THE UNIVERSITY OF WESTERN CAPE

Department of Anthropology & Sociology



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'Doing' Diabetes: A focus on local experience, medical knowledge systems and herbal management of Type 2 Diabetes among individuals in Genadendal, Western Cape

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Declaration:				
Master's minor dissertation submitted to Department of Anthropology and Sociology, Arts Faculty, The University of the Western Cape				
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	ker declare that 'Doing' Diabetes: A focus on local knowledge systems and herbal management of Type 2			
• ,	ividuals in Genadendal, Western Cape is my own work			
and has not been s	submitted to any other institution, department or for			
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Acknowledgements:

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Abstract:

In South Africa 3.5 million people (estimated 6% of the total population) are diagnosed and living with diabetes. The majority of the diagnosed group suffer from Type 2 diabetes respectively. Described as a metabolic disorder, diabetes is also understood as an 'illness and idisease and is usually handled through the intervention of biomedical perspectives, especially in the manner in which it is treated and managed. However, few ethnographies have interrogated how individuals living with diabetes in South Africa in negotiate between various medical/healing knowledge systems- both 'alternative' and biomedical. The study explores the area of Genadendal as a case study, using an ethnographic approach and a material semiotic approach (Mol, 2002) in relation to medical sense-making and treatments. I investigate the partial connections as discussed by Strathern (2004), between medical/healing knowledge systems, i.e. biomedical and herbal management through plant medicines, which inform diabetic realities. Ultimately, this study considers the various notions and understandings of diabetes, local knowledge, experiences of individuals with diabetes and the interfaces of different ways of knowing with each other.

Keywords

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Diabetes, Medicine; Illness; Disease; Genadendal; Alternative, Knowledge, Healing, Treatment

ⁱ Diabetes can be described as an illness. Kleinman (1980) refers to illness for example as a culturally constructed subjective experience of physiological characteristics of a medical condition.

ii Describing Diabetes as a disease focuses on physiological symptoms and how Diabetes is investigated under clinical scrutiny in various medical spaces.

Chapter 1- Introduction

Diabetes is a persistent and active medical condition around the world. An estimated 366 million individuals live globally with diabetes (Ferzacca, 2012). As a result of demographic and lifestyle changes, the prevalence of diabetes is on the rise worldwide (Shaw *et al.*, 2010). Additional factors such as ageing and urbanization contribute to an increased prevalence of diabetes in "developing" countries, where resources are scant and populations large. In this regard, Shaw *et al.* (2010) argue that the estimated number of people with diabetes will increase by 54% by 2030. In South Africa diabetes is currently a key factor in mortality and morbidity rates within the country, especially among urban populations (Shaw *et al.*, 2010).

My initial interest in diabetes was guided by the increasing impact of this metabolic disease, the manner in which it is practiced in orthodox (biomedical) medicine and how it affects scores of individuals in my own community (friends, family, and neighbours). My research was also motivated by the rapid increase in diabetes prevalence in the Western Cape province. In 2012, according to a leading South African health website Health24, a "Diabetes 'tsunami' hit South Africa" (Ottermann, 2012). Diabetes has become one of the fastest growing epidemics alongside human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) and tuberculosis (TB) in the country - and specifically in the Western Cape. The reports of Health24 indicated that many cases went undiagnosed and diabetes was usually only recognized when symptoms were already in advanced stages. Diabetes requires an extensive examination, especially in relation to its reality for individuals, who have to treat and manage living with this (mostly chronic) medical condition (Ottermann, 2012).

This is especially the case for Genadendal. According to the Annual performance plan for 2011/2012 for the Western Cape Government, the prevalence of diabetes and tuberculosis is high in the Theewaterskloof municipal area, which includes Genadendal.

"Doing diabetes": From theory to practice

The work of Mol (2002), a Dutch ethnographer of medicine and healthcare practices is important for unpacking my own study. Mol (2002) draws on medical anthropology and sociology, philosophy, science studies and social theory to scrutinize the day-to-day diagnosis and treatment of a particular condition, namely atherosclerosis. She shows that a disease is not a fixed entity. Instead it is a collection of facts that is delineated differently by various groups. I argue that, similarly, diabetes is biomedically described and can be 'done', 'enacted' or 'practised' as a chronic disease that influences the blood glucose levels in the body and requires special attention in relation to its diagnosis, treatment and management.

Mol (2002) argues disease does not exist in and of itself, but instead as a result of multiple situated practices. In her approach to demonstrating the ontological multiplicity of disease, Mol (2002) argues that there is a mixture of both subject and objects in practice therefore using material semiotics both as a method and tool of analysis. Similarly, Mol has also assisted in the development of a post- Actor Network Theory (ANT) as discussed by Bruno Latour (1999) and Michel Foucault (1976). Mol in her attempts to challenge previous notions of medical epistemology has provided an intimate view of studying disease to its "what" and "who". Mol's argument about ontology specifically relates back to her view about the body as multiple, therefore stating that ontology is always in practice producing a view of medical practice as adaptable but also tenacious in character.

Like Mol (2002), I draw on various scholars in this thesis to understand and similarly be understood in my attempts to make a medical condition such as diabetes visible through people living with diabetes. John Law, a sociologist who also an advocate for the Actor-Network Theory (ANT), worked alongside Mol in discussing the body as both an object and subject through an embodied action such as hypoglycaemia as a medical condition, for example. Together Mol & Law (2004) opened up discussions for anthropology and its method of studying disease by revealing that coherences do not challenge the tensions that exist within them. Similarly, the ability of medicine to be self-reflexive should progress from epidemiology and move toward the lived bodies that experience/live and narrate disease. In essence Mol (2002) in my opinion seeks to reframe boundaries in medicine addressing the

politics of practice and highlighting the intersections of medical influence with its various subjects and objects.

Mol and Law (2004) similarly focused on hypoglycaemia, a condition precipitated by diabetes. This medical condition is biomedically described as plasma glucose levels remaining constant under 3.5 mmol/l. However 'having' the body living with hypoglycaemia, 'knowing' about the medical condition and 'enacting' practices that inform medical practitioners for example, all focus on the practicalities of a medical condition that have remained absent from diabetes research in South Africa.

