 24082016]. He continued by saying his medicines were “*pure herbal, [with] no chemicals added, [and were] just fruits*”. By saying he gave patients a ‘juice’ and that it was “just fruits”, Mr Wanda was highlighting that his medicines were (just like) “food”, hence ‘safe’. He also drew on biomedical explanations of diabetes by saying his medicines helps both insulin and the pancreas to “work well”.

Because these medicines were “food”, providers of herbal medicine told patients could take them at any time of the day and even after being “cured”. This was slightly different from biomedical messages where food is not supposed to be eaten anyhow and the patient has to eat it “carefully”. It also meant that the herbal medicines were different from biomedical drugs which often have a precise dosage. By referring to these medicines as ‘food’, providers of herbal medicines implied that these herbal medicines were “harmless”, and a better option compared to biomedical drugs. An assistant at Hope Nutrition Services combined the idea of these medicines being “food” and their ‘naturalness’: “*we have medicines that we give. All our medicines are natural. They are food. They do not leave any things in your body*” [Interview, 15062017]. The ‘naturalness’ of the herbal medicines was also highlighted in the names providers for example Maranatha Natural Healing Ministries and Bayethe Naturals, and the medicines themselves. For Maranatha, the naturalness of their products is highlighted on their website where it says: “*Maranatha Natural Healing Ministries uses the inherent power of natural herbs to bring about wonderful results on the human body. The herbs are natural and 100% safe. Maranatha herbs help to enhance the body functioning in a herbal way. It pursues in natural treatment by focusing on diet and lifestyle changes* (Maranatha Natural Healing Ministries 2019).

For providers of herbal medicine, and just like among biomedical health care workers, food is the primary “cause” and “medicine” for diabetes. They also acknowledged that some food (those with ‘chemicals’ and ‘toxins’) might cause diabetes, while those foods that are ‘natural’ can “cure” diabetes and other diseases. Further to this, food that does not contains ‘chemicals’ and ‘toxins’ can be eaten (anytime) without causing problems.

Apart from being “harmless”, an additional factor made herbal medicines appealing to patients. It was the claim by providers of herbal medicines that herbal medicines ‘cure’ diabetes and other diseases. These medicines were said to ‘cure’ many diseases because

they were made from mixing various ‘herbs’, each of which was said to cure a specific disease. Each of those ‘herbs’ was believed to maintain its pharmacological properties independent of the others with which it was mixed. Brown Chapola, a provider of herbal medicine, described the ingredients of his medicine as a “mixture”, by which he meant:

... that there are several types of medicines in it. There is neem, ginger, garlic, cinnamon, honey, aloe vera juice, and other herbs (*mitengo*). Each of these is a medicine on its own. Each of these is medicine for some disease. Therefore, we mixed all these to produce these tablets which deal with many things. That is why it can cure several diseases at the same time, for example, BP, *shuga*, asthma, ulcers, and several other diseases. In total, it can cure up to 31 diseases, including *shuga*.

[Interview, 27062017]

These medicines were like “magic bullets” which could deal with many diseases in the body. According to Dr Ndalama, a consultant from Queens Hospital, the claim that they can cure many diseases was what made herbal medicines appealing. She said:

There is a vast market for herbs and herbal medication, that they are going to cure diabetes or that it cures everything – diabetes, blood pressure, TB, HIV. It is all combined in that one thing. If you are a patient, most of them want a way out. They want another way. They do not want to continue taking the tablets; and when someone comes to them, very convincing that this works, a lot of them will go for that.

[Interview, 18012017]

The rationale for combining different medicines to make one that cures ‘everything’ was clearly expressed by Brown Chapola, a herbalist. He said having separate medicines for BP, *shuga* “*would have meant having different medicines ... [Having one tablet] is also helpful in that if a person has several problems [mavuto, diseases] yet they do not have enough money, he/she can buy this medicine but have several of their problems addressed. That makes it helpful for those that do not have enough money. It is not only for those that are affluent/well to do*” [Interview, 27062017]. Apart from the financial implications,

these medicines are also ideal in situations of uncertainty. They can be used as a prophylactic. Taking these herbal medicines will supposedly deal with all diseases in the body, including those that are yet to be diagnosed. Moreover, these medicines can supposedly prevent these diseases. As such, patients can (and should) take these medicines even before being diagnosed or after being cured of diabetes.

If factors above were not appealing enough, it was probably other patients' "testimonies"<sup>66</sup> of the efficacy of the medicines that moved them to try these herbal medicines. Providers of herbal medicine made such claims, sharing stories of successful cure of patients who had used their herbal medicines. "Testimonies" are usually from people that have used the medicine and have since gotten 'cured'. Providers of herbal medicines share these 'testimonies' on social media platforms like Facebook, internet websites<sup>67</sup>, television programmes, and newspapers. For example, on 17 September 2016, a local newspaper carried a full-page advertorial titled "*Teras Juice ndi dilu – Allan Ngumuya*" [Teras Juice is the (real) deal]. Allan Ngumuya is a local member of parliament and a famous gospel musician. In the advertorial, he encourages people to start taking Teras Juice following "*healing that he received after taking Teras Juice*". He was diagnosed with diabetes in the year 2000 while he was living in the United States of America. Since then, he has "*taken different medicines but was never cured*". When his friend recommended for him to 'try' Teras Juice, he "*disregarded the advice because at that time he had taken much medicine without any cure*". Later, he then grudgingly took it because he thought it would not work. After taking it, he noticed an immense change: he could run without feeling any pain in the body. He concluded as follows:

*Shuga* is a problematic disease. If one misses a dose, they will have problems. With Teras, I can do that without feeling any bodily pains. ...I can now eat anything; I am no selective in what I eat ...My *shuga* was high, more than 100 [mg/dL]. However, now it has gone down, and everything is all right. ...Teras is the deal; Teras is capital. People

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<sup>66</sup> The use of the word 'testimonies' by providers of herbal medicines is interesting. This word is often associated with Pentecostal churches where members share testimonies of miracles that God has done.

<sup>67</sup> For example, <http://www.maranatha2014.com/> and <http://www.terasmw.com/> [Accessed 09/01/2019]

should have Teras in their homes. Just as people buy bread, I would love it if people would also buy Teras in the same way.

[Teras Juice Advertorial, Weekend Nation Newspaper, 17092016]

“Testimonies” of efficacy were not only shared by providers of herbal medicines but also by patients. Some patients share individual experiences of these medicines biomedical facilities as I will show below when I describe how these medicines are used in practice. Because providers of herbal medicines claim they cure many diseases, and there are “testimonies” of their efficacy, patients and their family members may be encouraged to “try” or “experiment” with these medicines. The desire to try these medicines can be buttressed by the characteristics of medicines and the credentials of the providers. However, patients may also be encouraged to try these medicines based on how they are supposed to work by *‘cleansing the body’*, which fits with some patients’ ideas of diabetes causation.

#### 7.1.2 *‘Cleansing the body’*

In Chapter 4, I showed that providers of herbal medicines and some patients believed that the accumulation of ‘chemicals’ and ‘toxins’ in the body from food, water and medicines cause diabetes. I also showed that diabetes is a result of *“having a lot of sugar in the body”*. From these understandings, diabetes treatment involves getting rid of the ‘chemicals’ or sugar that have accumulated in the body.

Some participants believed that the body could expel ‘chemicals’ on its own through sweat and urine. These processes were linked to physical exercise and drinking water. These ideas of how physical exercise is important for diabetes are in stark contrast as they are expressed within biomedicine. One of them, Mrs Modesta Juma, a type 2 diabetes patient from Queens Hospital, put it this way:

I used to feel the body itching and my relative, who is a doctor, told me to try some exercises because you can get rid of sweat. Moreover, I tried to [do that] when I was going to work at Shire Highlands [hotel], I [used to] get off [the bus] at Peretia and walk the distance to work.

Because I knew that I had to sweat, or I could run a little so that I could get rid of some bad things. That is what I was doing.

[Interview, 25052017]

While the body could do this on its own, some patients and diabetes educators believed encouraged drinking plenty of water to get rid of 'chemicals' and toxins. For example, during diabetes education, Mr Lucius Zimba, the diabetes educator, encourages patients to drink plenty of water to get rid of these 'chemicals' from their bodies via urine. For him, taking water was meant to 'flush' out 'chemicals' from the body so that biomedical drugs can be efficacious. He argued that over time, "*these artificial medicines build up in the body*", and as a result, the biomedical drugs do not work effectively [Interview, 15062017]. Mr Zimba uses water to '*cleanse his body*'. He said that he starts each day by taking plenty of water from 4 a.m. Both female patients then responded that they struggle with taking water. Mr Zimba clarified these ideas during one of the interviews I had with him. He said:

You know yourself. I always say that I do not want my body to be full of medicine. That is why sometimes I stop taking drugs [for a while] and then start again. I need to flush out the medicine that is in my body, then start again ..., Moreover, remember to take plenty of water to flush out the medicine that you are taking...these artificial medicines build up in the body. ...I always say I should flush out the drugs of metformin and HCTZ [Hydrochlorothiazide] through the amount of water that I take. I flush the system through the blood and veins and the kidneys. Then eventually, after some time, within a month, there will be no drugs in the body. If I start again, it will be a new thing, and it [the medicine] will be more effective in the body.

[Interview, 15062017]

Similarly, Mrs Anastanzia Kadewere (type 2 diabetes patient, Queens Hospital) takes water in the morning because it '*cleanses the body*': "*After a walk, I go and take a shower, and I drink about 500mls of water. I normally force myself to take at least a litre of water every morning because I am told that water is so helpful and when you drink plenty of water*

*especially in the morning; you also urinate more often hence clean up many things in the body” [Interview, 07112016].*

Apart from ridding the body of medicines, some health care providers and patients believed that drinking water lowers sugar levels when ‘*shuga*’ has gone up. The rationale for this belief was that the water would “dissolve” the excess sugar, and it would come out of the body as part of the urine. On several occasions, I heard Mr Zimba share this during diabetes education sessions. During one of the interviews, he said: “*...because blood sugar is within our body, when you drink plenty of water and sugar is high in the body, it is likely to go out of the body. In the process, it [water] takes with it other body contents...Not that water will cure [diabetes]. Some people say water is a therapy for other infections” [Interview, 15062017].* During a diabetes education session, Sister Mataka once said, “*We say you should drink at least 2 litres of water in a day because it washes the body. When one’s shuga has gone up, we give the patient IV fluid, which is water.” [Field notes, Queens Hospital, 13122016].* On another day, Sister Mataka said, “*The disease is in your body. Take the water frequently like rinsing [diluting]* (Field notes, Queens Hospital, 18102016).

Patients also shared similar sentiments, which they often attributed to diabetes education. Mr Peter Kambwiri, a diabetes patient from Queens Hospital, stated “*We are often told that when we experience such signs, we must take plenty of water. In a way, it is as if you are washing something. Therefore, that is what we do, taking plenty of water. It is as if you are neutralising [the concentration of sugar]*” [Interview, 24012017]. Mrs Sera Malewezi said, “*If it [sugar] has gone up like that, you need to take two litres of water at once before going to the hospital. Then you will also urinate a lot, just like washing. If there is no change, then you can go to the hospital” [Mrs Sera Malewezi, type 2 diabetes, 16092017].*

The ideas from the quotations above create imagery of sugar as being located in the body where it can be “dissolved” and “passed out” as urine. This idea is often taken further when health care workers tell patients that they can tell if their sugar level has gone up by tasting their urine. If it is sweet, then it means ‘*shuga*’ has gone up.

However, providers of herbal medicines and some patients believed that ‘chemicals’, ‘toxins’ or ‘filth’ that have accumulated in the body through eating ‘modern’ food and drinking water cannot come out through the body’s processes or drinking a lot of water. These ‘chemicals’ and ‘toxins’ can only be removed using medicines, in what some of them refer to as ‘detoxification’, ‘detoxifying’, ‘washing the stomach’ [*kuchapa mmimba*], or ‘washing/cleansing inside the body’ [*kuchapa/kutsuka mthupi*]. Patients talked about various medicines that they buy to ‘detoxify’ or to ‘*cleanse their bodies*’. For example, George Nyasulu, a type 1 diabetes patient from Queens Hospital, said:

One day I was walking at Sigerege, I found someone selling this [medicine] and [they] said that it *cleanses the body*. ... You take one spoon of each medicine [and add to porridge] .... At the association [clinic], I heard that this medication is for *shuga* and this other one [is] for *cleansing the body*. Therefore, when I bought this one, it was because I heard it from there.

[Interview, 20052017]

Even though patients and providers of herbal medicines talk about ‘*cleansing*’ or ‘detoxification’, there are differences in what it means and how it works, highlighting differences in their conceptualisations of the body and diabetes. For example, when Selina Mbewe, a young woman who sells Makhaya Herbal Mixture said, “*toxins accumulate in the body, and it [the medicine] is meant to clear them*” [Interview, 28042017], it is not clear where these ‘chemicals’ are and what it means to clear them. Both Cryton Njoka of Bayethe Naturals and Reverend Kachulu seem to make clarifications on this. However, there are glaring differences in their understandings. Cryton Njoka used language borrowed from biomedicine, referring to hormones, cells and the liver, to explain how “detoxification” works. On a TV programme promoting by Bayethe Naturals, Cryton said:

What are the benefits of Tchaka Detox Herbal? Firstly, Tchaka Detox Herbal has more than 49 uses. For now, I will mention only three of them: Firstly, Tchaka Detox Starter [I think he meant Herbal] washes the inside of the body [*Amachapa mthupi*] and removes all filth in the

body and opens all places which were clogged so that blood and hormones can circulate without any problem. On top of that, it also removes anything bad that has been in your body and kills organisms that cause different diseases without you getting diarrhoea.

[Bayethe Naturals Advert on Times Television]

When I visited his clinic, I followed this up by asking him about the meaning and importance of “detoxification”. He said:

“With detox[ification], first, we are removing body impurities. According to my understanding of human anatomy, we have cells that are living beings. They behave the way a human being does. The cells ingest but also excrete. ...The excretions have their pathways. These pathways are sometimes blocked. That compromises systems as well. It is as if you have a blocked sewer line. You experience perspiration. Therefore, detoxification, you are taking out the body impurities. You are helping the body to take out the impurities. At the same time, you are helping the liver. You are aiding the liver because if you do not take detoxification, what happens is that you penalise the liver. Sometimes, you find that the liver is not detoxifying adequately. It may only have about 50% capacity to detoxify things. When the liver detoxifies, impurities come out through urine and faeces. What then will the 50% do? The brain will then have another alternative, it is going to be a desperate measure, saying, “let us excrete through the skin”, and that is sweat. That means the journey is going to be too long. The toxins will then pass through other cells, other tissues. As a result, they can cause more complications.

[Interview, 27062017]

Cryton suggests that “detoxification” is a process that the body does through the liver. However, there is a need to “assist” the liver in “detoxification” using his medicine which helps in removing “impurities”. These “impurities” and filth are in blood vessels and cells where they block circulation and excretion, respectively. On its own, the body cannot do

these processes. For Reverend Kachulu, another provider of herbal medicine who uses of “detoxification”, the “impurities” are in the stomach rather than in the “cells” as Cryton suggests. Reverend Kachulu said:

This is what happens. Maize seeds [*njere za chimanga*] are one of the ingredients for making Double Cells [a type of herbal medicine from China]. Therefore, when you eat, you feel like to have bloated/constipated. Double Cells feels sticky, so when you chew it, it sticks on the walls of the stomach. When you take the tea, it rinses/removes everything that had stuck on the walls of the stomach. When getting these off, it also removes all the harmful substances that were there. ... If you use these [Double Cells] for three to four days, you would be surprised with the faeces that you produce. The things that come out are black. ...If you saw what comes out; you would even be surprised as to whether such things are indeed coming out of your stomach. It is very dark in colour. Therefore, medicine removes those things. After fourteen days, you feel that your body is relieved. If you had inflammation or any other damage, all those would be gone.