Mol (2002), who focused on atherosclerosis, stresses that an information leaflet might describe this condition as the gradual obstruction of the arteries. However, if interrogated and observed carefully, the disease in hospital practice seems to be a single medical condition but it simultaneously is many other things. From one instant, place, device, or treatment, to the next, "atherosclerosis" is discussed, measured, observed, or stripped away in various ways. In this manner a multiplicity of disease is 'done' (ibid). This however does not imply fragmentation; instead, the disease is made to cohere through a range of procedures within medicalised settings. I argue this as also a process for investigating diabetes as it exists within Genadendal.

The study area: Genadendal



Figure 1: Map of the Overberg region, in the Western Cape

Genadendal (Afrikaans for Valley of Grace/ Mercy) is situated just outside the area of Greyton and is the oldest mission station in South Africa. Genadendal is the case study area for this research and is part of the Overberg region in the Western Cape (see Figure 1). In 1738 Genadendal was established by Georg Schmidt, a member of the Moravian Missionary Society. It was in this area that Schmidt became familiar with Khoi people who occupied these parts of the land, and where there were many converts to the Moravian faith. (www.viewoverberg.com).

Today Genadendal is a close-knit peri-urban farming community. The current population comprises 8443 inhabitants according to the Theewaterskloof Municipality Overview Report of 2012/2013. The town and surrounding area form part of the Theewaterskloof municipality. Genadendal is well known for its cultural heritage sites such as the museums and old buildings which represent its religious, economic and medicinal history. However, it is also known for its diverse plant life, used in medicinal healing regimens for medical conditions such as tuberculosis (TB) and diabetes (both Type 1 and 2). The latter is diagnosed and treated by staff at the local clinic. Many people also use medicinal plants. Health care providers in Genadendal and surrounding areas depend on mobile laboratories for diabetes

(blood glucose) tests. For extensive test results, such as TB sputum tests, samples are sent to the diagnostic mobile laboratory of the Fraunhofer Institute for Biomedical Engineering in Caledon district hospital, located approximately 32.2 km away from Genadendal. This mobile laboratory service operates as an extension of the Caledon healthcare facility and assists in a variety of testing services. For specialised services such childbirth, surgical procedures (both invasive and non-invasive) and x-rays etc. ¹patients are referred to Caledon district hospital.

Specific information about diabetes in Genadendal is limited. With this study I wish to contribute to the field of knowledge concerning diabetes as a rapidly increasing medical condition in this semi-rural community. Unlike most ethnobotanical, biomedical and anthropological studies on diabetes that focus mostly on allopathic medical/healing for diabetes, psychological effects of diabetes or clinical interventions for diabetes management, I explored the intersections and partial connections between biomedicine and plant based healing and treatment practices related to diabetes. I also demonstrated how diabetes as both an ²illness and ³disease is treated and managed through various forms of medicines in Genadendal.

In various contexts, including for example the United States (US) (Garrow & Egede, 2006) and South Africa (Oyedemi *et al.*, 2009), pharmaceuticals e.g. Glucophage for Type 2 and insulin for Type 1 diabetes, and plant medicines are utilized as treatment and management strategies for diabetes, albeit not simultaneously. These medicinal treatments are usually understood as falling within distinct knowledge domains, procedures and practices that individuals use in complementary ways. Studies on the topic of diabetes have been conducted from various perspectives such as ethnobotany (van Wyk, 2000, 2009; Oyedemi *et al.*, 2009; Deutschländer *et al.*, 2009), biomedicine (Steyn *et al.*, 2008; Tahrani *et al.*, 2011) anthropology (Anderson *et al.*, 1995; Borovoy & Hine, 2008 & Rock, 2005) and public health (Puoane *et al.*, 2002; Wild *et al.*, 2004; Bradshaw *et al.*, 2007; Hall *et al.*, 2011, Mash *et al.*, 2014; 2015). However, there is currently a dearth of ethnographic studies that explore

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¹ In Genadendal clinic persons attending for treatment, diagnosis and management of their respective medical conditions are labelled as patients.

² Diabetes can be described as an illness. Kleinman (1980) refers to illness for example as a culturally constructed subjective experience of physiological characteristics of a medical condition.

³ Describing diabetes as a disease focuses on physiological symptoms and how diabetes is investigated under clinical scrutiny in various medical spaces such as examination rooms and medical laboratories.

diabetes and the processes of negotiation toward treatment of both biomedical and herbal management through plant medicines as I propose.

In my conversations with people living with diabetes concerning their experiences and knowledge of this condition, I observed how this information resembled previous medical research studies. Their experiences related to studies in which explanations of diabetes diagnosis, experiences and discuss diabetes as a disease and illness symptomatically are scrutinized. However, I also documented how significantly different versions of diabetes exist through the physiology/biology of each body living with diabetes, the material and objects that interface in diabetes practice and ultimately the extent to which diabetes is altered and transformed with each person living with diabetes.

Mol (2002) argues for a representation of ontological perspectives that rather than perceiving, e.g. diabetes as a stable or unified object, a singular entity examined and understood differently by e.g. medical staff, people with diabetes, laboratory assistants etc., indicate that diabetes can also be understood as a coming together of partially coherent and partially coordinated enactments in particular moments. Thus, ontologically speaking, diabetes is arguably decentered to a multitude of practices. Diabetes as a disease accordingly does not exist in and of itself, but instead as a result of multiple situated practices- that of the health care providers who use test results to diagnose and treat it, the people living with diabetes who test their blood glucose levels, change their diet, exercise and also those who utilize medicinal plants and allopathic medicine to treat it. These practices also center on the people who are knowledgable about medicinal plants and who collect and prepare the plant medicines and administer them. Ultimately, this research study answered the following three questions

How do individuals living with diabetes interface with various medical/healing knowledge systems?

I investigated how people living with diabetes make sense of various knowledge interfaces. The first looks at biomedical practices within the clinic. I also explored daily experiences in negotiating between medical treatments administered by the clinic for example, and using an 'alternative' medicine such as medicinal plants.

What are the partial connections between different medical/healing knowledge systems in managing diabetes?

I examined the 'partial connections' as discussed by Strathern (2004) between local knowledge and medical diagnostics of diabetes. I also investigated what this meant in terms of treatment and management of diabetes and other medical conditions by people living with type 2 diabetes.