[Interview, 07042017]

Cryton Njoka and Reverend Kachulu also differ in how to tell that ‘detoxification’ has been effective. Cryton insists that his medicine ‘cures’ without causing diarrhoea. For Reverend Kachulu, passing black faeces means that ‘impurities’ are coming out of the body. One can also notice it because “*after those two weeks, a person who has shuga will notice that if they were experiencing symptoms like sweating, those would no longer be there*” [Interview, 07042017]. Similarly, Brown Chapola another herbalist, talks about the frequent passing of orange urine. He said, “*You may start to pass orange/yellow urine often, sometimes the faeces have some mucus. That means the medicine is cleansing the body; it is working. Firstly, the medicine is cleansing the body as I explained at the beginning. Having an appetite for food very often means the medicine is working in the body*” [Interview, 27062017].

Other than this, Brown said one also notices that the medicine is working through re-

emergence of sexual desire, especially among men. He said:

BC: For people that previously had lost sexual desire, it returns. After having washed the body, that desire returns but at a proper level.

MJN: What do you mean the proper level?

BC: Sometimes, it is abnormal. For example, one may only have sex once every night when previously, you could do it three times in one night. You realise that your body is changing little by little. When you take this medicine, you return to the level that you had previously.

Despite the differences in what or where ‘impurities’ are located, or results of ‘detoxification’, both providers of herbal medicines agree that impurities are what cause ill health including diabetes and that ‘cure’ involves purifying the body. The idea of purifying diabetes bodies fits and make sense given the construction of diabetes as an accumulation of ‘chemicals’ and ‘toxins’, and that the herbal medicines, unlike biomedical drugs, do not contribute to this accumulation. It is to this that I turn to in the next section to highlight the experience of using herbal medicines in practice to highlight the complexity of therapeutic landscapes in which diabetes is managed.

### 7.1.3 Use of herbal medicines in practice

“Testimonies” that I referred to above informed how patients started using herbal medicines. Through testimonies, patients learn and manage diabetes from and with others, respectively. Mphatso Lemani, a type 1 diabetes patient, described how a woman who saw him at Queens Hospital felt pity for his ‘suffering’ because he looked sickly and weak. She recommended that he use leaves of a plant called bitter leaf. He was now using that plant to manage diabetes. He said:

She also has *shuga*, but she stopped taking medicine. She is the one who gave me this plant after she pitied me because I was suffering from *shuga*. She gave me, and I take it. When I said I inject when I want to, I meant that if I follow the advice from the clinic and then use this plant, my *shuga* is ‘all right’ [*shuga imayenda bwinobwino*]. It is low.

...Therefore, I followed that. When I started taking the water from this plant, it was highly effective because I had once reached a point where people were talking bad about me. The woman I spoke about helped me.

[Interview, 09042017]

Like Mphatso, other patients also described using herbal medicines concurrently with biomedical drugs. For example, Mr Isaac Stenala, a type 2 diabetes patient from Nguludi Hospital, makes a herbal drink from blackjack<sup>68</sup> (scientific name: *Bidens pilosa*) that he uses as diabetes medicine. When I asked how he uses it, he said, "*I did not stop taking [hospital] medicine. I was still taking the hospital medicine. The blackjack was extra medicine. I used to take it as my tea. At times, I used to take it when I was feeling thirsty. ...I used to take it in the morning and in the evening, while I was taking the other [hospital] medicine*" [Interview, 09012017]. Other patients stopped taking biomedical drugs in preference for herbal medicine. Some alter their prescribed dosage of biomedical drugs by reducing the number of tablets or amount on insulin, and or the frequency of taking these medicines. For example, Mrs Jacqueline Mangani (JM), a type 2 diabetes patient from Nguludi Hospital, was one of those that had altered her dosage of hospital medicines because she was using herbal medicines at the same time. In my first interview with her at her home, we started talking about her prescription of diabetes medicine. She informed me that at diagnosis, she was taking two tablets of glibenclamide and two tablets of metformin. Later, clinicians prescribed tripride 2 because her 'shuga' was getting extremely high. I then asked what its dosage was, and she said:

JM: I take two [tablets] in the morning and two in the evening, but I also use natural herbs, that is why sometimes it goes high and sometimes it is too low.

MJN: What do you mean by that?

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<sup>68</sup> Blackjack is also known as farmers' friends, beggar's ticks, pitchforks, or stick-tights. In Malawi, it is used as relish. Cooking it involves boiling it and draining water for three times. This is done to reduce its bitterness. It is the water that is drained after boiling that Mr. Stenala was drinking as 'tea'.

JM: There are some herbs I believe are helping me a lot, and when I am taking those, I do not take two tablets of tripride 2 in the morning and two in the evening because tripride 2 is a powerful drug; the herbs I am taking are also powerful. The herbs I am taking are extraordinarily potent. For example, there was a time it could go to as low as 73[mg/dL]. When it gets to such levels, I cannot even walk; I feel weak that I cannot even walk to the lab. Therefore, when I take too much of the herbs sometimes, I stop taking that because I fear that I may pass out.

MJN: What dosage do you use for the herbs?

JM: When I am taking the herbs, then I reduce the dose for my tablets. Sometimes I take two in the morning and one in the evening

[Interview, 11112016]

For Mrs Mangani to know this, she had “experimented” – tried combining herbal medicine and observed what happened afterwards. Like Mrs Mangani above, Mphatso Lemani had reduced the amount and number of times that he injects the insulin because he was also using bitter leaf. We were talking about injecting insulin, and I was curious about which part of the body he usually injects himself. His response was about how often he injects himself. He said:

I have not been injecting myself often. I can say I have now minimised [the number of times that I inject]. Curing of *shuga* is what is yet unresolved. However, when I have eaten something that is not good [*zosakhala bwino*], it comes back. These days I do not have any problems [with *shuga*] such that people cannot tell that I have *shuga* [*ndimadwala shuga*].

[Interview, 09042017]

At that time, he was supposed to be injecting fifteen units of insulin in the morning and ten units in the evening. He had reduced the dose to twenty units because he was having problems to sleep at night when he used to inject twice a day. I have previously described

how other patients also decide to alter their doses for several reasons, for example, Mr Nakanga, who increased the number of tablets he takes when he has travelled. Mphatso Lemani and Mrs Mangani reduced their medication because of the fear of experiencing a low 'shuga', experience of side effects after using biomedical medicine and use of herbal medicines that inform the reduction for medicines that they use. While some patients reduce their hospital medication, others like Mr Sembereka, a type 2 diabetes patient from Nguludi Hospital, stopped taking them altogether. He told me that he had stayed for about three months without taking hospital medicine. He said, "*We wanted to see, to try [and see] what would happen without taking medicine*" [Interview, 10032017]. In doing so, Mr Sembereka was "experimenting" with herbal medicine.

However, providers of herbal medicines often said that there is no problem with taking biomedical drugs concurrently with their medicine, which is how most patients do it. For example, Stella Chipeta, an agent for Muhinge Farms, said they do not ask patients to stop taking biomedical drugs; patients are free to do what they want – whether they stop or not. Similarly, when I asked Mr Pempho Galimoto, the herbalist who founded Healthful Living Products, whether patients should take his medicine on its own, or he can take them alongside biomedical drugs, he said, "*The patient can take it while also taking hospital medicine. It is can also be used on its own, especially after they have finished the hospital dosage. At that point, we tell the patient that they must continue drinking this until they are sure that they are fine*" [Interview, 10032017]. For other providers of herbal medicines, patients should not take herbal medicines and biomedical drugs at the same time. For example, when I asked Brown Chapola, a herbalist, as to what patients that are taking biomedical drugs are supposed to do, he responded:

Firstly, we do not stop people from taking biomedical drugs because they are also taking our medicine. What we ask of them is that if they are also taking biomedical drugs, they should allow for some time before they take our medicine. For example, if they have taken biomedical drugs, they should wait for about thirty minutes before that can take our medicine. This is because, within those thirty minutes, the biomedical drugs will have functioned within the body. They can then take our medicine; there is no problem with that. ...It does not matter which one they start with, either the

hospital one or our medicine. It is the same. However, they should allow for thirty minutes before they take our medicine to allow the other medicine to function thoroughly. It is the same with some things. For example, someone who has taken tea with milk must wait for about thirty minutes before he or she can take our medicine. This will allow the milk to be fully absorbed [*kuti ugwire ntchito*] because if they take our medicine soon after taking tea with milk, the milk will disturb the processes around the functionality of the medicine.

[Interview, 27062017]

What Brown Chapola wants to prevent is what, in biomedicine, is known as a “drug interaction”. In his case, biomedical drugs would prevent his medicine from working as it is supposed to, at least for some time. It is interesting that health care workers raise a similar point against the use of herbal medicine: that there is no knowledge of how these herbal medicines work and interact with biomedical drugs<sup>69</sup>.

Providers of herbal medicines who have no problems taking biomedical drugs also envisage other ways in which the use of herbal medicines depends on biomedical practices. This is through the uses of these biomedical practices to validate the efficacy of herbal medicines. For example, Mrs Jacqueline Mangani “confirmed,” through a laboratory test that the herbs she was taking were “healthy” and that they were working because “*there was a time it could go to as low as 73[mg/dL]*” [Interview, 11112016]. By “healthy”, Mrs Mangani means the herbs were not harmful to her, that they did not have “side effects”. What is interesting here is that confirmation of effectiveness of herbal medicine is through a sugar level, a number from a biomedical practice. When patients attribute these numbers to herbal medicine and share them with others, it becomes a strong “testimony” for those that have not tried the medicines.

Herbalists like Dr Kambewa (The Herbal Clinic) and Cryton Njoka (Bayethe Naturals) ask their patients to get a diagnosis at a biomedical facility before they are given medicine. Dr

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<sup>69</sup> In biomedical practice, the importance of drug interaction is that some combinations can not only prevent drugs from working as they are supposed to, they can also be harmful and unsafe.

Kambewa, a herbalist, said he referred patients who came to his “clinic” to go to Queens Hospital for a ‘*shuga*’ diagnosis. He said:

Once there is a confirmation of a *shuga* diagnosis, they should come back and tell us, show us their health passport. They can then tell us what they are experiencing in terms of symptoms, whether their *shuga* is getting extraordinarily high or low. That is when we give them medicine, which is informed of herbs. We recommend these herbs. After taking them, their *shuga* will be at the right level.

[Herbalist, the Herbal Clinic]

The importance of this diagnosis is that it will be used to show whether the medicines have worked after taking them. This is because patients are asked to go back to the health facility to confirm that their ‘*shuga*’ has been “cured”. Of course, what they get at the hospital is whether their sugar has gone down.

Once a diagnosis has been confirmed, the patients can then buy the medicine for their disease. Providers of herbal medicines tell patients to follow specific instructions after curing their ‘*shuga*’. There are stark similarities between what providers of herbal medicine instruct their patients and what health care workers tell patients as part of diabetes education within biomedical health facilities. Thokozani Stima from Hope Nutrition Services said, “*After the bad things from the body have gone out [zonyasa za mthupi zikachoka], they then need to eat appropriately to ensure that the bad things do not return into the body*” [Interview, 15062017]. During diabetes education, patients were often told that they should be eating appropriately. On a bottle of “Betta Life” Diabetes Mix that is sold at Health Foods Shop in Blantyre, there are “*additional tips for diabetes sufferers*” including “1. Exercise once or twice a day – moderate exercise or brisk walk after eating 2. Drink lots of pure water, between meals 3. Eat lots of raw fruits and vegetables (especially raw onions)”. According to Dr Kambewa, a diabetes patient who is taking the medicine he sells is supposed to avoid fats. He said:

The patient must avoid food with much fat. He or she must avoid food that has starch, which is those that have yeast. He or she also must avoid [*Nsima* made from] fermented maize flour and white rice, for

there are several types of rice. He or she must avoid those are types of food. Because they have *shuga*, they must avoid those foods. One is not supposed to use white sugar. I recommend that they can use brown sugar, albeit a little bit of it so that there is a little sweetness. If he or she avoids those foods, they will notice that their *shuga* will be 'all right' and without any problem.... Those that are taking our medicine and following what we have instructed them often testify that their *shuga* has 'stabilised' ...The main point is that this medicine only works if one is following what we have instructed them; [It does not work] if they take medicine without following the instructions. If they do not [follow the instructions] it may seem as if the medicine is not working.

[Interview, 21022017]

After taking the herbal medicines for some time, patients were asked to be tested at biomedical facilities to verify that they are improving or that have been "cured". For example, Dr Ernest Kambewa recommends that after taking 'diabetic coffee' for three months, "*patient [must] to go to a hospital so that they have their sugar level checked. They will find that the sugar level has changed; it has stabilised*" [Interview, 21022017]. Similarly, according to Brown Chapola, after taking his medicine, "*When the patient goes to the hospital, they find that they are much better than they were before, meaning that [the medicines] are working*" [Interview, 27062017].

Not only do providers of herbal medicines rely on biomedicine, but but some of them also invoked aspects of religion in how their medicine was supposed to work. For example, Mr Wanda, the proprietor of Maranatha Healing Ministries, traced his herbal medicine to the biblical story of creation. He said: "*As a ministry, we believe that herbal therapy began in the Garden of Eden (Genesis 1vs29) and we started manufacturing herbal products from God's nature in 2012*" (Kamanga 2017). During a conversation, he told me that he encouraged patients to pray before using his medicines, while the website for Maranatha Healing Ministries states: "*We believe in vegetable juicing, immune-boosting supplements, stress-reducing techniques and above all prayer*"(Maranatha Natural Healing Ministries 2019).

Mr Pempho Galimoto, another herbalist, also referred to biblical verses which justified the use of herbal medicine. He said:

I am in Adventist. I studied the Bible. In the Bible, it says that when God created man, he designed the body with specific ways to get protein, vitamins, and carbohydrates. This is because these are what makes the body. You understand. Therefore, it is biblical that a person's body is made from what they eat. As such, God created what man ought to eat during creation. He made things for man to eat because He knew that those would give what man requires in their body so that it is continuously healthy. When sin came in, things were disrupted. Diseases started coming after this disruption. However, God saw that even though disease was afflicting man, there should be things that can heal him. As such, God made it that plants should have medicines in them. Let me just say, God put different medicines in these plants, only that it required us to study the medicines which were put in the plants. If you read the Bible, go to Psalms 104 verse 14 which clearly shows that God put different medicines in plants. What is missing is the personal wisdom/knowledge to discern what medicines are in different plants, and how it can assist people. That is what is lacking for people to learn. Therefore, plants have medicines.

[Interview, 10032017]

In this section, I have shown how patients use herbal medicines alongside biomedical drugs and religion. I have also highlighted how patients and providers of herbal medicines use biomedical practices to confirm the efficacy of the medicine, highlighting the interconnectedness of the practices. This highlights the complexity of the “therapeutic landscapes” in which diabetes is managed. The importance of considering this complexity lies in the fact that different therapies influenced how patients used others for example altering biomedical drug dosages because of herbal medicines. It also highlights the complexity of the “experiments” that patients engaged in, and the multiplicity of factors that can potentially influence the outcomes.

## 7.2 Religion and managing diabetes

Religion features in many aspects of living with and managing diabetes. Some patients often linked prayer, faith, God, miracles, and grace to their level of sugar, hospital medicines, consultations, the experience of symptoms, and having diabetes itself. Some health care providers like Sister Mataka often encouraged patients to read the Bible and pray as they live with and manage diabetes. Except in instances where religion and its practices claim to cure diabetes fully and hence not require further treatment, patients concurrently used religion and biomedical practices and drugs in diabetes management.