How do different medical systems think, speak and address diabetes?

I attempted to describe how diabetes intervenes and presents itself to various medical/healing knowledge systems. I demonstrated how diabetes is identified and defined in various medical/healing environments such as the clinic and within the home. I explored the strategies of individuals treating and managing diabetes by various medical/healing knowledge systems. Through an ethnographic approach and a simultaneous focus on the objects (these include instruments of diagnosis and treatment for diabetes) within interactions of diabetes I attempted to provide extensive descriptions of people living diabetes, health care practitioners and local people with plant based healing knowledge, their understanding and experience of diabetes (Mol, 2002). In this way techniques from processes of diagnosis to various treatment and disease management systems are considered, in the manner in which they make a disease condition (i.e. diabetes) visible and also knowable to various health care practitioners, as well as the individuals living with diabetes. Disease becomes visible in practices, actions and performances in treatment of a condition such as diabetes. However disease also becomes 'knowable' when various understandings of diabetes meet with the procedures and local meanings of diagnosis, detection and treatment. My assumption is that diabetes can be usefully analyzed and understood in ways similar to that used by Mol (2002). This is also how I approached this study. This research incorporates the various aspects surrounding diabetes treatment and management and aims to address the following objectives:

• To investigate the experiences that arise out of the interfaces with various medical/healing knowledge systems by people living with diabetes.

- To explore how each of these medical/healing knowledge systems (plant medicines, biomedicine) view or 'enact' or 'perform' diabetes - i.e. through different ways of 'knowing' diabetes.
- To explore how diabetes is understood, managed and treated in different settings (clinic, Department of Health, the individual living with diabetes and his/her home).

More research needs to talk inside medicine and not only about it. Therefore Mol (2002), through her story seeks to challenge normative ideas of the medical tradition and speak *through* these intellectual dimensions by laying them open for further investigation to the broader scholarly community. The influences of Bruno Latour and Erving Goffman that Mol (2002) utilises in her ethnography are especially important for this paper. Their unique texts demonstrate a departure but also parallel perspective to the ideas in *The Body Multiple* from various literature settings (anthropology, philosophy, sociology for example) and different periods of time to contribute to understanding the enactment and practice of disease in a medicalised setting.

Overview of Chapters

The chapters following will provide a trajectory of the ethnographic journey in and around the various spaces of Genadendal tracking diabetes in networks of theory but more importantly, practice.

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In Chapter 2, I propose *Rethinking diabetes in practice* through a theoretical lens. I translate how the theoretical insight of Mol (2002) can be applied to understanding of diabetes and its knowledge and procedure within the context of Genadendal. I attempt to provide a path from an orthodox medical definition of diabetes towards a connection that pulls together the manner in which we converse about diabetes and the body. I also look to medicinal forms of diabetes, all individually notable, but more importantly relevant for this study.

A *Methodology* in Chapter 3 will describe and interrogate the process in which diabetes can be explored through both an ethnographic and material semiotic perspective. I focus on multisensory experiences whilst also detailing a multispecies approach in the relationship

between people and other living organisms (medicinal plants). I provided the foundation for which this methodological perspective can be possible toward an ontological turn for diabetes research within the South African context.

An ethnography of the clinic as presented in Chapter 4 details the manner in which a disease such as diabetes exists and is managed in a medical setting like the Genadendal clinic. It considers how various agents (persons living with diabetes, clinical staff etc), move within the space, documenting the changes through people living diabetes and its procedures: the processes of diabetes in a clinical setting, knowledgable people who engage with it, but also a consideration of the importance of disease in context.

Chapter 5 labelled as *Living with suiker (diabetes)* examines an understanding of diabetes through the individuals who treat and manage the disease within its progress through various stages from undiagnosed, to being a diabetic (as described within a clinic). I look into the process of diagnosis and the procedures of making diabetes visible and try to produce an ethnographic illustration of diabetes as it negotiates through material and non-material forms guided by diabetic, and at times non-diabetic, individuals.

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Medicinal plants: An ethnographic encounter in Chapter 6 attempts to provide a walking ethnographic demonstration of the spatial but also the ecological characteristics of Genadendal and moreover how these characteristics relate to the use of medicinal plant forms as a treatment for diabetes as a medical condition. By detailing the physical and sensorial, this chapter focuses on the role of medicinal plants as a treatment for diabetes but also a medicinal influence within the historical and perpetual confines of medicine in Genadendal.

Chapter 7 summarises the collective conclusions of each chapter and produces the over-all argument of this study.

Chapter 2- Rethinking diabetes in practice

Introduction

I became interested in Medical Anthropology as an undergraduate. Initially, my naïve understanding of medicine was informed by two major groups: biomedicine and the 'alternative' (i.e. traditional medicine). Gibson & Oosthuysen (2012) argue against this essentialist representation of medicine in Medical Anthropology courses and during my postgraduate studies I became interested in the discourses, practices of medicine and the plurality of medicinal knowledge systems.

During my MA coursework I was exposed to medicinal knowledge systems, their ontologies, epistemologies and practices, whilst focusing on multifaceted relationships that produce them. I became aware of the objects and subjects of medical inquiry and how they interface with knowledge about disease and illnesses such as diabetes. I decided to investigate diabetes as a medical condition and to interrogate the plurality of understandings and practices of diabetes and the use of medicinal plants among individuals in Genadendal. I was particularly interested in the day-to-day negotiation of treatment and management practices for diabetes. In this regard I was influenced by the work of Mol (2002, 2008), who foregrounds the importance of *practice* (Mol, 2002; 2008) as essential to understanding how e.g. diabetes is produced and exists in various spaces.

It is the 14th of May, an icy Wednesday morning at the Genadendal clinic. After having previously discussed my research topic and objectives, I walk in and follow Nurse D into the examination room. She allows me to sit in on her morning shift. She will be doing diabetes and hypertension testing. She prepares her desk. First, she reads through the medical history of Aunty M found in her folder. Nurse D sees that Aunty M was previously diagnosed with diabetes and hypertension (five years ago) at the Genadendal clinic.

Nurse D immediately begins to move around in the room as she prepares the instruments she will need and use: the A1C monitor (glycosylated haemoglobin test or

shortly called A1C), test strips, sterilized gauze, needles, gloves and blood pressure monitor. She will need instruments to assess the current state of Aunty M's diabetes and hypertension. Biomedically speaking, these are the diseases Aunty M has. She (Aunty M) enters the room and sits down.



Figure 2: Aunty M sitting in the examination room, while getting her blood pressure taken before her random blood glucose test

Aunty M says she is concerned that her persistent headaches and chest pain indicates her blood pressure, well as her blood sugar levels are too high. This is how, for instance, she experiences her diabetes in her body. Nurse D explains to Aunty M that the diabetes test is the only way in which she can confirm her "feeling diabetic", i.e. Aunty M's own assumption that both her blood sugar and blood sugar levels are too high, i.e. "not normal" or as described in clinical terms as abnormal - outside the norm as described in medical textbooks and the national primary health care guidelines (Department of Health, 2003). Nurse D then proceeds to administer the first test: checking the blood pressure of Aunty M. Nurse D asks Aunty M if she is regularly taking her hypertension medication (Atenolol) and she politely answers yes. Nurse D gets up from her chair and moves the digital blood pressure monitor (sphygmomanometer) closer toward Aunty M. She advises Aunty M to relax and take deep breaths, in aid of producing the most accurate results. After Aunty M appears relaxed and calm; she watches as Nurse D further proceeds with the procedure by removing the strap from the machine and wrapping it around the upper arm of Aunty M. She puts Aunty M's arm at 'heart level' on her desk, palm facing upward. The blood pressure monitor

beeps and reveals the results of Aunty M. Her blood pressure reads as being 120/81. Which, as displayed on the blood pressure chart in the examination room, is an 'abnormal' reading i.e. Aunty M's blood pressure is as indicated 'high- normal'. Nurse D tells Aunty M that her own symptoms and assumptions correctly correlate to these numbers. Following the blood pressure test Nurse D is ready to do the diabetes test and draws a sample of blood by using the "finger prick" method (a small device with a lancet in it to pierce the finger... (Fieldnotes, May 2014)

During the procedure, Aunty M explains to me that her own experience of the diabetic rise in blood sugar levels - which she suffers as increased headaches and chest pain (but also in other ways which I will return to later) - becomes medically "real" (in that particular moment) through the blood sugar test done with certain instruments that provide results for her blood glucose count levels. She looks directly at me and stresses the importance of having *die masjien* (the machine, which for her comprises a hand-held measuring device) and most importantly *die strokies* (the strips) at home as an alternative to visiting the clinic for testing. Nonetheless, Aunty M largely relies on the clinic for this procedure. She anticipates the moment when the needle will prick her finger, even though she is looking at me. Her expression indicates her concern for the results as Nurse D squeezes blood from her finger onto the test strip. During the short waiting period for the A1C monitor to produce the results of the level of blood glucose in Aunty M's body, she grins, looks in my direction and confidently says that she can predict the outcome. She "feels" and "knows" her blood glucose is high.

I begin to understand how Aunty M considers the manner in which her body reacts and feels (headaches, pain) as an effect of diabetic symptoms as these exacerbate the manner in which she experiences diabetes: not only as a medical condition in theory but through practices in which her body partakes (diabetes testing) within the medical setting. (Fieldnotes, May, 2014)

As seen from the above, and in line with the material semiotic approach proposed by Mol (2002), diabetes can be understood as meaning different things for different people, depending on how it is being 'done'. For example, for Nurse D, the medical practitioner, it involves blood glucose measurements, monitoring of the disease through science and

technology and nutrition or adhering to a particular kind of diet. However for Aunty M, who lives with diabetes, it is symptomatic but may also present as depression, anxiety and a challenge to balance her lifestyle i.e. her dietary practices and insulin therapy adherence. Thus diabetes can potentially be analysed as "multiple". Similarly, the bodies (people living with diabetes, medical staff involved), can also be understood as "multiple" (Mol, 150:2002). Each of these bodies in the Genadendal clinic for example, perform a different diabetes. For Nurse D, diabetes is a metabolic condition that requires her medical expertise in detecting and reporting the results of the A1C monitor. For Aunty M, who lives with diabetes, it is the physiological experience of diabetic symptoms (among other experiences) and actively seeking medical clinical assistance. These, I argue, can be related to diabetes management and treatment.

Diabetes moves through a multiplicity of realities in relation to various procedures and the people who experience and attempt to understand it, e.g. doctors, individuals/clients, and even scholars like an MA graduate student. Scientific and medical processes to detect diabetes, usually begin with screening and diagnosis in the clinic. Although these activities (screening and diagnosis) are different from self-diagnosis, the positions of its actors and procedures often intersect. For example, in the clinic, diabetes is detected through doing tests, reading and understanding the results of the A1C. However, detection may also be done by identifying symptoms presented by an individual, like Aunty M.

The clinical experience of Aunty M provides an example to detail and explore a theoretical 'coming-together' of several theoretical perspectives and observations that focus on the manner in which diabetes is discussed, practised, understood, managed and treated. In this regard Mol's (2002) work greatly informs this thesis. The author argues that as actors we affect not only the ways in which we and others perceive reality, but we impact on reality, we enact it through practice. Furthermore, since relationships between objects (like diabetes) are 'done' (and not necessarily given) in different ways in a variety of places and by different actors, disease or a sick body is not singular, but rather is "multiple". Ontology, or reality, according to Mol (2002:26)

is not given in the order of things but ... instead, ontologies are brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices.

Mol (2002) argues that, through careful empirical ethnographic work, the distinctions made between subject/object, natural and social worlds, disease and illness can be shown as limiting. This material semiotic approach, as discussed by Latour and Woolgar (1979) Law (2002), Mol (2002), Barad (2003) and Gardner *et al* (2011), suggests a kind of ontological gap between our perspective of reality and of reality itself in theory, but more importantly, method. While the many perspectives may vary or shift, reality apparently stays the same. However, it becomes evident that these differences in definitions and understandings, although limiting, cannot be eluded in the process of making connections between discourses and practices of diabetes.