### 7.2.1 Religion and healing in Malawi

The importance of religion in Malawi is highlighted when one considers that most of the population belong to either Christian or Islamic religions. A recent survey estimated that 87% are Christians,<sup>70</sup> while 12% are Muslims (National Statistical Office (NSO) [Malawi] and ICF 2017). According to the survey, only about one per cent among women and 2.9 per cent among men reported no religious affiliation. This is well captured by Swidler (2010: 164) who wrote: “if one asks Africans today, almost all will describe themselves as participants in one of the major “axial” faiths [Judaism, Buddhism, Christianity, Islam, Confucianism, Hinduism, and their successors]—believers in one God, and active members of either a Christian church or an Islamic mosque. Not to “believe in [one] God” is almost unthinkable, and indeed, one of the matters of significant interest to Malawians is a visitor’s response to questions about his or her church. This question is framed as “Where do you pray?” [*Umapemphera kuti?*] or “Which church/congregation do you belong to?” [*Ndiwe wa tchalitchi/mpingo wanji?*]. The assumption behind the question is that everyone belongs to a church, or pray to God. It is rare for someone to respond that he or she does not belong to a church. Among other things, belonging to a church/mosque entails attending congregational worship with other members on designated days of the week (Friday for Muslims, Saturday for Seventh-Day Adventists/Baptists and Sunday for Roman Catholic, Church of Central African Presbyterian, and many Pentecostal churches

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<sup>70</sup> These belong to the following churches: Roman Catholic (19%), Church of Central Africa Presbyterian (18%), Seventh Day Adventist/Baptist (7%) and Anglican (3%). About 40% belong to “Other Christian” churches, which include Pentecostals churches.

that have been set up in recent years). Some of these churches have regular community meetings among members during the week.

In Malawi, religion is used to intervene in many aspects of social life. Alongside the



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**Ministering:**  
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**MONDAYS - FRIDAYS: 5:30pm - 8:00pm**  
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**SUNDAYS: 06:00am - 07:30am, 07:45am - 09:30am**  
**09:45am - 11:15am**  
**11:30am - 1:00pm (Chichewa Service)**

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**Opposite Chinese Houses**  
**099 118 615**

Figure 5 Poster, Signpost and Newspaper Advert on healing and deliverance

government, churches have historically been involved in the provision of social services, including education and health. There are several mission hospitals and schools running in Malawi. The Christian Health Association of Malawi (CHAM) is the second biggest healthcare provider after the government. Apart from setting up hospitals, churches also intervene in health and healing through prayer. For example, the Zion Church does not allow its members to seek healthcare from biomedical or traditional healers' practices. Instead, church elders pray for sick members and give them blessed water, which is supposed to heal them through faith (Munthali, et al. 2016). Even those like the Catholic church, now conduct services involving healing and speaking in tongues through the

Catholic Charismatic Renewal movement in what some have referred to as “Pentecostalisation” of churches (Manglos and Trinitapoli 2011).

In Pentecostal churches, healing through prayer, and preaching about prosperity are the main aspects of the religion. Over the past three decades, there has been a proliferation of such churches in Malawi. According to van Dijk (2002:256), these churches exemplify “a high level of religious emotion and ecstasy related to the search for healing, protection and fortune. The preachers focused on spirit-healing, prosperity gospel, and personal conviction, by “working upon the Holy Spirit” (*Mzimu Woyera*)”. To be a member of Pentecostal churches, one has to be ‘Born-Again’ which entails conversion, “perceived as a process of dying and the emergence of a new person, and the reception of the “infilling” of the Holy Spirit as a way to become cleansed of worldly, defiling forces” (van Dijk 2002:257).

Advertising plays an essential part in the proliferation of these churches (see Figure 8 above). Within townships, one is likely to come across signposts for one Pentecostal church or another. Churches advertise their services in local newspapers, inviting people to attend to receive miracles that include healing. Some of the churches have programmes on local television channels and are active users of social media platforms, including Facebook. Through these platforms, Pentecostal churches share and advertise healing and prosperity miracles and testimonies.

Through prayer and faith, members of Pentecostal churches can intervene in all aspects of life including healing for diseases like diabetes and AIDS, getting a job, finding a marital partner, succeeding in business and many others. According to Englund (2007: 487), belonging to these churches is because of “the security provided by the name of Jesus against misfortune, hunger and disease that attracts newcomers, many of whom have previously sought security through the medicines of healers (*asing’anga*)...”.

Having highlighted the proliferation of Pentecostal churches with their messages of deliverance and healing, I now turn to how prayer and faith intervene in diabetes management.

### 7.2.2 Prayer, faith, and medicines

Most of the participants used prayer and faith alongside, concurrently with, and within biomedical practices and facilities, respectively. The idea behind is that God will work through those practices and the practitioners to improve diabetes and its management. At the start of diabetes education session at both Queens and Nguludi Hospitals, diabetes educators and nurses ask patients to pray or if they have prayed. During one such session at Queens Hospital, patients responded that they had “already prayed” and Sister Mataka responded by saying: *“this means that God is with us”* [Field notes, Queens Hospital, 13122016]. Later as the session progressed, Sister Mataka said, *“What we are teaching here is meant to improve your wellbeing. We [Health Care workers] have our part [in managing diabetes]; the patient also has their part. God also has His part.”* [Field notes, Queens Hospital, 13122016] The role of health care workers is to give diabetes education that, among other aims, will help in improving the wellbeing of patients. The patient’s role is to take responsibility for their disease by following what health care workers teach them.

Among other roles that God supposedly took was that of ‘watching’ what patients were doing. Other than health care workers having the ability to “know” or “tell” if patients had been eating “inappropriate food” or are otherwise “non-compliant”, some nurses also told patients that *“God was [also] watching”* them. During a diabetes education session at Nguludi Hospital, Mrs Njewa, a nurse, said this to patients: *“Do not deceive yourself by eating what you are not supposed to eat. Do not say to yourself that the nurses cannot see me. God is watching you”* [Field notes, Nguludi Hospital, 03012017]. On two separate occasions at Queens Hospital, Sister Mataka also invoked God to ask patients to be honest about what they do as every day. On the first occasion, she had asked if people do exercises, and all the patients had responded that they did. She responded, *“Please respond as God-fearing people”* because He is listening to what you are saying [Field notes, Queens Hospital, 13122016]. On the second occasion, she was teaching about breakfast that is right for a *“person with shuga”*. She asked patients how many slices of brown bread they eat, and responses ranged from two to four. She then said, *“You need to say what you do in practice. I assume you prayed before we started. You prayed, right? Then say the truth”* [Fieldnotes, Queens Hospital, 24012017].

Some patients also believed that prayer and faith in God, used alongside biomedical practices, were essential for the management of diabetes. One of such patients was Mrs Linly Mbawala, a type 2 diabetes patient from Queens Hospital. I had asked whether she was worried about diabetes and her response included ideas of using biomedical practices alongside prayer and how God has the power to give a long life even for someone that has diabetes. In response, she said:

Worries come when you think that after diagnosis with *shuga*, you may die any time. However, they encourage us not to worry but accept it. If we follow the advice given, God may give us long life. Others give testimonies that this is their 12<sup>th</sup>, 17<sup>th</sup> or 20<sup>th</sup> year since diagnosis [with diabetes], but they are still all right [they are still alive] .... The most crucial thing they encourage us to pray to God and fear Him. This is because the beginning of wisdom is to fear God. If we fear God and pray to Him, He is the one who gives life. We may say we are still here because we take medicine, but God works through medication. God can do miracles. We cannot say that the medications are the only things helping us. Yes, they do, but we should put God first. We should commit the disease in His hands so that He gives us more days; we will see that we are staying [alive]. Besides, people will be surprised that how it possible for you to stay that long while others have died. ...There are many friends, some have died, but God is keeping us for some reasons. We cannot say it is because we are smart or because we are taking medication, no. We should put God first because He is life. Because you may take medicine, but you should put God first and take medicine. ...We put the medicine in the hands of God, and we commit the doctors in the hands of God, so that they should love us, and we should love them. What they tell us is that we should take them into action. Our God first and use the medicine, and we should follow the advice of the doctor. ...taking the advice from the doctors with [that from] our God, and then we may live for some years.

[Interview, 15052017]

For Mrs Mbawala, living a long life with diabetes required putting God first, committing doctors and medicines in God's hands, taking medication, and following the advice of doctors. Ideas of praying for medicine and the need for the faith were also mentioned during diabetes education by Sister Mataka when she said, "*We should take medicine with faith. Pray for the medicine that you take.*" [Field notes, Queens Hospital, 24012017] Similarly, Mrs Dalitso Gwengwe, another patient from Queens Hospital, believed that one must pray for the medicine that he or she gets from the hospital and the doctors that are involved in providing care. Referring to a motto that I have seen at Blantyre Adventist Hospital, a local private hospital run by the Seventh Day Adventist Church, and at Dr Ernest Kambewa's Herbal Clinic, she said, "*We care, God cures*". Mrs Gwengwe said she prays before coming to the hospital for her appointment. She further stated that patients must pray for the doctors for they cannot provide care on their own without God's help. Sister Mataka also encourages patients to pray before they come to the hospital (that was a prayer at home, this a prayer for here). She said the scripture [Bible verse] that say "*you are healed*" was always on her mind. She then referred to two verses in the Bible that emphasise that God would heal. According to Mrs Gwengwe, to eat anyhow as she was doing, one needs faith: "*One should not just take medicine, one needs faith as well; one also needs Jesus [Christ]*" [Conversation, 04042017]. She does not tell other patients about what she does because if they were to stop eating well without faith, their '*shuga*' would go up, and she would be to blame for misleading them. Therefore, to manage diabetes, patients should not only take medicine but also have faith and Jesus Christ.

Mrs Sera Malewezi, from Queens Hospital, echoed this need for faith by highlighting that it is a form of "trying harder" or striving. While admitting that pastors can cure a person through prayer, she emphasised that "*on your own, you need to commit to it*" [Mrs Sera Malewezi, type 2 diabetes, 16092017]. I asked her what she meant by this commitment. She said, "*You should pray with all your heart, with faith that Lord, I need this disease to end. That means you should not leave it for the pastor to do the praying. The disease will not end if you are not committed [kulimbikira]. That is not possible. Nevertheless, you also need to be committed, prayers by the pastor and yourself*" [Interview, 16092017].

Mrs Juma, a born-again Christian with type 2 diabetes from Queens Hospital, had not gone for such prayers because she was "working hard" on her own. Apart from 'committing',

she emphasized that it cannot happen without faith and believing that she would stop taking diabetes medicine. She said:

I work hard [*limbikira*] on my own [Laughs]. I commit on my own; I pray to the Lord that I want to stop taking medicine for *shuga*. That I should stop taking medicine for *shuga*. ...With faith, it will happen. ...It cannot happen without faith. I need to believe it myself that if it has happened this far, it should happen in future as well. What is outstanding is not much. I have faith.

[Interview, 16092017]

Some pastors explicitly encourage their patients to use their faith and biomedical practices. At more than three occasions, I met different pastors who had come to the diabetes clinic to get their medication. At Queens Hospital, Pastor Jeke, was asked by Sister Mataka to pray and give a short talk on prayer and living with diabetes. A pastor at a church which Mrs Jenala used to attend, who also had diabetes, always encouraged her to attend the diabetes clinic because God works through medicines. Recalling her conversation with the pastor, Mrs Jenala said:

I have reached a point of saying when it comes to sugar, there is a need to be careful. It is something that will always be there. In addition, the other thing that happened is that the pastor of my current church once said to me: "My sister, no one should deceive you. I am a preacher of the Good News and I stand on the pulpit to talk to people about their faith. However, I also have sugar and you know it. .... You should know that I decided that I would be taking medicine. I will also be doing everything that I am advised at the hospital while praying that God should intervene in the decisions made by the doctors so that they treat me appropriately so that I should live longer, and that God should grant me his grace. However, I should not stop taking medicine. You made the greatest mistake of your life". Therefore, after that, I told myself even though I pray and I am a born again [Christian], I will not

stop taking medicine. This is because I experienced it. This is a condition that I will always have as it cannot be cured.

[Interview, 16092017]

At several diabetes education sessions, health care workers warned patients not to stop taking medicine. In the introductory chapter, I referred to Mrs Jenala who said she had stopped taking medicine because she had been deceived by prophets and evangelists. Similarly, during diabetes education, patients were told not to be “deceived” by pastors<sup>71</sup> to stop taking hospital medicine. At one such education session, Sister Mataka said:

A diabetic cannot stay a day or so without taking medication; so, do not be cheated. We are supposed to take our drugs the way people take ARVs, the purpose is to prolong life. Even if you have been prayed for, do not stop taking the drugs. I have never heard anyone claiming that she or he has been healed from BP or sugar because he or she visited a pastor for prayers. Do not stop taking your drugs because someone has influenced you to stop taking them because he or she does not even know what diabetes. Many people were once influenced to stop taking drugs

[Fieldnotes, 13122016]

However, despite encouragement by some pastors and diabetes educators like Sister Mataka above, some patients had stopped taking biomedical drugs citing faith and prayer. This was related to a belief among some members of Pentecostal churches that as ‘God’s children’, they were not supposed to be sick. Several patients believed that “*God did not create us to take drugs daily*” [Lucius Zimba, 15062017] and that “*A child of God is not supposed to get sick, it [sickness] is the power of the devil*” [Anastanzia Kadewere, type 2 diabetes patient, Queens Hospital, 07112016]. Mrs Sera Malewezi put it this way:

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<sup>71</sup> The idea that patients should not be “deceived” by pastors emanates from the Bible where it states: “Then many false prophets will appear and deceive many people” [Matthew 24v11 Good News Bible]. With the proliferation of Pentecostal Churches, people believe that some of them are false and mislead people with their messages.

I started thinking whether the Lord created my body so that I should always be taking medicine; that my life should be all about medicine. I asked myself whether my body would not survive without medicine and that I would die. I said, Lord, from today, I would like to stop taking this medicine. Then I started doing it slowly, but no one knows at the hospital

[Interview, 16092017]

Both Mrs Kadewere and Mrs Jenala had stopped taking hospital medicine because they believed prayer had cured them. During the time that she stopped taking medicine, Mrs Kadewere was not attending appointments at the diabetes clinic. When she started experiencing symptoms of high '*shuga*', she came back to the hospital where she was told that her '*shuga*' was extremely high. Mrs Kadewere was still hopeful that one day, she would stop taking medicine, that prayer, and faith would cure her.

### 7.2.3 God's "grace" and "miracles"

Some patients believed that being alive and a 'good *shuga*' were manifestations of God's "grace" and a "miracle". For example, Mrs Florida Kandulu, from Nguludi Hospital, described the time she was diagnosed with diabetes as follows: "*My condition was extremely critical, as I have said that I was taken to the hospital in a coma. It is just by [the] grace [of God] that you can see me like this today*" [Interview, 07102016]. For George Nyasulu (type 1 diabetes patient), it is because of the grace of God that some patients that have been injecting insulin for fifteen years.

For Mrs Dalitso Gwengwe and Mrs Modesta Juma, lowering of sugar level was a "miracle" and a "testimony" respectively; confirmation of these was done by using numbers from blood glucose tests. Before her appointment in April 2017 when we first met, Mrs Dalitso Gwengwe had had two other appointments: one in September 2016 when her sugar level was 226 [mg/dL] and in February 2017 when her sugar level was at 230 [mg/dL]. A sugar level of 166[mg/dL] was her "miracle" as she had been "*eating whatever she wanted*" rather than following what doctors had recommended. She said she ate sweets and often took "sugar drinks" (soft drinks) like Fanta, all of which are "forbidden" for diabetes patients. She said she had been doing that all along as an "experiment" to see what would

happen. Soon after she received her results, she exclaimed: “*Thank God!*”. A sugar level of 166mg/dL meant her ‘*shuga*’ was “all right”, and she would have a consultation with a nurse rather than a doctor. Mrs Gwengwe’s “experiment” was successful because even though she had been eating “forbidden foods”, her ‘*shuga*’ was at “good”. In her reckoning, she could then continue what she has been doing all along – eating “forbidden foods” and faith in God and prayer. As we were parting, she waved the piece of paper with her blood glucose test results and said, “*This is my miracle today*” [04042017].

Mrs Modesta Juma’s sugar level had gone down from 800 [mg/dL] to 140 [mg/dL] over two years. She said this was a ‘testimony’. She said:

I know that one day, I will be healed. Why do I do [say] this? It is because the time it reached around 800 [mg/dL], some doctors from the College of Medicine were coming to tell me that your *shuga* is extremely high, and your life is 50/50. I told them that my life could not be 50/50 because they are not God and I am not God; and one God created us all. It is only God because He is the one who created me and put me on earth, and He is the one who will take me. ...However, I know that I am sick but not being sick as compared to when it was around 800 [mg/dL]. Because for me, this is a testimony, from 800 [mg/dL] to 114 [mg/dL] there is a significant improvement.

[Interview, 25052017]

When Mrs Juma said her life could not be ‘50/50’, she meant that her condition was so bad such that she could have either lived or died. For both Mrs Modesta Juma and Mrs Dalitso Gwengwe, numbers were particularly important in confirming their “testimony” and “miracle” respectively. For Mrs Gwengwe, the “miracle” is in the reduction from 230mg/dL to 166mg/dL and the fact that she was eating whatever she wanted. For Mrs Juma, the “testimony” is the size of the reduction: from 800mg/dL to 114 mg/dL. Notably, patients use these numbers as self-evident – that these reductions show that they are doing well. Both reductions occurred over a period: about eight months for Mrs Gwengwe and more than two years for Mrs Juma. The importance of such ‘testimonies’ and

'miracles' is that, like herbal medicine, patients share them with others and most importantly, they influence others to 'try' or "experiment" with faith and prayer.

### 7.3 Conclusion

In this chapter, I have highlighted the proliferation and 'professionalisation' of herbal medicines and religion that emphasise healing through prayer in Malawi, how they appeal to patients through ideas of 'naturalness' (for herbal medicines) and testimonies, and how they work in practice through '*cleansing the body*', prayer, and faith. I have also shown the interconnections among these different practices and how ideas they use similar ideas especially the need for "trying harder". I have also shown that patients engage in these practices despite several factors that may prevent them, key among which are prohibition by biomedical practitioners, costs, and failure to lower sugar levels. In doing this, I contribute to the qualitative research literature on the use of other practices on diabetes management by moving beyond reasons why patients use herbal medicines to consider it as part of "experimentation" within in therapeutic landscapes. I conclude this chapter by reflecting on two ideas that have emerged: '*Cleansing the body*' and the complexity of therapeutic landscapes within which diabetes is managed.

#### 7.3.1 'Purification' of bodies

While I have separated herbal medicines and religious practices in the structure of this chapter, therapeutic landscapes are complex. This complexity of these landscapes is evident in the interconnections and dependencies among biomedicine, herbal medicine and religion. This complexity was also highlighted in how patients put them to use as there are many options that patients can 'try'. Patients "experiment" with herbal medicines, food and biomedical medication in multiple ways and combinations. Mr Stenala (type 2 diabetes, Nguludi Hospital), for example, was taking a herbal potion made from *Bidens pilosa* while also taking biomedical medication. Mrs Gwengwe "experimented" with food rather than with religion. Finally, complexity was also highlighted in how these practices take place over time. Over time, different medicines including herbal and hospital medicines are used as part of the management of diabetes. For example, Mrs Singini, a type 2 diabetes patient, had been taking herbal medicines and hospital medicines for about a year while some patients like Mrs Jenala, type 2 diabetes

from Queens Hospital, stopped for a while because of the belief that they had been cured, for most patients. Further, the practices of the herbalists that I have described above borrow from biomedicine. When Cryton describes how detoxification works, he borrows the language of biomedicine in terms of cells and their functionality. Healers did not only borrow from biomedicine. Herbalists like Reverend Kachulu and Pempho Galimoto invoke ideas of religion and how their practices are informed by it.

In Chapter 4, I showed that providers of herbal medicine and patients attribute diabetes and other non-communicable diseases to various aspects of 'modernity': agriculture, medicine, and sexuality. 'Modern' bodies are filled with 'filth', 'toxins' and 'chemicals' that are causing 'modern' diseases like diabetes. Within the religious practice, 'modernity' through various sins like alcohol drinking is also implicated in causing ill health. Practices within biomedical facilities also implicate this 'modernity', albeit focussing on different aspects of it: sugar, salt, cooking oil, 'modern' sedentary lifestyle and others. As part of a complex therapeutic landscape, herbal medicines, religion, and biomedicine have diverse ways of dealing with 'modernity' and the ills that come from it. Managing the ills from 'modernity' involve preventing its illness-causing aspects from entering the body or removing them from the body if they have already entered.

While it is used as a means of dealing with 'modernity', the idea of '*cleansing*' is not new in Malawi. From as early as the 1930s, anthropologists have reported on witch-cleansing movements which, among other ways, involve giving a concoction to witches and sorcerers to cleanse them (Chakanza 1985; Ross 1969; Schoffeleers 1999). In 1994, a healer named Billy Goodson Chisupe from Machinga District in Southern Malawi had a dream in which the spirit of his deceased grandfather and another person showed him a tree whose bark he was to boil and use the potion to cure the nation of AIDS (Schoffeleers 1999). Like the witch-cleansing movements, Chisupe's potion was called '*mchape*' (purgative or cleanser). His 'cure' was popular, such that about 300,000 people (5% of the population of Malawi at that time), mostly from urban areas, went to drink it (Probst 1999). Another form of "cleaning" was reported in Birgitte Bruun's ethnography on people's practices of self-treatment in Malawi (Bruun 2002). Based on fieldwork conducted in 1999, Bruun (2002) reported that informants used herbs or pharmaceuticals for '*cleaning the body*' to prevent the development (called '*service*'), or as treatment of sexually transmitted diseases which are attributed to contamination by

'bad blood'. 'Cleaning' was also meant to improve "*power in the house*" – increased sexual potency which is a sign of good 'health'.

There are continuities and discontinuities in the practice of 'modern' healers from the ones that Morris (2011) described, between herbal medicines and religion. The 'modern' healers have embraced some of the ideas of the 'traditional' healers while abandoning others. The idea behind 'cleansing' remains mostly the same – take medicine to cleanse and remove disease or unwanted substances from the body. However, modern healers have moved on to address other (modern) 'problems' and through 'professionalisation', they have even attempted to portray themselves as being at par, or even superior to biomedicine. These healers used other explanations for ill-health, often borrowing from biomedicine; partly as a consequence of doing so, they considered themselves as being superior to 'traditional' healers (Hampshire and Owusu 2013).

One such idea that diabetes is a result of the accumulation of either sugar or "chemicals", makes it possible for therapy through 'cleansing' (cf Van der Geest and Whyte 1989). In this case, 'cleansing' is meant to remove sugar, salt and anything else that has accumulated in the body and is causing 'problems'. To achieve purity, '*cleansing*' requires the use of objects and practices that will not make the body 'dirty' again. Referring to herbal medicines as 'natural' was meant to highlight this purity. Providers of herbal medicine consider 'naturalness' as good, harmless and something to be strived for (just like 'good *shuga*'). They also link 'naturalness' to a period before the introduction of 'modern' ways that are causing 'pollution'. Some participants link 'naturalness' to location, as in when food from the village is considered more 'natural' than the food in the cities or when they say they take their ingredients from forests that are far from the city.

These ideas of purity are also expressed in religious practice in terms of getting born again and deliverance in Pentecostal churches. Being 'born-again' entails "declaring one's past social life to be immoral, thereby rejecting a past life in all its aspects, a person can instantly become fully Born-Again" (van Dijk 1998: 164). The past life is characterised by impurity, which is removed through the process of being 'Born Again'. Being 'born again' entails purity.

## Chapter 8

### Social relations and “trying harder” in diabetes management

In the previous two chapters, I described patients’ practices of diabetes management as “experimenting” and improvising within complex therapeutic landscapes that include herbal medicine and religion. The first part of this chapter addresses the theme of social relations that emerge in diabetes management. While diabetes is often portrayed as a disease that patients must control individually, it is through and within social relations that patients live with and manage it. During diabetes education, educators understand the management of diabetes and its attendant uncertainties as predicated on the emergence of a moral subject within social relations with family members, health care workers and other patients. I describe social relations among patients through belonging to the diabetes association; between patients and their relatives; and between patients and health care workers within and outside health facilities in the management of diabetes. In the second part of the chapter, I consider what patients often referred to as “trying harder” in response to questions about how they were managing diabetes. Each of the means through which they managed diabetes (experimenting and improvising, using various medicines and healing practices, and maintaining social relations) on its own, but also considered together, constitute diabetes patients’ attempts at “trying harder”, striving to be “*munthu wa shuga*”.

Social relations that influence diabetes management are within patients’ homes but also within biomedical settings. For example, within patients’ homes, the family is more than just a resource or a hindrance in diabetes management. In this regard, Guell (2011) has shown that all aspects of diabetes management involve some family members and that changes in lifestyle are negotiated as a family rather than individually. Dietary changes may entail either changing the diet of the family so that it complies with what diabetes patients must eat or cooking (and having) meals separately. Pollak (2018) reported similar findings by showing that among the Chicago Native population, care within most homes which have multiple diabetes patients was provided directly through activities like cooking and reminding patients what they should eat or not. Indirectly, care was provided through encouragement from seeing a family member perform diabetes care tasks. Care was also done beyond the home and across multiple spheres, including

community-wide events and collective behaviours. Such care work, according to Pollak (2018), shapes sociality by strengthening ties within the community through working together to care for diabetes and shared identity through common vulnerability to it. By altering and structuring community events to suit the needs of diabetes patients, especially diet, diabetes care was not just a family but also a communal task. These findings by Pollak (2018) suggest forms of care and surveillance in diabetes management that go beyond the individual practices in terms of the important role of others (family and community members) and the consequences on forms of sociality..

The emergence of new forms of subjectivities, identities and sociality from sharing a biological disease category and its management practices has been explored among patients living with chronic diseases including HIV and AIDS. One of the concepts used to describe these forms of subjectivities and identities is that of therapeutic citizenship. It has been defined as a “form of stateless citizenship whereby claims are made on a global order based on one’s biomedical condition, and responsibilities worked out in the context of local moral economies” (Nguyen 2005:142). As therapeutic citizens, patients negotiate access to resources, social relations and rights through a shared illness condition/shared treatment. In HIV treatment, therapeutic citizens are expected to be responsible citizens by taking care of themselves through treatment adherence, healthy diets and lifestyles and abstaining from alcohol and smoking.

An emphasis on claims and responsibilities, argues Whyte, et al. (2013), may serve to minimise the significance of other aspects of management of illness for example relations arising in care. Focussing on relations around HIV treatment in Tanzania, Marsland (2012) argued against privileging only the ‘bio’ in biosociality by showing that the ‘social’ in biosocial groups may also be more prominent. Marsland (2012) showed that people associated based on pre-existing social relations rather than their biological status alone. In this context, groups were formed around kinship relations and ensuring survival rather than claiming one’s rights was the motivation for belonging to such groups. Whyte and others (2014; 2013) introduced the concept of “therapeutic clientship” to highlight relations between patients and health care workers, between different treatment programs, state of belonging and obligations and expectations. They showed the emergence of long-term, personalised relations with lopsided exchanges emerging within the rational bureaucratic organisation of antiretroviral therapy care in Uganda. Exchange

in these relations was in the form of medicines, discipline in the use of medicine, and the openness regarding how patients were experiencing and managing their illness. According to Whyte, et al. (2014), discipline in the use of medicines was documented through paperwork and converted into numbers which facilitated relations between health care workers and their supervisors and donors.

Among participants in my study, relations between patients and the organisation of diabetes care, and between patients and health care workers revealed aspects of both “therapeutic citizenship” and “therapeutic clientship”. However, as Whyte (2009b) noted, concepts like these are not a given, but rather are empirical questions in terms of how they work in particular circumstances. I now explore the various ways in which social relations were implicated and called upon in the management of diabetes among participants in this study. Following Marsland (2012), I seek to re-centre attention on the social facets of biosociality. While diabetes education involved taking up new kinds of identity, in particular by encouraging patients to join the diabetes association, this belonging encapsulated the successful adoption of strategies of living that help manage uncertainty beyond providing new platforms for making claims based on disease identity. In this sense, maintaining social relations was one of the means through which people dealt with and managed uncertainties, and engaged in ‘trying harder’.

### 8.1 Relations with family members and friends

Among my study participants, social relations facilitated diabetes management but also, in some instances, were perceived to contribute to raising sugar level. When I described patients’ diagnosis of diabetes, I showed how family members were involved in deciding where to seek care. For example, in Chapter 5, I showed that Mrs Sera Malewezi’s mother and uncle, after noticing that she had swollen legs for several months, decided to take her to a herbalist and a medical doctor at Chiradzulu District Hospital, respectively. Family members were also involved in other aspects of managing diabetes. Relations with these family members and others (patients and health care workers) facilitated the management of diabetes

Spouses of some patients ensured availability of food that is appropriate for diabetes. Family members were also involved in ensuring that diabetes patients ate what health

care workers tell them. For example, Mr Zimba recalled how his wife, who also had diabetes, used to make sure that he did not put sugar in his tea and helped him to stop taking it. He said, “[Before], I used to take a teaspoon of brown sugar because [having tea without sugar felt like] ... I was not taking tea. I was using a quarter teaspoon of sugar [in my tea]. However, my wife was extremely strict. She was always telling me not to take sugar. I then stopped taking it” [Interview, 15062017]. For Mrs Monica Chisale, a type 2 diabetes patient from Nguludi Hospital, her granddaughter made sure that she “complied” with her diabetes diet and that she did physical exercises. She said, “My granddaughter is a bit strict with me. She helps, she will say, “Gran, you are not supposed to be eating what you are eating now” [laughs]. No, my granddaughter helps me; she does. My granddaughter [also] helps me to do the exercises...She always tells me, “Let us do the exercises” [Interview, 01032017].

Patients’ parents, children, spouses and other relatives also assisted in them to access medicine. For example, upon being diagnosed with diabetes, Sosten Kandewu (type 1 diabetes patient) moved from Blantyre City to his home village in Nguludi, Chiradzulu so that he could be closer to his family members who would be assisting with his care. Among other things, that assistance was in the form of buying medicine. At that time, his mother was working as a cleaner at Nguludi Hospital. One of the benefits of working at Nguludi Hospital was that she was a member of the Medical Aid Society of Malawi (MASM), a form of health insurance, which involves paying a small monthly contribution. MASM provides financial cover for medical treatment and related expenses for a member and his or her dependants. Even though he was married and had three children, Sosten was registered as a ‘dependant’ on his mother’s MASM subscription. As such, he could get his medicine from Nguludi Hospital without paying. When his prescription was changed to tripride 2, a more expensive drug, he was getting it through the MASM membership subscription. Unfortunately, his mother died, and her MASM subscription was cancelled. That meant Sosten had to buy medicine like other patients. As he could not afford it, he asked the clinician to refer him to Chiradzulu District Hospital, a government health facility where the medicine was free of charge.

Mrs Kandulu’s two children were buying her medicine. When I first met Mrs Kandulu at Nguludi Hospital, she was taking tripride 2. However, because tripride 2 was expensive and not readily available in most private pharmacies, she reverted to metformin. Her

sugar levels started going up again. Her children, both of whom were working at that time, decided that they would be buying the medicine for her. When I met her in September 2017, she had just resumed taking tripride 2, and she was hopeful that her sugar level would go down at her next appointment. Mrs Singini's daughter sometimes drove her to the diabetes clinic for her appointments. Her daughter had also bought her herbal medicine called Teras Juice. Mrs Singini was supposed to take seven bottles of Teras. Her daughter was encouraging her to continue taking medicine, often calling to remind her. On one of my visits to her home, her daughter called to find out if she had taken medicine. Mrs Singini responded: "*you mean the bitter medicine? Yes, I have been taking them*" [Interview, 16092017]. Mrs Matewere's daughter had arranged to have members of the Pentecostal Church to which she belonged visit her mother to pray for her diabetes to be cured.