Firstly, diabetes as a biomedical "entity" is discussed and scrutinised through various scholarly lenses to highlight its definitions, understandings and practicalities for this study. Secondly, I attempted to discuss how diabetes is framed and ontologically situated within various locations and practices. Lastly, I will consider the process of creating diabetes knowledge through individuals like Aunty M and the *multiplicity* (Mol, 2002) of diabetes practices whilst making "partial connections" (Strathern, 2004) between material and non-material elements to re-frame diabetes discourses in practice.

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From definition to diagnosis: Constructing diabetes knowledge

Defining diabetes: The body in theory and practice

Diabetes mellitus - in the clinical setting and by scientific/medical definition - is an organic condition caused by the under-production (or nonproduction) of insulin by the body (specifically the pancreas). For most people living with diabetes, and medical practitioners for example, as a disease diabetes mellitus or simply diabetes is understood as a physiological condition. It is broadly speaking a condition that arises when a person's body does not produce or properly use insulin. The latter, in turn, is a hormone the body produces to transform sugar, starches and such into energy.

The physical symptoms of diabetes involve a combination of frequent urination, unusual thirst, hunger, weight gain or loss, fatigue, irritability, blurred vision, poor healing of cuts and

bruises: these are how diabetes is initially 'enacted' by the body of the sick person, like Aunty M, before diagnosis and treatment begins. Diabetes as an embodied experience, a disease entity, and medical diagnosis is mostly presented in the clinics, hospitals and community health care centres where most individuals/clients go for treatment (Steyn *et al.*, 2008).

There are two main types of diabetes. Firstly, there is Type 1, or insulin dependent diabetes. This condition is mainly caused by a progressive autoimmune response, in which the beta cells that produce insulin are slowly destroyed by the body's own immune system (Murray& Lyon, 2003). Both a genetic predisposition and environmental factors, such as a viral infection, are aetiological explanations for the disease. Having Type 1 diabetes, and being insulin dependent, can put the individual at risk for hypoglycemia. This is when insufficient blood glucose reaches the brain and body and may lead to loss of consciousness (Murray& Lyon, 2003). Over time, Type 1 diabetes can lead to damage of the retinas and cause blindness. Sufferers may also develop kidney problems and severe nerve damage.

There are a range of symptoms and procedures that inform a health care practitioner like Nurse D and alert her to the possibility that a client or patient (as people are called in the clinic) may be diabetic. Aunty Natalie, who works in the Moravian church office, is a diagnosed Type 1 diabetic. Although she does not use the Genadendal clinic for regular monitoring she nevertheless describes her experience of diagnosis:

Aunty N: My father passed away from type 1 diabetes. They (medical staff at Caledon district hospital) told us that he had type 1 diabetes. His condition just got worse and worse over time. In his last days, he was in hospital...

HP: Why did he end up in hospital, if you don't mind me asking?

Aunty N: I can't remember exactly what they said but something like the sugar in his blood crystalized and was clotting. The doctor told me and my brother that it is genetic and we should get tested too. I immediately got so scared; me and brother decided we will get tested too, while we were in and out of hospital anyway visiting my father.

HP: How did you find out about your diabetes? What procedure did you have to go through in the beginning to know if you are possibly a diabetic too?

Aunty N: I did what they called a fasting test (Transcribed interview, December, 2013)

The most common tool doctors and nurse practitioners use to diagnose diabetes Type 1 is the blood glucose test. In the Genadendal clinic and in Caledon hospital, as experienced by Aunty M, this diabetes test is administered after a person has fasted overnight for more than eight hours. After the fasting procedure a blood smear sample is drawn from the individual by pricking the finger. Sometimes venous blood samples are taken as well, to test for autoantibodies that commonly appear in type 1 diabetes. From the fasting sample, the concentration of sugar in the plasma of the blood is then analyzed by specialized medical staff in the laboratory at Caledon hospital to determine the presence of diabetes. Other than the fasting blood sugar test (above), an oral glucose tolerance test can also be done, but only in Caledon at the district hospital.

The second is Type 2 diabetes. This particular form of diabetes is caused by a deficiency of insulin resistance. Variables that may contribute to Type 2 diabetes include obesity (biomedically described as a body mass index of 30 and above) and poor nutrition. These variables indicate the multiplicity (Mol, 2002; Rock, 2005) of diabetes through stimuli and experiences that affect the body. A biomedical description of Type 2 diabetes emphasizes this particular category as elevated insulin levels within the plasma of the blood. However this is combated by insulin receptors that lose their receptivity in permitting the flow of glucose and insulin into cells (Murray& Lyon, 2003). People with Type 2 diabetes generally die five to ten years earlier than those without the disease. The most common long-term effect of type 2 diabetes is damage to blood vessels, resulting in a high prevalence of cardiovascular disease, stroke or heart attack. There are various medical technologies (A1C monitor, needles, gauze etc.) used in detecting the presence of diabetes.

Nurse D demonstrates the various instruments used to test for diabetes. She switches on the A1C monitor, inserts the test strip of Aunty M into the designated slot. Once inserted the test strip is read by the monitor and the results display a blood glucose level of 7.2 mmol/l. Aunty M's assumptions are confirmed according to baseline medical/clinical standards, Aunty M's blood glucose level, or *suiker* (sugar) as many of Genadendal people refer to it, is above the 'normal' range of 4-7mmol/l....(Fieldnotes, May, 2014)

Aunty M had been diagnosed (Type 2 diabetes) earlier; a random blood glucose test is administered by Nurse D. The particular test does not require previous fasting by Aunty M. This procedure is often performed when symptoms of diabetes are persistent and chronic. This test is less expensive; it is convenient and easy to administer for Genadendal nursing staff. According to Mol & Law (2004) diabetes is a physiological medical condition; it is understood as existing underneath the skin, within the blood vessels. Symptoms represent visible cues and makes diagnosis possible. Diabetes is also situated or located in various practices and materials (Mol & Law 2004). For example the diabetes test involves a process: blood is drawn from the body by piercing the fingertip with a sterilised needle. These physical procedures done 'to the body' and 'by the body' through diagnosis and testing (both medical staff and person living with diabetes); is not the sum of the diabetes experience. The manner in which diabetes is discussed and analysed is also a practice of knowing (Mol, 2002) this medical condition.