On the other hand, Mrs Modesta Juma, a type 2 diabetes patient from Queens Hospital, relied on her nephew to assist her access medicine and other services. Her nephew was a medical doctor who once worked for a non-governmental organisation in Chiradzulu District before joining the civil service in the Department of Nutrition. Mrs Juma told me that: "*...he is the one that I ask from time to time when things have gone wrong, for example, if there is no medication at Queens Hospital. There was a time when the medication was out of stock. He asked his colleagues at the College of Medicine to give me medicine and they did. They even gave me syringes as well*" [Interview, 25052017].

Controlling food consumption has implications for how food is prepared within households. Either the patient must have their food prepared separately, or they eat the food that has been prepared for other members of the family. For some male patients, their food must be prepared separately as was the case with Mr Mosses Botomani, diabetes patient from Queens Hospital. He said to me: "*They prepare my food separately, Nsima ya mgaiwa and roasted relish. If they want fried food, they prepare it for themselves. They are not denied that*" [Interview, 15052017]. Preparing food separately was meant to ensure that the rest of the family could prepare their food in whatever way they want – usually adding cooking oil and salt. For other patients, family members have become used to having a 'diabetes diet'. At the diabetes clinic, I once overheard a female patient describing how members of her family now opt for a 'diabetes diet'. She said she does not need to cook two meals because the other family members now want to be eating her

food saying, “*Food that has not been fried is delicious*”. Mrs Vera Kumbani’s two grandchildren are also used to eating her “diabetes compliant diet”. Similarly, Mrs Modesta Juma said this about her niece who lives with her, “*I think she understands; she is now used to eat food without salt*” [Interview, 25052017].

Social relations that facilitated the management of diabetes were not confined within kin relations. For example, Mr Alinafe Mandele’s employer gave him two glucometers and a weighing scale. Sosten Kandewu’s former employer bought tripride 2 at the time he was no longer getting medicine from Nguludi Hospital. At that time, he already had two packets of metformin that he had been using. When he got the tripride 2, Sosten gave some of the metformin to Charles Tebulo, a type 2 diabetes patient from his village. Initially, Charles was also getting his medicine at Nguludi Hospital but had to transfer to Chiradzulu District Hospital because he could no longer afford to pay for the medicine. Getting metformin from Sosten meant that he could afford to miss his next appointment to Chiradzulu District Hospital.

Thus far, I have considered how patients drew on their relations as they manage diabetes. However, social relations were also perceived as contributing to aggravate diabetes through stress. In the introductory chapter, Mrs Jenala spoke about stress from her relations with her siblings and parents, which she felt was increasing her sugar level. Mrs Matilda Moleni, a patient whom I first met at the foot care clinic at Queens, attributed her increased *shuga* to stress from her children.

## 8.2 Relations among patients

Relations that emerged within health facilities among patients also contributed to how they managed diabetes. Patients looked out for and corrected those that deviated from how they were supposed to manage diabetes. It is for this reason that during diabetes education, patients often ridiculed and reprimanded others who mentioned that they eat ‘inappropriate’ or ‘prohibited’ foods. An example of this occurred during the diabetes education session at Queens Hospital. One of the patients was holding a 250ml glass bottle with an orange drink inside. When one of the patients saw it, she asked the woman with the glass bottle, whether she was a patient. She responded that she was, to which the other patient asked, “*Then why are you drinking that? That is forbidden!*” [Field notes,

2542017]. The woman holding the glass bottle responded that it was not the original drink [which supposedly was the one which was forbidden] and that the juice she was about to drink was sugar-free. Mrs Jenala also told me of an incident where she rebuked a diabetes patient who was selling second-hand clothes at a market in Ndirande Township. She said: *“She recognised me from having seen me at the diabetes clinic. She had a small basin filled with tangerines which she was having for lunch. I told her that even though we are supposed to eat fruits, but it should not be as much as she was having* [Interview, 16092017].

It was also through the activities of the Diabetes Association of Malawi that patients' relations were highlighted in the management of diabetes. The Diabetes Association of Malawi (DAM) was formed in 2007 by some patients from Queens Hospital. The aim was to “spearhead the interests of all people living with diabetes in Malawi” after noting that “patients were experiencing a number of challenges with respect to the provision of treatment and with the availability of appropriate drugs” (Diabetes Association of Malawi 2013:1). According to the Constitution of DAM, the founders of the association had further noted that “these issues needed to be communicated to hospital authorities and other stakeholders using an organised common voice” (Diabetes Association of Malawi 2013:1). To be a member of the Diabetes Association of Malawi, they must pay an annual membership fee of K1,000 [approx. £1]. Apart from that, members may also get a Diabetes Association of Malawi identity card for K500. According to Mr Malekano, a senior member of the diabetes association, the money is used for travelling to the Ministry of Health Headquarters for meetings, to pay a membership fee for the International Diabetes Federation and to pay for office rentals for the association. According to Mr Malekano, when presenting issues to government, the association estimates the number of patients that have diabetes based on those that have paid their annual membership fee. Mr Malekano further said, without elaborating, that having more paid-up members was necessary because it gives the association a ‘voice’ at the international level as a member of the International Diabetes Federation.

Consider the following quote from Mr Zimba, the diabetes educator and a senior member of the association: *“Those that have not yet paid their [Diabetes] association [annual] membership [fee] should see me. The membership fee is K1,000. We need to pay the membership, especially those that are on insulin. Do not go to Room 1 before you do”* [Mr

Zimba, Field notes, Queens Hospital, 24012017]. This quote from Mr Zimba, a diabetes educator and senior member of the Diabetes Association of Malawi, highlights one of the advantages of belonging to the association. He singles outpatients who were using insulin because, at that time, the association had received a donation of paediatric syringes from the United States of America. Adult patients were getting the paediatric syringes mostly because they usually received few syringes which would not last until their next appointment. Even though DAM officials were not strict as to who received the paediatric syringes in terms of whether they had paid their annual membership, they would still ask if one was a paid-up member. Patients that had not paid their membership fee were also getting the syringes, albeit after being reminded to pay.

The advantages of belonging to the DAM had to do with the uncertainties that emerge because of having and living with diabetes and its management in the Malawian context. One of the uncertainties that patients experienced was about the availability of medicine and syringes for those that use insulin. For example, on 17<sup>th</sup> January 2017, Mr Zimba walked into the diabetes shelter at Queens Hospital carrying a plastic bag full of medicine. After greeting the patients, he then started telling the group that the medicine that he was carrying was for diabetes patients from Thyolo District who were members of DAM. He said the district hospital had run out of diabetes medicines and the members had agreed to contribute money to buy medicine. Mr Zimba then said this that one of the advantages of belonging to the association was that patients could mobilise to buy medicine at a lower price if the hospital had run out of medicine. One of the patients asked: *“Does that mean the pharmacy does not have medicine?”* To which Mr Zimba responded that while the medicine was available then, *“one can never be sure when they are going to run out”*.

During another diabetes clinic, Mr Zimba highlighted that the prospects of diabetes drug stock-out were very high. He said:

Before you leave, let me tell you that this year, we might have a drug crisis. Even in other places where we buy them, they are not in stock as of now. Therefore, for us to import drugs from the country we buy from, they need several patients available here. We estimate the number of people that have diabetes based on how the number of those that pay their membership fee. Therefore, I want to ask you

because our membership is K1000 per year. If you want to get an identity card, then it is K1500. If we register a small number of patients, where we get these drugs, they sit down and see what to do. If they find out that the number is small, they conclude that the government will manage to buy the drugs for these patients. Even if we must ask for the drugs, they say we can manage ourselves. Sometimes they send assistance based on the number of patients registered. Therefore, if they send those drugs, we do not give it to those who did not pay the fee. We give to those who paid their membership. Even if we must go to the ministry, they do ask where we are from, and we respond to say we are from the Diabetes Association. If we go to the officials here, they want to know how many members we have, and they say okay with the number we can help. However, they require those who have paid the membership. Therefore, I am begging you that if you like these lessons, please hear me out in all these things I have highlighted here: diet and the membership fee so that we can freely express our problems to the headquarters in Lilongwe.

[Diabetes education, Queens Hospital, 13062017]

Mr Zimba's conclusion suggested that the payment of membership fee was just as important as talking about diet. At Nguludi hospital, apart from paying the annual membership fee for the association, patients also made a monthly contribution of K250 [approx. £0.25] which was used for buying testing strips. As Mr Stenala, the then treasurer of the committees said, "*We must buy the testing strips. Each box costs about K15,000 [approx. £15] and there are 50 strips in each box. The strips we are using today are from the hospital, but we must buy them ourselves. The money I am collecting is used to buy those strips*" [Field notes, Nguludi, 31012017]. This is because a blood glucose test at the laboratory costs about K900. During diabetes clinics, sugar levels are measured using a glucometer. At times, as was the case on the day that Mr Stenala was talking, the strips were from the hospital. However, there is no guarantee that the hospital will always provide these strips.

Patients were also encouraged to buy a diabetes bracelet. In a way, this was a means of showing belonging to the 'community' of diabetes patients. Some health care workers called it an 'identity'. According to Mr Zimba, while the bracelet was previously sold at K500 (£0.50), the price was expected to rise. He said:

Let us also make sure that when we have bracelets at our [DAM] offices, let us all buy them. ...Expect to buy them at a higher price of either K700 or K800 from K500 because we have ordered them at a higher price than before. We have ordered them at K1,000,000 (£1000). Is that right, Mr Malekano?

[Diabetes education, Queens Hospital, 27062017]

Mr Malekano corrected the diabetes educator by saying that they had spent K2,600,000. The diabetes educator then went on to highlight that the bracelets as they had only managed to order 3000 of them. Sister Mataka emphasises the importance of having a diabetes bracelet when she said:

However, if you collapse with a low sugar level, it is difficult for doctors to know that you have *shuga*. That is why it is advisable to wear a diabetes bracelet. It helps that when you come to the hospital, nurses can easily identify you as a diabetes patient and start testing for that. When they see that your sugar levels are low, they give you proper medication.

[Field notes, Queens Hospital, 15102016]

During another diabetes session, she put it this way: "*This [the diabetes bracelet] is an identity for all patients with diabetes... the bracelet speaks on our behalf when you cannot*" [Field notes, Queens Hospital, 25042017]. Patients also acknowledge the importance of the diabetes bracelet. In the introduction, I described how Mrs Jenala said that it was because she was wearing a 'diabetes bracelet' that when she collapsed in Blantyre City, she was taken to Queens Hospital. During diabetes education sessions, some patients also expressed the importance of the diabetes bracelet by suggesting that it was like an

identity card for people to know that the holder has diabetes. The exchange between the patients and nurse who was conducting diabetes education went as follows:

Nurse: Can we all see this? (She holds up a diabetes bangle that is sold by the Diabetes Association). What is its use?

Patient 1: It is vital in the case you are in an accident

Patient 2: That is an identity [like an identity card]

Patient 3: It is for people to know that we have *shuga*.

[Field notes, Queens Hospital, 18102016]

Having the diabetes bracelet was one of the means of preparedness that sugar levels can go extremely low or high at any time. As such, since one cannot speak if sugar levels are extremely low, they need to have the bracelet that can then ‘*speak*’ on their behalf. Therefore, having a diabetes bracelet is to acknowledge the uncertainty as to when sugar levels will go up or down. The bracelet also serves another function. As the nurse and one of the patients told me, it is a form of an identity that one has diabetes. It is giving a sense of belonging. These functions are beyond what the diabetes bracelet was designed for. According to the International Diabetes Federation, the blue diabetes bracelet represents the global symbol of diabetes. It is meant to raise diabetes awareness and it is embossed with the words “Act on Diabetes. Now”.

In Chapter 3, I indicated that because patients must pay for services at Nguludi Hospital, the DAM committee agreed with members to be contributing money for buying testing strips. In June 2017, some members of the association decided to approach the District Health Officer for Chiradzulu District and request that they get free medications for diabetes just like those that have tuberculosis and HIV do. Many of the patients from Nguludi Hospital raised this issue during interviews. While the trip did not take place by the time I finished fieldwork, what was important was that the patients mobilised themselves to effect some change in how they were managing diabetes. One of the reasons that the trip did not take place was that the Hospital Manager was sceptical of its success. When I asked her about the trip, she said that the District Hospital was already

struggling in sending medicines to them and that the success of the ART and tuberculosis programmes was because they were organised at the Ministry of Health Headquarters rather than the District Hospital.

### 8.3 Patient relations with health care workers

Patients interacted with different cadres of health care workers, including laboratory staff, clerks, nurses, doctors/clinical officers, and pharmacists. I focus on patients' interactions with nurses and doctors/health care workers to highlight ideas of belonging and negotiations that characterise diabetes management. Patients' relations with nurses tended to go beyond the diabetes clinic itself to hospital wards and patients' homes. During diabetes clinics, patients were advised that they should ensure that they have a 'good' sugar level at all times because if they do not and are admitted to the hospital, it is the diabetes nurses that are expected to care for them. Sister Mataka often repeated that other nurses in the wards often call her to "*come and assist her patients*". She also said that doctors also reprimand the diabetes nurses if a diabetes patient has been admitted, saying they do not teach the patients about controlling their '*shuga*'. Sister Mataka used to tell patients that if they do not eat as appropriate food, doctors reprimand nurses from the diabetes clinic. On one Tuesday morning, Sister Mataka came late to the diabetes education session. She told patients that she had just spent most of the morning with a diabetes patient who was admitted to one of the wards because his '*shuga*' was too high. Therefore, patients belonged to the diabetes clinic, but also to the nurses who run the clinic.

This belonging was evident in some of the practices by nurse whereby they engaged in activities that went beyond what other nurses would do. For example, at Queens Hospital, two nurses, Sisters Mataka and Njikhó, often visited diabetes patients that had been admitted to male and female wards. On several occasions, I saw Sister Mataka escorting her patients who had been referred to other departments to ensure that they are assisted promptly and appropriately. In one such instance, she escorted a diabetes patient to the Adult Emergency and Trauma Centre (AETC). The patient had to have a blood glucose test before a doctor could see him. However, the young nurses who were attending to him could not find a glucometer. Sister Mataka then started looking for a glucometer herself

until she found one. She did not leave the AETC until the patient was admitted to the Short Stay Ward.

During diabetes education sessions, Sister Mataka used to ask patients to write her phone number at the back of their health passports. She once said, "*For those patients who are on insulin, we advise you that you at least have one phone number for health personnel. When you are not okay, we can call*" [Field notes, Queens Hospital, 13062017]. She used to tell patients that they could call her at any time of the day if they were in an 'emergency'. She often tells the story of a 'guardian' who once called her at 4 am. She said:

He called to tell me that his wife had collapsed. He did not know what to do. That is why you must tell your relatives what you are supposed to do or eat. Your guardians must know. Those who are attending the clinic for the first time should come with their guardians next time. They must know what *shuga* is and what they ought to do. Therefore, I asked the man who had called whether they had *shuga*. Make sure that you do not run out of sugar in your household. I then told him to put some sugar under the patient's tongue. He called back thirty minutes later to report that she had gained consciousness. I then told him to prepare some porridge for her. At 6 o'clock, he called to tell me she was now talking.

[Field notes, Queens Hospital, 24012017]

On another day that she told the same story, she ended it by asking "*Had it been that she did not get the number, the phone had no airtime, what would have had happened?*" [Field notes, Queens Hospital, 13062017]. One of the aspects that this story highlights is the preparedness that a person with diabetes must have for uncertainty when their sugar level goes down. The patient has to have the phone number for the health care workers, they must have some sugar that they can use when the '*shuga*' is low, and there has to be someone who knows what to do when the sugar levels go down. Patients and their caregivers must get knowledge about diabetes and its symptoms. Both patients and caregivers must be prepared. This highlights that managing diabetes is beyond self-care. It is more of group surveillance and monitoring. The story also shows how the nurse goes

further than provide services within the clinic by telling patients that they can call at any time, highlighting the diverse ways in which health care workers use personal mobile phones in Malawi (cf Hampshire, et al. 2016).