Intersections of diabetes "talk" in objects of disease and the body

Latour (2004:205) argues against the representations of the body in academic discourse - about what the body is, rather than what it does - toward a more "effectuated" understanding rather than *affected* manner of experiencing medical conditions. The body is *effectuated* by other entities - both human and non-human - because it *learns* how to be affected by surrounding stimuli. It is not enough to simply have a body; the body also engages in the realm of world. The way people living with diabetes like Aunty M speaks about her body or what Latour (2004) labels "body talk" (pg.214), reflects this engagement between the body living with diabetes and external stimuli.

Anthropologists who work in the field of health, healing and medicine are often expected to interrogate the 'subjective' experiences, understandings and meaning-making of e.g. people living with diabetes. This kind of research supposedly complements that of medicine and the medical sciences, which in turn focus on the 'objective' aspects and qualities of sick bodies. By doing this, Latour (2004) argues, social scientists engage in 'body-talk' that reproduces deep-seated dichotomies between subject/object, mind/body, perception/reality and such (Latour, 2004).

My approach, in accordance with Mol (2002: 33), will be that people, whether health care providers or the sick, 'do disease', or 'enact' it. However, from the above it is also clear that diabetes as a disease is also essentially an idea, a concept. In this regard it is important for this study to e.g. understand how diabetes is diagnosed, understood and 'done' by health care staff, people living with diabetes and people knowledgeable about medicinal treatment behaviours in practice. Law (2000) plays a contributory role in the argument of this thesis, which is the importance of highlighting the role of the object of disease (diabetes) in medicine as variable, spontaneous and complex, in various situations.

The object of diabetes: Technologies of disease

As in reality; to which Law (2000) argues, matter in itself is inconsistent. Similarly when looking at diabetes, it is incapable of remaining holistic and fixed in understanding this medical condition. Law (2000) also suggests that the identities these objects possess (different versions of diabetes for example) are fragile and varied. These multiple identities can be demonstrated through the manner in which objects are 'enacted' 'done' or simply 'practised' and the various ways they are identified by different staff, people living with diabetes, and scholars, as in Mol (2002) and her example of hospital Z.

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This attempt to understand objects in this setting (a clinic or hospital) has less to do with its construction and instead leans toward how they come into being through practice. In line with Latour (1993) Mol (2002) also wishes to escape the subject/object dichotomy in practice. However unlike Latour (1993), Mol (2002) wishes to foreground practice. Through this perspective, objects are given a more complex insight and in my study they also demonstrate how a disease such as diabetes - through various actors, instruments and information - becomes a reality. For example: diabetes testing, i.e. processing and diagnosing the presence of glucose within the plasma of the blood through a monitor, is not passive in providing results. Instead it intervenes in the relationships between people living with diabetes, such as Aunty M, and materiality, such as instruments of diagnosis (the 'finger prick'). The material things used for medical conditions in the Genadendal clinic, where the instruments 'determine' the presence of disease (and for the diabetic her illness) play a significant role in understanding a condition such as diabetes. For these individuals (diabetic persons in

Genadendal) these objects, for example the medical technologies used, are significant in bringing diabetes to reality and represent the living body as it experiences diabetes.

Although the living body is considered both an object and subject for medical knowledge and in practice, it embodies discourses of self- awareness and tensions that exist within the body (Mol & Law, 2004). Therefore, a shift in the understanding of disease should transcend the pathological gaze toward understanding the body we 'are', but simultaneously the body we 'do'. Foregrounding practice as it is emphasized in my study, is essential to make sense of the connections, interfaces, processes and knowledges that produce and enact diabetes in and through various bodies. The approach of this study is not simply the *doing* of anthropology in itself but instead a philosophical turn toward locating knowledge in practice.

Making connections: The sense-making of diabetes medicine

Knowing is a practice: it only becomes possible to talk about 'a blood sugar level below 3.5 mmol/l' if someone's skin is pricked, a blood sample is taken, and its sugar level is measured (Mol & Law, 2004:46)

The practice of knowing, although vital in comprehending physiological descriptions of the medical condition, diabetes, is similarly reflected in the networks of people living with diabetes, healing knowledge production and materiality of the social world in which these actors connect. The relationship between people living with diabetes and the materiality of this medical condition is also productive. It produces knowledge that is transferable in the form of advice and stories of diagnosing diabetes and medicinal knowledge that is shared among people. Aunty Susan, a Home Based Care nurse mentioned in an interview:

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Genal is a klein plekkie, almal ken almal, soos hulle almal se besigheid ken (she laughs)....dit is diselfde vir raad van die medisyne wat mense mekaar gee. Ek se altyd vir my pasiente as ek iets uitvind van die kruie of as hulle iets weet, sal hulle vir my sê (Genadendal is a small place, everyone knows each other, like they know each other's business(she laughs) it is the same for advice about herbs/ medicinal plants that

people provide one another with.. I always tell my patients if I discover something and if they know, they tell me). (Transcribed interview, December, 2013)

This transference of knowledge demonstrates the various paths that are formed by the people in terms of movement, actions and materials, and create spaces for the sustenance of life. Anthropology has made valuable contributions in exposing the complexities of medicine and the body beyond its physiological and scientific presentations; however what Cohen (2013), for instance, also deems important are relationships between the 'objective' nonhuman world and the 'subjective' human worlds as they coexist and together help each other transform. This can be seen within medical practice and diabetes. The practices and skills acquired by individuals through their interactions with i.e. clinical staff have assisted their own transformation and through each action, bring diabetes into being every-day. This becomes apparent in this study as I try to re-think conventional discourses of illness and disease.

Instead of reinforcing these dichotomies (objective/subjective, nature/culture) when investigating diabetes, for example, one should rather consider how these aspects interface with one another. Therefore when attempting to understand diabetes, describing how individuals 'do' life in this world and create themselves as nurturers and cultivators of their own bodies and environments is vital. For example: while walking in the streets of Genadendal one sees the variety of herbs and medicinal plants growing in various gardens. I learnt to identify the homes of individuals who use the *kruie* in treating their diabetes or other medical conditions.

It is a Wednesday afternoon and I find Aunty M outside again, picking the leaves off of her guava tree. She laughs as I approach her home and says: *Daai ander flessie* (jar) *is klaar ek gaan gou nog maak* (the other jar is finished, I'm going to make some more). (Fieldnotes, May, 2014)

In the information above, I have demonstrated that diabetes goes through a multitude of processes and is understood differently by various actors, environments and through multiple discourses of disease in practice. However this is not to assume the knowledges gained in practice present a holistic representation and interpretation of diabetes. Disease as an idea or concept has long been an object of study (Mol, 2002) and as such has been the focus of the production of knowledge, especially in biomedicine. Medical practitioners and their

knowledge are often represented as homogenous and hegemonic (Gibson & Oosthuysen, 2012). However while doing so, we (anthropologists, scientists, medical practitioners) fail to unpack the shared knowledge or partial connections of technologies and the various enactments of medical practice, for example, in relation to diabetes.

Strathern (2004) views the world (and knowledges) as 'fractal' and argues that that we can always make connections (between knowledges), however partial they may be. Strathern's (2004) emphasis on 'Partial Connections' describes a shift in anthropology toward a post-plural metaphysic where distinctions between 'opposing' aspects (of knowledges) - in this case biomedical/allopathic and 'traditional' knowledges - are not necessarily dichotomous but can be understood as partially folded into each other.

The idea of 'partial connections' as discussed by Strathern (2004) within the domain of knowledge production and in understanding various social phenomena - in this case diabetes - reveals a blurring of boundaries between subjects and objects. As with Actor Network Theory (ANT) as discussed by Callon (2007) Law (1999; 2006) and Latour (1999) making connections creates symmetry between dualisms: human/nonhuman, and material and nonmaterial realities. In my study this approach is used to highlight how meaningful connections are exposed and made visible in a social phenomenon like diabetes. (These connections will be visible and discussed in more detail in the chapters following).

I draw on Strathern (2004) to demonstrate the complexity of knowing the world while stressing opportunities for knowledge dialogues or connections for anthropology and the people we observe, practice with and understand through diabetes. In the South African setting, Ragaller (2012) for example demonstrates how different knowledge systems provide particular ways of thinking about phenomena. In Genadendal explicit distinctions between biomedical treatments such as insulin therapy and medicinal plants are not always emphasised. In moments where insulin fails to alleviate symptoms of pain, medicinal plants may assist. However, the people like Aunty S and Nurse D work together in providing symptomatic relief. In this thesis knowledge concerning the utilisation and combined use of medicinal plants and allopathic medicine reveals how seemly opposing medicinal healing systems often collapse and become partially connected or intertwined.

'Alternative' knowledge interfaces for diabetes

There has been a large number of studies on diabetes in relation to issues such as lay discourses and understandings of this condition, its self-management and even the influence of genetic disposition (Montoya, 2007; Schoenberg *et al.*, 2005; Rock 2003, 2005, 2008; Ferzacca, 2000, 2012; Mendenhall *et al.*, 2010; Lieberman, 2004; Helman, 2001; Liburd, 2003; Coovadia *et al.*, 2009). There have also been ethnobotanical and scientific studies on medicinal plants used for metabolic diseases, including diabetes, hypertension and high cholesterol (Erasto *et al.*, 2005; Thring and Weitz, 2006; Oyedemi *et al.*, 2009; Afolayan & Sunmonu, 2010; Semenya *et al.*, 2012).

Practices of nurturing and cultivating 'indigenous' knowledge act as responses to a broader debate in South Africa in terms of promoting indigenous knowledge systems (IKS). Green (2012) highlights the neglect by the state of indigenous knowledge systems, in favour of economic exploitation and intellectual heritage. In Genadendal people living with diabetes and other medical conditions (as diagnosed within the clinic: hypertension, cholesterol, tuberculosis etc.) are active in cultivating their own knowledge when treating their diabetic symptoms. *Oumens medisyne* (old people's medicine) in the form of household remedies, where the utilization of medicinal plants in practices of healing are invaluable. However, to these individuals it also means exercising treatment knowledge transferred within a network of family, friends and other community members.

Diabetes has no cure. There is, therefore, growing interest in 'alternative' knowledge systems and medicinal plants in the 20th century (Farquhar, 2012). Indigenous knowledge systems have been variously labeled 'traditional', 'complementary' and/or 'alternative' forms of medicine practices and knowledge, and are often characterized as "wild cards in the politics of health" (Farquhar, 2012:153) Complementary, alternative or traditional medical healing and /or knowledge systems are frequently represented as competing with what is considered as the 'true' or legitimized knowledge of science/biomedicine.

In African countries local systems of healing are often seen as alternative forms of medicine. In South Africa, such knowledge is increasingly being perceived as part of the health care services that are available to South African citizens. Similarly in my experiences of

Genadendal, these knowledge systems are also inclusive of biomedical and scientific interventions and of healthcare practices for diabetes. However, it is more important to consider how these knowledges contribute to the "doing" but also "knowing" (Mol & Law, 2004) of disease as it moves through spaces, people and objects in medicine. (The use of medicinal plants as a treatment regimen for diabetes will be further detailed and discussed in Chapter 6.)

Individuals in Genadendal are active in their responses to how government intervenes in their diabetes. Persons living with diabetes purposefully and creatively react to the environment, and strive towards well-being, maintaining their spirits and finding strength through practice. These attempts become part of the rhythm of everyday life. Nevertheless, given these different ways of understanding and experiencing diabetes, the argument I put forward seeks to highlight that diabetes is still 'done' differently, and not only through biomedical diagnosis, despite these dominant procedures within health care. This is especially the case in the South African context, where an understanding of healing has shifted from a 'holistic' perspective of diabetes, to an inclusive network of interrelated knowledge systems, which each provide an understanding of the realities of a seemingly single medical condition.

Conclusion

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The 'multiplicity' (Mol, 2002) of diabetes in this study attempts to re-frame a reductionist perspective to viewing diabetes knowledge in its definitions, management and healing practices. Knowing as a practice, intervenes in diagnosis and treatment but more importantly the experience and 'in-between' moments in which a person living with diabetes comes to understand his/her medical condition. Investigating diabetes in the context of healing through traditional medicine and/or allopathic treatment has to be considered through the knowledge encounters of various actors: clinical and other medical staff, diabetic people living with diabetes, self-proclaimed bush doctors (*bossiesdokters*) and people in Genadendal (which will be detailed in chapter 6). Consequently the movement in viewing diabetes in this manner provides an interesting trajectory not only in South African clinical and herbal management practices for diabetes but also the various knowledge systems (scientific, anthropological, 'traditional' etc.) that intersect and (more importantly) enact diabetes.