The interactions between some nurses and diabetes educators at Queens Hospital showed some tensions regarding whose knowledge was more useful for patients. For example, during one diabetes education session, Sister Maria Mataka came into the diabetes shelter as Mr Zimba was concluding it. Soon after he finished, she stood up and started to teach as well. Mr Zimba insisted that he has covered 'everything', including foot care. However, Sister Mataka said she should proceed as, "*repetition is the mother of all learning*" [Mphini yobwereza] [11042017].

The interactions between doctors and most patients tended to be confined to encounters in the consultation room. Diabetes consultations followed fixed routines in both settings. A clinical officer (Nguludi Hospital) or medical doctor (Queens Hospital) usually started by asking the patient about their lifestyle, diet, the experience of symptoms, how they were taking medicines, 'history' of diabetes in their families and why '*shuga*' was high or low. By asking about patients' lifestyle, diet, and medicines, health care workers were trying to ascertain if they were "complying" with what they had been taught at the clinic. Patients were also asked if they had any 'problems'. In sum, the consultation involved clinical officers/doctors asking questions which patients must answer; most importantly, the patient must follow what they have been advised to do. The doctors determine what ought to happen, and the patient must go home and implement it. However, there was always room for negotiation between patients and doctors.

#### 8.4 What prevents 'trying'

Thus far in this thesis, I have shown how patients use hospital and herbal medicines, prayer and faith, and maintaining social relations as part of trying to get a 'good *shuga*'. However, there are times that patients 'fail' to try. For example, biomedical providers were sometimes indifferent, did not tolerate, or even discouraged the use of both herbal medicines and religion as part of diabetes management. The indifference of health care workers towards herbal medicine was apparent as these medicines as patients shared or sold them within biomedical facilities. Biomedical providers were not entirely against the

use of other healing practices. For example, Dr Ndalama, the lead clinician in the diabetes clinic at Queens Hospital, once told me: *“I generally do not recommend people to take herbal medication unless you know what is in that. People sell other things [medicines] for example they combine garlic and some other herb. If it is just nutritional things, why not just add that to your regular diet?”* [Interview, 18012017].

However, biomedical providers did not always accept or “allow” the use of other therapeutic practices, especially because of the uncertainty of their efficacy. For example, Henry Kufeyani, a pharmacist in Blantyre City, was indifferent yet accommodative to having herbal medicines in the pharmacy which he was managing. He said:

Herbals usually are not something that I push on people that have diabetes. If they want to be on herbals, [we do not stop them] ...This is because herbals are a little bit misleading. ...I would say many people are dying because of the saying that herbals have fewer side effects. ...People cling more on herbals but at the same time, they are not even sure what they are getting apart from whatever they write on the label. ...I do not push it on people because of the same fear that you are not sure of what you are saying. Let us say you encourage someone to start taking Moringa; they have diabetes, and they want to be on Moringa, and then the results do not come out [as they expected], I will be on the other side [of the counter] and [they] will say you told me that this would work. As I am not sure of these medicines, I would not stand there and tell someone that this drug does this or that.

[Interview, 04032017]

The crucial issues for Henry were the uncertainties about ingredients of herbal medicines, what they were supposed to do, and the claims made by those that make them. In short, he did not have confidence in what herbal medicines were said to do.

Dr Ndalama, a consultant and head of the diabetes clinic at Queens hospital, shared the perception of possible harm caused by herbal medicine. She was concerned with patients that present with liver or kidney failure, which could be attributed to the herbal

medicines whose ingredients have not been proven to work as they are said to do. She said:

The problem with many of those things is that you do not have proof that they work. Many of those it is because a friend or a neighbour said it worked and people take that medication. The problem for us is that we do not have proof that the medication works. The other thing is that you are not sure about the content, the exact chemicals that are in each product and you do not know what that product will do if you have taken it over a year. You do not know what effect those products have on kidneys or liver. We have patients that come in with kidney failure or liver failure just from taking herbs because we do not know what the exact content in those herbs is.

[Interview, 18012017]

Because of the uncertainties around their ingredients, content and 'side effects', Dr Ndalama and other clinicians discouraged patients from using herbal medicines. Doctors' resistance to using herbal medicine was most noticeable when patients altered their dosage or stopped taking biomedical drugs. It was for this reason that patients like Mphatso Lemani (type 1 diabetes patient, Queens Hospital) did not tell doctors that they were using herbal medicines; they were afraid of being reprimanded for altering or stopping the medicine.

Apart from the stance from doctors who discouraged taking herbal medicines, there were also costs involved in buying these medicines. The "modern" herbal medicines were expensive and not affordable for many of the patients. When I asked Reverend Kachulu how often people bought his medicine, he noted that people were no longer buying them as they used to because they were expensive. He said:

Yes, some are using it. Some want it, but the thing is, they are expensive. One bottle of Chitosan is being sold at K24,000 (£24); Double Cells is at K12,500, this one is at K10,500 while Zinc is at K9,000. After first, we used to sell many of the medicines because they were a bit cheaper. Then Chitosan was at K5,000. The cost of all this

was less than K20,000. However, the cost of all this is now at K40,000.

There are very few who can manage to get that amount of money.

[Interview, 07042017]

For patients like Mr Mapwesera, a diabetes patient from Queens Hospital, it was because of the cost of these medicines that he had stopped taking Teras Juice. A year before our interview, he had taken one bottle out of seven required. He was expecting that once he saves some money, he would buy another bottle. He said:

This year, because of the challenges in sourcing money, I have not taken it. I am planning that at the end of the month, I will buy another bottle. ...In the beginning, you may experience fatigue. After that, you feel relieved [*kumva thupi kupepuka*] such that all the illness that you had...is lessened. The other time I told you that sometimes the *network is lost*. By that time [after taking Teras], you realise you are healthy.

[Interview, 13062017]

Despite the costs, Teras Juice was perceived as 'effective' for Mr Mapwesera. By saying '*network is lost*', he was referring to the loss of sexual desire, a significant concern among men with diabetes in Malawi (Cooper, et al. 2018). Its significance was evident when, after taking Teras Juice, he realised he was 'healthy'. Saying he is 'healthy' also emphasizes the perception of the effectiveness of Teras Juice for having restored 'network'.. Yet the use of herbal medicines or religion was not always perceived as successful; this was one of the reasons that prevented some patients from continuing trying these healing practices. For example, after taking nine bottles of Teras Juice (instead of seven "prescribed") mainly due to the persistence of her daughter, Mrs Victoria Singini, an elderly type 2 diabetes patient, felt that "*there was no change*". She perceived it as a waste of money but could not stop because her daughter was buying the medicine and encouraging her to take it. She said:

[Not] even a small drop of my blood sugar [level]. I think diabetes has opened business opportunities. I am saying this because as we are talking now, people are told to try such drugs and people are moving

up and down to have each drug available but to no avail. ...I have tried many drugs. Others drugs we were buying them at K30,000 (approx. £30) for only two small bottles. After those drugs, then we go back, and we were given other bottles at K20,000, making a total of K50,000 (approx. £50). All these drugs but nothing changed.

[Interview, 16092017]

### 8.5 When trying 'fails', keeping on trying, try harder

There were many times that patients 'failed' in trying to have a 'good *shuga*'. According to health care workers, it was up to the patient to tell why their sugar has gone up. Patients had to know the reasons for a high or low sugar level. During one consultation at Queens Hospital, Dr Nkoloma said this to a patient: "*Your shuga is exceptionally high – it has gone up to 470 [mg/dL]. Only you would know why it has gone up to that level. It could be because you are not injecting yourself correctly. [Alternatively], it could be that have been taking a lot of Coca-Cola*" [Field notes, Queens Hospital, 30052017]. At Nguludi Hospital, I often heard nurses ask patients: "*Your shuga has gone up. What have you been doing?*"

In response to questions as to why their sugar level had gone up or down, patients offered several explanations. These explanations were about what the patient had done or failed to do which had then caused sugar levels to rise; these explanations were often linked to what was taught in diabetes education and involved self-blame. For example, during a consultation at Nguludi Hospital, one of the patients said, "*What I did wrong was that I ate the fried maize that the nurse was talking about*" [Field notes, St. Joseph, 31012017]. At Queens Hospital, one female patient aged about 50 years characterised her reasons as greed and negligence. Dr Mapira had asked her why her sugar was not going down, and she responded: "*We are told not to take tea with sugar. If one adds one spoon, have they done something wrong?*" [Field notes, Queens Hospital, 11042017]. Dr Mapira then started telling her some of the foods that she was not supposed to eat. When she mentioned fruit juice, Dr Mapira told her that she should not be taking all juices as she has a lot of sugar in her body. She responded, "*It is negligence doctor. I should not give you a headache. ...It is greed. It has just happened. I have been having Nsima from fermented flour these past years.*" [Field notes, Queens Hospital, 11042017].

Probably because of fear of being ridiculed by doctors, some patients gave explanations that showed it was not out of negligence that they had a high or low sugar level. Some said they were blameless for raised sugar levels. During a clinic consultation with Mphatso Kansilanga, a clinical officer at Nguludi Hospital, the patient blamed the rise in '*shuga*' on lack of medicine that she did not manage to buy.

Mphatso: Your *shuga* has gone up. The previous measurement was 146mg/dL and today it is 182[mg/dL]. It has gone up. Tell me what happened?

Patient: I did not buy one of the prescribed medicines. Nevertheless, I will buy it today.

[Field notes, Nguludi Hospital, 01112016]

In response to these 'failures', patients keep on 'trying'. For example, during one consultation at Nguludi Hospital, Mrs Florida Kandulu presented with a high sugar level. At that time, she had been using metformin. The clinical officer decided that he was going to change her medication to insulin. Because Mrs Florida Kandulu "knew" someone whose '*shuga*' had gone down because of tripride 2, she wanted to 'try' it as well. As such, she requested it from her doctor at Nguludi Hospital. She said:

The doctor asked if I should start using insulin again, and I was not comfortable because it was making me very weak. I asked if he could prescribe a new drug that is a combination of metformin and glibenclamide called tripride 2. By then, I knew of someone who had tried it out before. The doctor asked if I could manage [to buy it] because the price for that drug was higher than the other medicines. Knowing that I was sick, I had no choice. Therefore, he gave me a prescription of that, and after a few days, my glucose level went down from three hundred and something to around two hundred and ninety-something.

[Interview, 07102016]

Other patients refused insulin because they felt that it was a burden. For other patients, it was because they perceived insulin as signalling that diabetes has deteriorated. Some patients refused insulin because they wanted another chance to continue “trying”. One such patient was Mrs Sera Malewezi (type 2 diabetes patient). She described her experiences as follows:

However, before that, my glucose level was not going down, and they [health care workers] advised me to start using insulin injection. However, I always told them that I did not need it. They said they had done everything they could, but my glucose level was not going down; it was just always between around 200[mg/dL] and 300[mg/dL]. Then I requested for one more chance that I should try to observe my diet.

[Interview, 17102016]

Mrs Malewezi felt she was doing everything as she had been advised, including eating fruits. One of her friends advised her to try doing some exercises. She then started jogging with her husband. However, there was not much change in her sugar level.

When I went to the clinic, the sugar level was around two hundred fifty-something. Later the sugar level remained at 200[mg/dL] for some time. Therefore, at the hospital, they said they were going to give me insulin because the tablets were not working. I refused and asked for more time for me to work on it. So, I would run from Jumbe to Mkwate and back, every day. When I went back, my sugar level was around 180[mg/dL]. In July, it had gone down to 165[mg/dL]. The last time I went to the clinic was on 20 September. We first met that time. It was at 154[mg/dL].

[Interview, 17102016]

Patients also kept on ‘trying’ herbal medicines: either using the same one despite failure or trying other medicines, healers, or practices. This could be because of relatives/children are persuading and pressuring them, “testimonies” from other patients or hope that they will be lucky ‘next time’. For example, despite that Mrs Singini has always maintained that there was no ‘change’ after taking Teras Juice, she still had it in her refrigerator. She continued taking medicine for two reasons. Firstly, her daughter,

who had bought the medicine insisted that she should take it. Secondly, she also hoped that it would work. She said, “*I do not think this medicine is helping me at all but [I will continue taking it] since my daughter wants me to. Maybe there will be some changes when I get to finish the fifth or the sixth bottle. However, as of now, there is no improvement*” [Interview, 17102016]. Patients could continue using the same medicines that had failed, with the hope that it might work someday, or they could try other medicines. Most of the patients who had used herbal medicines often mentioned several types that they had tried. Other patients were influenced to continue using herbal medicines by the encouragement of providers of herbal medicines. Where these herbal medicines were perceived to have failed, providers of herbal medicines usually blamed it on patients’ lack of striving as I showed earlier. Because it is not the medicine that is to blame, providers of herbal medicines then encourage patients to continue taking the herbal medicines while following what they have been advised.

Beyond ‘trying’, patients were “trying harder” by engaging in various practices to get a ‘good *shuga*’, a demonstration of taking responsibility for their illness. This is the idea of ‘working hard’ on the illness to make sure the sugar levels are ‘normal’. For example, Mr Zimba told some patients that managing diabetes needed “trying harder”. During one diabetes education session, he had just told some patients that he stops taking his medicine. The patients did not believe him; they suspected that he was using different and more ‘powerful’ medicine. His response, which highlighted the need for “trying harder” was:

LZ: It is the same medicine. Diet is essential [means of management]. We must try extremely hard. We must take plenty of water.

P: Nevertheless, we are trying extremely hard, Mr Zimba.

P2: She is not lying. We are trying, but you find that the *shuga* has still gone up.

[Field notes, Queens Hospital, 13062017]

The need for “trying harder” was also mentioned by health care workers when advising patients about their management. Dr Mapira advised an elderly patient who turned up with a high sugar level as follows: “*You will continue taking medicine as you were, but you*

*need to try hard when it comes to food. On its own, the medicine does not work. You need to be observant on the food. Your next appointment will be in three weeks”* [Fieldnotes, Queens Hospital, 11042017]

For Providers of herbal medicines like Dr Kambewa, not “trying harder” which he described as not persevering, was the reason some patients’ *shuga* was not stabilising. He said:

We [people] are not the same...Some do not persevere/endure. They eat the thing that they should not eat because they are used to it. For example, putting salt when they are not supposed to. They say let me eat food cooked with cooking oil which they are not supposed to eat, or they eat *Nsima* made from fermented maize flour. Doing that disturbs/disrupts the working of the medicine.

[Interview, 21022017]

According to Dr Kambewa, ‘*shuga*’ for such patients will not ‘stabilise’ because of lack of perseverance among patients rather than the ineffectiveness of their medicine. It is interesting to note the similarity between what Dr Kambewa and biomedical providers tell patients not to eat, which highlights the interconnections, “borrowing” or appropriations between their practices. When talking about “*some people who fail to persevere,*” Dr Kambewa highlights the need for striving in using his medicine, another requirement similar to biomedical providers’ advice. He reiterated this when he said, “*People are born different. For some it [not following what Dr Kambewa told them] is about negligence, while others it is about lack of trust/belief/faith, saying that is just the way I am somewhat negligent. ...They do not trust that if they take medicine, I will be fine. It is just negligence. If you put your heart to it [trust] that the medicine will help with my disease, they indeed do so*” [Interview, 21022017]. When I asked Brown Chapola, a herbalist, if the medicine that he was selling ‘cures’ ‘*shuga*’, he said, “*it requires hard work [perseverance]*” [Interview, 03042017]. On another day, when I also asked if the medicine works in the same way for different diseases, he said, “*... for shuga, it does not matter how long one has had it. They are still required to force themselves [mozipanikizabe]*” [Interview, 27062017].

## 8.6 Conclusion

Creating and maintaining social relations becomes significant in the context of uncertainties surrounding diabetes management. Social relations facilitate access to care and medicine. Guell (2011) reported similar roles among Turkish Berliners. Most importantly, she showed how diabetes management practices are negotiated within the family. Despite this, such a patient cannot manage the uncertainty on his or her own. Relatives are also involved in managing this uncertainty. Mostly women cook for male members and children in a family. Uncles and cousins facilitated accessing medicine. Personal relations with nurses facilitated getting a blood pressure measurement, a blood glucose test or even being seen by a doctor. Diabetes education sessions also highlight sociality among patients as they give each other advice and testimonies of their experiences, admonish (and sometimes ridicule) others who are seen not to be “complying”. However, the relations that I report between patients and nurses were unique patients and nurses belonged to each other. These relations went beyond those described by Whyte and others as therapeutic clientship in the context HIV programmes in Uganda through belonging to the clinic (Whyte, et al. 2013). Patients belong to nurses by their biological characteristics. Nurses belong to the patients by their expertise. The significance of these social relations also lies in that they drive patients towards striving for a ‘good *shuga*’.

The idea that social relations were called upon in the management of diabetes was also shown through the activities of the Diabetes Association of Malawi. The activities of the Diabetes Association of Malawi could be considered as forms of therapeutic citizenship, which is a way of using health status to make particular kinds of citizenship claims or as means to understand or enact forms of citizen-like belonging. Following Whyte (2009b) that concepts like biosociality are not a given but an empirical question, I show below that for diabetes patients in Malawi, belonging and what was expected in return were a matter of addressing uncertainties. In the Diabetes Association of Malawi, it is payment of an annual membership fee that is emphasized for one to get the benefits of joining the association. DAM was formed to “fight for the rights of the patients”. The association leadership has repeatedly reiterated that when there is a problem, patients can approach them, and the association can then forward their problems to management. Patients were not supposed to deliver their grievances to hospital management on their own.

Furthermore, the association also facilitated access to medicines through donations that they get. Some of the benefits that one got from belonging to the association were contingent on having paid the annual membership fee. It appeared that most of the patients, especially at Queens Hospital, had not paid the membership fee, hence could be excluded from the benefits of being part of the association. I did not observe the DAM senior members refusing to give non-members/those who had not paid the membership fees because there was no significant stock out. Still, most of the people that received syringes from DAM were often reminded that they needed to pay their membership fees. The forms of sociality that emerge through the diabetes education are not the same as those that Steven Robins (2005) noted when he wrote about how patients moved from near-death experiences to become social activists. I also do not see patients' experiences as those that could be characterised as second chances following Susan Whyte (2014). Belonging is used here as a form of insurance and assurance, as a means of dealing with uncertainty.

#### 8.6.1 Trying and “trying harder” in complex therapeutic landscapes

'Trying' was an active process. It required action on the part of the patient, among which was to make choices as to what was to be 'tried'. It required an assessment to ascertain effectiveness. As such, “trying” involves 'work'. For both herbal medicines and religious practices, one needs faith in either God or the medicine for religion and herbal medicines respectively to work as said by Dr Kambewa, Sister Mataka and Mrs Dalitso Gwengwe, a patient from Queens Hospital. Having or maintaining faith in God or medicines is a form of striving, working hard. In religion, this may come with praying and reading the Bible, praying before going to the clinic, and praying for doctors and medicine. One must keep faith even in situations of perceived failure. This sort of striving is necessary for these practices to work. There are costs in both time and money involved in the use of religion and herbal medicines. Most patients struggle to get money to buy these herbal medicines. They must work hard to save money to buy these medicines as Mr Mapwesera does. Alternatively, they must ensure that they maintain social relations that will facilitate access to these medicines. In both cases, 'trying' involves striving or “trying harder”.

Because diabetes is a disease that has no cure, and because of the 'failures' in management as manifested by high *shuga* or complications, patients keep on 'trying'.

'Trying' can go on and on for a long time, with the same medicine or with different medicines and practices because of the availability of various options that one can "try", testimonies of their efficacy and the imperative for patients to take responsibility for their disease. "Trying harder" continues despite failure in the improvement of sugar level or symptoms. Partly, it was because providers of herbal medicines claimed that their medicines are 'natural', hence posed no 'harm' or 'side effects' for patients. However, both patients and providers of herbal medicines did not acknowledge (potential) 'side effects'. Potentially, the need for patients to keep on 'trying'/for "trying harder" can be an obligation on the patients to keep on trying. As a result, patients may be living in a state of perpetual trying, especially considering the uncertainties of diabetes in terms of when it will go up/down. Such a state is demanding for patients as they engage in perpetual 'trying', hence posing as harm on their wellbeing. Trying was further encouraged by the relations that existed between patients and clinicians. In asking patients to "try harder", doctors were trying to make patients responsible for their illness. This responsibility was further highlighted in instances where patients turned up with a high or low sugar level. By blaming them for the low or high sugar level, patients are put in a position to try anything that will lead to a 'good *shuga*' while also not disrupting their social relations.

There was no guarantee of success after "experimenting". Despite this, patients still "experiment" with hope of success. They "try harder" with the hope that they will not experience symptoms but also that they will be seen by health care workers to have been doing something about their health. Mol (2009) noted why patients keep on "trying harder". She wrote, "As control is illusionary, as all the elements involved (bodies, technologies, food, colleagues, what have you) are capricious, the task is that of attuning everything to everything else, one way or another. What to fiddle with and what to keep fixed, is rarely obvious. What you try to do may not work out. Try something else. Keep on tinkering. Doctoring. Caring"(Mol 2009:1757).

## Chapter 9

### Managing is about/because of uncertainties

The main question for my research was how patients and health care workers manage diabetes in Malawi. To address this question, I explored how patients perceive and describe diabetes, its types and causes. I suggest that the ways people interpret these causes shaped whether and how patients intervened in the management of diabetes and its symptoms. Patients' perceptions of causes were partly informed by existing cultural understandings of disease causation and diabetes education, whose aim was to fashion a 'new' and changed patient who followed what health care workers taught. Such a patient was supposed to take responsibility and 'control' of their diabetes and, by extension, their bodies and life because this was the 'right' (moral) thing to do. In short, patients were supposed to be active, engaging in self-management. Numbers (sugar level, weight, blood pressure) were used to index whether patients had been 'responsible' or in 'control', and whether they had been 'actively' taking care of themselves. Patients also used these numbers to index their 'health' and wellbeing.

Patients described uncertainties about causation, the experience of symptoms, and the context within which they managed diabetes. In terms of causation, patients did not suspect they had diabetes before diagnosis and did not know what caused it. Uncertainties in the experience of symptoms included not knowing whether the symptoms they were experiencing were because of diabetes or other diseases; not knowing whether sugar levels were high or low; not knowing when and whether sugar levels would go up or not (not knowing whether they would have 'good *shuga*' or not). Uncertainties in the context of diabetes management were about ignorance as to whether and/or when there would be a stock-out of diabetes medicines or not. There was also uncertainty emanating from the fact that different diabetes educators (including nurses) and healers (biomedical, religious and herbal) gave different messages, for example that patients had to eat in moderation (but do not get hungry) or eat until they were full. The other uncertainty regards whether diabetes could be cured or not (differences between claims by biomedical health care providers and sellers of herbal medicines). Health care workers also experienced uncertainty as to whether patients were "complying" with what they had learnt and, in the absence of HbA1C, whether the sugar levels during a

consultation reflected how patients have been over time. To manage diabetes, patients and health care workers had to deal with these uncertainties.

Uncertainties in diabetes as a disease, its experience and management drove improvisation, “experimentation”, and ‘trying harder’. In general, both health care workers and patients improvised the use of syringes for insulin injection (using disposable syringes more than once or using paediatric syringes), glucometers and the process of monitoring sugar levels. They also “experimented” with biomedical drugs, food, and their bodies. Apart from food and medicine from the hospital, patients also “experimented” with other healing practices that form part of the broader therapeutic landscape within which people manage disease in Malawi. In “experimenting”, patients adopted a form of ‘activeness’ which was different from the one envisaged by health care workers during diabetes education. By “experimenting”, patients sought life without symptoms alongside and through a moralised endeavour of (being seen to be) doing something about their disease. Improvising and “experimenting” were part of patients’ strategies as they were striving or ‘trying harder’ to have a ‘moral’ self without disrupting their social relations, obligations and life.

Therefore, I argue that to manage uncertainties is to manage diabetes. Because the target of this management (a ‘good *shuga*’) and the means of attaining this target (as taught in diabetes education) were also uncertain, “experimentation”, improvisation and being seen to strive became the only ways that these targets could be attained. Because of uncertainties and through “experimentation” as a means of management, diabetes was made liveable and possible to deal with by both patients and health care workers. By exploring diabetes through the lens of uncertainties, I show that its management is not about control. For control was uncertain. Instead, it is about how to live without symptoms and be a ‘good enough’ patient; it is about striving (and being seen to do so) with any resources that may be available to achieve a good sugar enough level. Where uncertainty cannot be eliminated, it is embraced and perpetuated through practices that are deemed well enough, through being seen to do something about it.

## 9.1 Uncertainties of diabetes and anthropology of uncertainties

The anthropological studies of uncertainty have explored its emergence, temporality, and productiveness (Cooper and Pratten 2015). Others have explored uncertainty as part of a context within which people live with and manage disease (Haram and Yamba 2009a). In my study, some uncertainties were acknowledged and discussed during diabetes education and consultations while others were not. I grouped these uncertainties into those related to the context of diabetes management, uncertainties related to the making of and being “re-active patient”, those that are experienced as part of the diabetes bodily experience, and the uncertainty of practices of diabetes management and their outcomes. I reflect on these uncertainties by considering how they emerged, are managed, and inform what is considered proper management by both patients and health care providers. I consider uncertainties relating to bodily experiences of symptoms as vital because they are essential in determining the results of patients’ “experiments” and experiences of diabetes.

The context within which diabetes was managed in Malawi can best be described as precarious. Within the health system, this entails the uncertainty over the availability of medicines and other equipment for diabetes management. In government hospitals where services are free of charge, patients and health care workers are uncertain as to when there will be stock outs of diabetes medicine. Such stock-outs are frequent and are not restricted to diabetes medicines. The importance of considering the uncertainty relating to the availability of medicine is because patients are supposed to take medication every day, for the rest of their lives. In private facilities, patients who cannot afford to buy medicines that will last until their next appointment experience similar uncertainty. In the event of a stock out in public hospitals, patients were asked to buy medicine from private pharmacies. For diabetes patients (or those with relatives) who can afford to buy medicine, this is not a problem. However, those who cannot get medicine live with the uncertainty of when they will get them and what will happen to their sugar level because of not taking medicine. This uncertainty is about what will happen to sugar levels since medicines were necessary for management, and that patients cannot live without taking these drugs.

The precarity of the context in which patients and health care workers manage diabetes is also manifested in the absence of some services for diabetes management. I have shown earlier that the use of symptoms for diabetes diagnosis can potentially result in a false diagnosis, and hence prescribe medicine. In biomedical management of diabetes, it is the reliance on fasting blood glucose (a cross sectional measure) rather than glycosylated haemoglobin (HbA1c)<sup>72</sup> (an average measure of sugar level over a three-month period), for monitoring sugar level that raises this uncertainty. Without HbA1c, an average of sugar levels over two to three months, patients can have high sugar levels for long periods without being detected, as long as on the day of the test they present with a 'good *shuga*'. In terms of management, patients can engage in "non-compliance" over some time, but still present with a 'good *shuga*'. Therefore, by using only fasting blood glucose, health care workers were making decisions on diabetes management based on uncertainty of whether patients were "complying" with what they are supposed to manage diabetes. Health care workers, had to rely on patients' reporting of their management practices, which may not reflect what they did in practice. Doctors did not often admit this uncertainty. They made decisions to increase, reduce, or maintain dosage depending on the information that patients gave and their hospital records, which are often partially complete as there were variations in the details that different health care workers put.

Other than the context in which diabetes is managed, a set of uncertainties appear around how diabetes and its management are described during education sessions and consultations. For example, while diabetes educators specify various foods that patients are supposed to eat or not, it is not practically possible to talk about all foods that patients might consume when they are at home. Since patients are from different social, economic, and ethnic backgrounds, the range of foods that they eat will vary considerably. That patients are uncertain about the foods that they must eat or not eat was clear from questions they asked during diabetes education sessions. Often, patients asked whether they could eat a particular food or not. Others would say that they ate food that they are not 'supposed' to eat (often such patients are ridiculed by fellow patients who 'knew' they are wrong). As a result, often, diabetes educators talk about the most common food. It was not possible to mention all food that patients come across in their day-to-day life,

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<sup>72</sup> In the UK, HbA1c is supposed to be measured every 3 to 6 months. The WHO recommends that HbA1c should be measured twice a year for people with type 2 diabetes and more frequently for people with type 1 diabetes (WHO (2016)).

hence leading to uncertainty. Further to this, even when for the food the educators talked about, the 'appropriate' amounts that a diabetes patient was supposed to eat were often shrouded in uncertainty by the use of phrases like "eat a little", "do not eat a lot of...", "eat in moderation," or "eat carefully". Framing messages for diabetes management in this way allowed for many interpretations for the patients. Each patient must decide on their own what constitutes eating 'in moderation'. Not knowing what eating in moderation means was a form of uncertainty then raises questions about how to get a 'good *shuga*'.

A unique set of uncertainties has less to do with the context of diabetes management and the forming of 'active' patients through diabetes education and consultations. However, they contributed to whether one is considered to have a good *shuga*' or not. These are existential uncertainties that all patients experience because of having diabetes. These are uncertainties that patients experience with and within their bodies, and which relate to the idea that the "*body speaks*". These uncertainties relate to the fact that even when patients follow all the rules, they cannot tell whether and when their sugar level will go up or not<sup>73</sup>. Similarly, when patients experience symptoms, they are sometimes uncertain as to whether these are because of diabetes or other diseases like malaria. Experiencing these uncertainties becomes embodied as part of the diabetes experience. Over time, there are two potential outcomes: either the patient adjusts his or her ability to tell when '*the body speaks*', or they are so much used to diabetes such that they do not 'hear' when '*the body speaks*'. In either case, the idiom of '*the body speaks*', and the advice for patients to "*be their own doctors*" become problematic for most patients as they must always pay attention to the body and what it says. Further to this, it also calls for the patient to decide as to what is happening, and whether there is a need to intervene, to be a doctor for themselves.

What makes these uncertainties unique is that they are not related to the context of the uncertainties about diabetes messages. Firstly, while they also "imply unpredictable outcome, often of a negative kind that makes life precarious" as suggested by Haram and Yamba (2009a), one needs their bodily experience to determine this outcome. A patient does not need their bodily experience to know about the uncertainties of availability of

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<sup>73</sup> It is important to highlight that in some cases sugar will go up because someone has eaten a particular food. In this case, uncertainty is linked to the event of eating. However, the uncertainties that I am interested in are those that patients experience which do not have a direct link to a particular event.

medicine. On the other hand, if one is experiencing a symptom, they must determine whether it is because of diabetes. Ideally, this uncertainty should be sorted using technologies like glucometers. However, as I will highlight below, glucometers also raise other uncertainties. Because few patients have glucometers, most patients then must deal with these uncertainties based on their bodily experience. Secondly, these uncertainties are unique because diabetes itself is said to be unpredictable. Sugar level can go up without patients knowing, but also at any time. It can go up/down when you do not expect it. Even if one eats food that is not allowed, their *'shuga'* may not go up to the extent that they will feel it. As such, these uncertainties are not tied to a particular event. They are an outcome of having diabetes, rather than specific events as people live with and manage diabetes.

Further to this, it is more prudent to talk about uncertainties rather than just uncertainty. There are many types of uncertainties that patients experience, and most often at the same time. Patients do not address these uncertainties in isolation. Instead, they are addressed as part of the diabetes experience. I now turn to how diabetes management is mostly about dealing with these uncertainties because of the characteristics of the disease itself but also the context within which it is managed.

## 9.2 Managing uncertainties, managing diabetes

Dealing with uncertainties is about acknowledging, perceiving and responding to them. The question to consider is what do people do about uncertainties appearing in diabetes and its management? I argue that patients and health care workers deal with uncertainties using three diverse ways: improvisation and “experimenting” and through social relations. In diabetes management, uncertainty is a problem but also an opportunity. The uncertainty of when sugar levels will go low is a problem because patients can die from that. On the other hand, it is an opportunity for patients to “experiment” and improvise, to engage in diabetes management practices. When responding to uncertainties, people keep on trying available means even in the face of failure (Whyte 1997). According to Whyte, “When misfortune befalls, you mean to do something about it. You face it with purposes that are more or less explicit in your mind. You try, consider the consequences, doubt, and reconsider, revise your purpose perhaps, hope and try again” (Whyte 1997:224).

Considering uncertainties that characterise diabetes management, therefore, reveal new forms of surveillance/and or monitoring that appear in diabetes management in Malawi. Uncertainties create new forms of surveillance for diabetes management that are characterised by improvisation. Uncertainty of diabetes experiences result in patient's practices where the body cannot be trusted, and one needs a glucometer to confirm their experiences. When patients attend the diabetes clinic, fasting blood glucose is used to index how they have been managing diabetes since the patient's previous visit. However, the result of a fasting blood glucose test is a cross-sectional measure of sugar level. The WHO recommends that glycated haemoglobin (HbA1c) is a measure of choice for monitoring glycaemic control as it reflects average blood glucose concentration for the previous weeks rather than at the moment of the test (World Health Organisation 2016b). The WHO further acknowledges that because HbA1c is expensive, the use of the fasting blood glucose test is acceptable. Using fasting blood glucose tests is often supplemented with doctors checking patients' previous records from their health passport and asking patients to describe how they have been managing, e.g. dosage of medicine and whether they have been experiencing any symptoms. However, patients do not always report the truth about how they have been managing diabetes (cf Fainzang 2016). Several patients admitted that they lied or did not tell the doctors everything about how they were managing for fear of being reprimanded, especially concerning those practices that they were prohibited from doing. Because of these uncertainties, patients must attend at least four appointments in a year. Patients are also told to go to their nearest hospital if they are unwell. What is poignant about these forms of surveillance is that they are just 'good' enough. Health care workers are not striving for perfection in surveillance methods.

Diabetes management is also through various relations within and outside the clinic. These include relations with health care providers, other patients, friends, or relatives. Uncertainties of availability of medicines are managed using these social relations, for example, belonging to the Diabetes Association of Malawi. Through these social relations, patients participate in mutual surveillance of one another's activities. Through belonging to the diabetes clinic and the association, one can access care that others do not. Relations with health care providers, especially nurses, extended beyond the diabetes clinic, facilitate access to services in other departments in the hospital. On many occasions, nurses followed up diabetes patients that had been admitted to the wards. This highlights

a new form of belonging beyond what Susan Whyte observed in ethnographic studies of AIDS treatment in Uganda. She referred to this as therapeutic clientship (Whyte, et al. 2014; Whyte, et al. 2013). As patients in an ART clinic, they are clients of the clinic. They belong to the clinic, and this is facilitated through records that are kept at the clinic. In terms of belonging, I take further Susan Whyte's idea of therapeutic clientship (Whyte, et al. 2014) to highlight not only patients belonging to the clinic but also patients belonging to 'diabetes nurses', and to one another. This belonging involves going beyond what nurses are expected to do in the diabetes clinic. For example, some health care workers share their phone numbers and tell patients that they can call at any time if there is a problem. This form of belonging may also include sharing of 'gifts' as tokens of thanks and following up and escorting patients in other departments so that they are assisted faster.

Most studies of diabetes management report that patients do not practice self-care as health care providers tell them. They miss clinic appointments, eat foods that they are not supposed to eat, do not take medications as prescribed or do not engage in physical activity. In my study, health care workers formally discouraged "experimentation" among patients. However, patients did not stop "experimenting". As such, patients did not admit to health care providers that they had been "experimenting" for fear of being reprimanded. I argue that "experimentation" was made possible, and even inadvertently 'encouraged' by the health care workers who discouraged it. It was 'encouraged' based on health care workers' reaction to patients that presented with high sugar levels. The fear of being reprimanded for having or constantly presenting with extremely high or low '*shuga*' encouraged most patients to try out medicines and at the same time "trying harder" using whatever means were available. The reason for doing was a quest for a 'good *shuga*' at their appointments. Not "trying harder" was considered as not taking good care of themselves. It was immoral. Other reasons for "experimenting" had to do with the consequences of presenting with a high '*shuga*'. Apart from being reprimanded, type 2 diabetes patients who regularly presented with high '*shuga*' would be prescribed insulin. Most patients were not willing to get an insulin prescription because of bad experiences of others (e.g. parents), difficulty and pain when injecting, and the perception that getting insulin means one's '*shuga*' is worse. The other reason for "experimenting" was that it was a means of avoiding symptoms that could disrupt social lives.

I have shown that “experimenting” aptly describes what participants were doing in that it captures both the practices of changing doses and combining medicines but also the rationale for doing it. While the ultimate goal of doing these “experiments” was “making illness and ill bodies liveable”(Guell 2009:80) by reducing symptoms, the most immediate aim for patients is “to see what happens”. Also, of importance is that “experimentation” highlights evaluation: patients must make decisions whether medicine is effective or not. That evaluation is based on experiences of symptoms and how they feel. To evaluate, patients must pay attention to the body after taking these medicines. Further to this, “experimentation” acknowledges uncertainties that surround diabetes. It acknowledges that “experimentation” emerges from uncertainties and that other uncertainties emerge from it.

The idea of “experimenting” builds on the work of both Mol (2008) and Whyte (1997). I showed in Chapter 2 that Whyte (1997) suggested that “experimenting” was part of dealing with uncertainties manifested in various misfortunes among the Nyole people of Uganda. For Mol (2008), “experimenting” is part of ‘tinkering’ which constitutes ‘good’ care. ‘Tinkering’ suggests that doctors are collaborating with the patients, adjusting, or ‘attuning’ to reach an ideal practice of management. ‘Tinkering’ is a response to patients’ circumstances that prevent them from managing diabetes as doctors have told them. It is a collaborative practice between patients and health care workers. Patients and health care workers ‘tinker’ together. Practices that I consider as “experimentation” were also a response to patients’ circumstances albeit with different aims for example a quest for a ‘good *shuga*’. It is, as Guell (2012) would put it, a *tactic* of diabetes management. However, this tactic is not about how to put in practice recommendations. It is about pragmatic ways of finding what works to achieve a goal, a ‘good *shuga*’, in the face of uncertainty.

By privileging “experimentation” over other conceptualisations like ‘tinkering’ and ‘bio-tactics’, I do not suggest that all patients who do not follow what they are told in hospitals were “experimenting”. Some patients may have given up “experimenting” because they do not perceive any changes or improvement in their symptoms. Some do not want to do anything about their disease, those that health care workers would aptly label “irresponsible”. Further, by characterising patients’ diabetes management practices as “experimenting”, I am not suggesting that they are rational beings who assess the pros and cons of their “experiments”. As health care providers often pointed out, some of these

“experiments” could have long terms of catastrophic results in terms of complications like damage to kidneys. I have also stressed that the “experiment” was far from being controlled. Many ‘variables’ could potentially influence the outcomes.

I have shown that despite the uncertainty of attributing outcomes to interventions because of inability to control; patients make evaluations of the effectiveness of their “experiments”. However, by highlighting “experimentation”, I am suggesting a new form of ‘activeness’ for the patient. I am suggesting that patients, in the quest to live a life without symptoms or to attain a ‘good *shuga*’, undertook different activities that they believed would lower their sugar level and evaluate the success of each of these. The fact that patients were “experimenting” also points to the struggle that they engaged in as they manage diabetes. This is what I describe as striving or “trying harder”. “Experimenting” and striving are all part of the broader aim of being a ‘good’ and responsible patient as described above. I now turn to forms of patient ‘activeness’ that is displayed by patients with diabetes.

### 9.3 Re-active patients of diabetes management

Susan Whyte proposed that research on non-communicable diseases should pay attention to identities and sociality that emerge in managing these diseases (Whyte 2009b). According to Lupton, a ‘new’ form of public health “privileges a certain type of patient who is self-regulated, ‘health’ conscious, ...rational, civilised” and with a “body that is constrained, under the control of the will” (Lupton 1995: 131). This new public health is about “exhorting people to take responsibility for maintaining personal bodily health ...[while focussing] on the individual by associating the so-called lifestyle diseases with individual behaviours” (Lupton 2012:35). In this case, taking responsibility for personal health is manifested through “accepting and adopting the imperatives issuing forth from the state and other health-related agencies concerning the maintenance and protection of good health”(Petersen and Lupton 1996). ‘Good’ health is considered as a virtue worth striving for, as its benefits extend from individual to the social body. ‘Good’ health is attained through self-control and self-regulation of the individual patient. Patients are assumed to be empowered to make (rational) choices regarding their responsibility to care for themselves (Mol 2008). This form of the active patient is manifested in ideas of self-care/management/control/regulation. This idea of the active

patient is about what the individual patient should do as they manage the disease. It is assumed that through knowledge, the individual is empowered to regulate, control, and manage themselves, and their illness.

One of the modes through which the imperatives for 'good health' are issued is through health education about how individuals are to conduct their bodies, including food that they consume, and amount and frequency of physical exercise. Biomedical providers suggest that a specific form of 'active' patient-hood formed through the transfer of knowledge through education and attending clinic consultations is necessary to manage diabetes. The assumption is that patients will learn and use what they are taught in diabetes education. This is premised on the idea that they are self-interested to take care of themselves because it is the right thing to do. Among participants in my study, two related idioms namely "*the body speaks*" and "*be your doctor*" highlight how patients are supposed to take responsibility of diabetes and its management.

However, there are differences between the active patient envisaged in biomedical practice and one that appears in practice. In practice, diabetes is not only learnt through diabetes education. It is learnt through other sources, including, but not limited to individual experience and other patients' experience of living with diabetes. Through living with diabetes, patients 'know' what works and what does not. They have retrospectively analysed consequences of various activities, for example, eating certain foods. During clinic consultations, they are 'encouraged' to do this. For example, when '*shuga*' is exceptionally high, patients are asked to say what they ate that has caused their '*shuga*' to go up. Closely related to this knowledge is that which is obtained through "experimentation", deliberately undertaking activities "to see what happens". At times, this experiential knowledge is privileged over what is referred to as 'knowledge from books' that is shared by health care providers who do not have diabetes themselves.

While knowledge from biomedical providers was meant for patients to learn how to manage diabetes, it had unintended consequences. Firstly, diabetes education accentuates the uncertainties of diabetes as an experience. I have shown above how uncertainties lead to "experimentation" by both health care providers and patients alike. For the patients, "experimentation" entails some activeness: patients must pay attention to their bodies to notice any changes after taking medicines or eating certain (amounts

of) food. Patients also must evaluate the efficacy of medicines. Patients also share the results of their “experiments” with other patients in the form of testimonies of efficacy. The idea of the active patient that is espoused in diabetes education and management is antithetical to “experimenting”. As health care workers often said that patients are not supposed to “experiment”, that is they are supposed to follow what they have been taught in the clinic (despite the contradictions and uncertainties). However, the “Re-active patient” continue to “experiment”, disregarding the advice of biomedical providers. Secondly, diabetes education is limited in what is covered. Most sessions last for less than one and half-hours. Within that time, diabetes educators do not discuss everything about diabetes management. There are still things that patients must decide on their own. This is also where activeness is shown.

Even though health care workers acknowledged the challenges of management of diabetes, not following what one has been taught or coming to the clinic with high sugar level is still blamed on the patient. The question from most nurses and doctors is often: “*what have you been doing?*” or “*What did you do for your ‘shuga’ to go up?*”. At no point did I see doctors and nurses sympathising with patients who turned up with high sugar levels. At times, the clinic consultation resembled a religious confession, where patients must admit their mistakes that have caused ‘*shuga*’ to go up. Therefore, health care providers blamed patients for outcomes for which they did not have much control. Patients fully accept responsibility as shown by patients admitting what they did wrong for diabetes to start or for sugar level to go up, and patients’ insistence that they are ‘trying’ when asked about their management of diabetes. By taking this responsibility, patients also decide to “experiment” to get a ‘good *shuga*’ at their next appointment. In the ‘logic of care’, Mol (2008) suggested an idea of the active patient reflected in shared ‘doctoring’, where patients’ experiences and struggles are taken into consideration in the management of diabetes. The “Re-active patient” exhibited their activeness outside the clinic as they strove to ensure that they have ‘good *shuga*’ at their next clinic appointment live without symptoms, or just manage diabetes. His or her “experiments” were not done in collaboration with health care workers. That “activeness” may also include strict “compliance” with diabetes advice a few days before their appointment.

The experiments that patients engaged in, and diabetes management itself, were meant to produce something that is ‘good’ enough that patients and health care workers can

work with as they manage diabetes. When doing so, patients are not aiming for perfection. When striving, they aim for something good enough to show that they are doing something about their disease. The idea of striving for something good enough is not restricted to the management of diabetes in hospital settings. This is pervasive in many settings of Malawian social life. There are many instances where even failure is greeted by saying “[at least] you have tried”. In the same way, in hospitals and for patient’s management, ‘at least’ trying is what is highlighted. The idea of ‘at least’ suggests that one should be content with what is there, as it could have been worse. That is the attitude that that “Re-active patient” exhibits as they manage diabetes. They “experiment” and improvise as part of diabetes management, even though this may not be as good as health care workers expected them.

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## Appendices

### Information Sheet

#### **EXPERIENCES AND MANAGEMENT OF DIABETES IN MALAWI: AN ETHNOGRAPHIC STUDY**

##### **Information Sheet**

###### **Introduction**

My name is Misheck Julian Nkhata. I am a PhD student at Durham University in the United Kingdom. As part of my studies, I am doing research on diabetes management in Malawi. As part of this research, I am interviewing diabetes patients, health care workers and family members/friends who are involved in diabetes management, Ministry of Health Staff involved in diabetes programmes, NGOs running diabetes programmes and alternative providers of diabetes management, including traditional healers, herbalists etc.

###### **Research purpose and procedures:**

The aim of the study is to understand how diabetes patients experience and manage diabetes in their everyday lives, within their homes and in health facilities. The study will involve interviews and discussions on how you manage diabetes. These interviews will be conducted here at the hospital but also at your home. It is anticipated that these interviews will last no more than 1 hour thirty minutes.

###### **Potential Risks and discomforts of the research study:**

I anticipate that the study will not cause any risk on your part as a result of participation. I am aware that recalling experiences of diagnosis may be emotional for some participants. If that is the case, feel free to stop the interview.

###### **Potential benefit of the research study:**

The study results may not have direct benefits to you as you participate. The results will be disseminated to the Ministry of Health and the management of your facility. These results may influence policy and how diabetes is managed in your facility.

###### **Confidentiality:**

With your consent, this interview/discussion will be audio recorded. Your name and contact details will not be used to identify this interview.

###### **Voluntary Participation:**

Your participation in this study is voluntary. You may decide to discontinue your participation in this study at any time. Your decision to participate or not will not result in any penalty or loss of benefits including the support you receive at this facility.

If you have questions or require more information about this study please contact:

The Chairman,  
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P.O Box 30377,  
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Consent Form

**EXPERIENCES AND MANAGEMENT OF DIABETES IN MALAWI: AN ETHNOGRAPHIC STUDY**

**Consent Form**

Participant ID:

I have read the information sheet/the information sheet has been read to me. I have been told what participation will involve, and I voluntarily consent to taking part in this research study. I understand that I can withdraw at any time and will not suffer any disadvantage in doing so. All of my questions have been answered and I have been offered a copy of the information sheet to take home for reference.

Do you consent to participate in the research study?

Yes       No

Do you consent to have this interview/discussion recorded?

Yes       No

Do you consent to have further interviews at your home or at a venue you will agree with the interviewer? (For patients and caregivers)

Yes       No

Name of participant: \_\_\_\_\_

Signature/thumbprint: \_\_\_\_\_ Date: \_\_\_\_\_

Name of witness: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Interviewer: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_