Chapter 3-Methodology

Introduction

In 2014 I participated in a survey on the use of medicinal plants for diabetes, hypertension, cancer and the common cold in four towns in the Matzikama area, Western Cape. I also participated in a retrospective treatment outcome (RTO) study on chronic coughing and its treatment and management techniques in Genadendal. During this time I became aware that many people, who had been diagnosed with diabetes, also used medicinal plants – both in the Matzikama area and in Genadendal. I decided to do my own research in the latter site. In 2014 I also joined in a training workshop on ethnobotanical studies and retrospective treatment outcome studies, held at the University of the Western Cape. Then I presented a paper at a Phytomedicine symposium in George. I was not only hooked on plants, I wanted to know about the interfaces between medicine and local knowledge practices, disease and illness, the interconnections between medical specialists and local sufferers, between ways of knowing and doing diabetes.

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This research seeks to contribute to the production and exploration of medical/healing knowledge systems (biomedical and medical plants) within Medical Anthropology in Southern Africa with a focus on medicinal plants and their practices in Genadendal. I hope to provide a contemporary insight into diabetes as a fast growing epidemic within South Africa, its management and treatment, and its position in the broader field of social science inquiry. The information produced by this study does not seek to revolutionize or transform various perspectives of diabetes but rather to critically engage in the interfaces and realities diabetes progresses through, in order to be understood, enacted and 'seen' (or made visible) in various spaces of Genadendal.

Genadendal: First encounters

The fieldwork for my study consisted of prolonged field research visits between September 2013 and August 2014. In September 2013 I visited Genadendal to evaluate the feasibility of a study of diabetes and medicinal plant practices within this area. The town is approximately

a 90 minute drive from Cape Town. I had not conducted a research study which incorporated both an ethnographic but simultaneously material semiotic perspective before. I felt overwhelmed by the expectations that could arise within this study and from the people who live in the small town. According to the Theewaterskloof Municipality Overview Report, 2012/2013 there are 8 443 residents.

I drove with my fellow student and friend, who has previous experience in ethnobotanical research. He enthused about his enjoyment of working with medicinal plants, people and their plant practices and discussions surrounding holistic healing from various perspectives - including medical anthropology, ethnobotany, 'science' and epidemiology. His stories described healing within the context of his previous study sites, the Eastern Cape and Strand. I slowly began to recognise the importance of interacting with local ecological knowledge and relationships that arises through experiences, narratives of well-being and the actors (healers, herbalists, scholars) in this investigation.

The route to Genadendal featured plush green scenery against grey rocky hills which eventually faded into fields of green with yellow flowers and touches of purple. Every road leading to Genadendal seemed to create a feeling of familiarity as I anticipated upcoming places: From the Houhoek Farmstall to Dassiesfontien and eventually signage which indicated straight ahead for Caledon and right for Genadendal... (Fieldnotes, November, 2013)

When we entered the town, the environment seemed to present a harmonious flow of flora and fauna in the local farm areas that lead to Genadendal. This historical town is the oldest mission station in South Africa. It is surrounded by a semi-rural farming community, and falls under the auspices of the Theewaterskloof Municipality. It is a predominantly Afrikaans speaking town. Genadendal presents as an old-fashioned and somewhat frozen in time in terms of its architecture, social and structural arrangements.

After settling into my room at the Hester Dorethea Conference Centre and walking in the area, I began to notice the landscape. My own presence was curiously monitored by *Genalers* as I walked within various spaces - the information centre, the museums in the Mission Square and local supermarkets located along Strydom Laan. I introduced myself to various people. On my subsequent visits I became better acquainted with the people, the

environmental specifics and the "rhythm" of life in the town. This in turn also resonated with me as a *home* that I had created for myself. According to my fieldnotes:

When I arrived here late Monday afternoon I was first taken by the after- effects of a winters day rain that has passed the previous evening. The floors were wet, the trees smelt of soaked pine and water puddles were almost everywhere. The area, in which I was staying, was particularly busy nevertheless. My previous visit to Genadendal was rather quiet, relaxed and very few people were in the dormitories and flats. This visit started with the hustle of noise as the staff of this centre was cleaning and rearranging furniture. I booked into the same dormitory as on my previous visit. The room has enough light and space for me to do my work. Although the bedroom was a bland space I slowly started to make it home. Once settled in, I decided to head out for a little while and greet some of the favourite people I got to know on my previous visit. Walking toward the information centre I noticed that this area of Genadendal was particularly busy too. There were cars parked that I haven't seen before and residents were walking in all directions and it seemed more lively than usual. At the information centre, which is also a little café, I see aunty Magda standing behind the counter. Her smile reminded me about the friendly nature of people in Genadendal and in essence that I am home again. (Field notes, June 2014)

The aesthetic of the environment and of *walking* is a local practice, but more importantly, a manner in which people in Genadendal connect and re-connect every day. I decided to take a walk around the town and re-connect with people I had met on my previous visit. I also met new staff such as medical nursing staff at the clinic. The clinic (the only medical service centre in Genadendal) plays a substantial role in this research in documenting how diabetes patients and other chronic sufferers receive treatment and medical attention when ill. Although the clinic is a small space, the staff are enthusiastic and accommodating toward patients and are Genadendal residents themselves. In other spaces such as the Victoria Centre for the Aged, staff and carers updated me on changes that had occurred whilst I was away: for example, the appointment of a new personal assistant, Varushka, schedule changes and suitable times for visiting the women and men in 'the home' as many referred to it.

In moving in between these various spaces and conversations among people in their respective environments (homes, clinic, library, and centre for the aged) I began to appreciate

the complexity of diabetes in this context. I visited the local library, but found little information on diabetes education. This was also the case in the clinic. It became clear that there was a general lack of public information about having *suiker*, (sugar) as diabetes was referred to.

Nonetheless, *suiker* was considered to be "a big problem among the old people" (Nurse I). The clinic was a central space for people living with diabetes to discuss their medical condition which included a focus on diabetes type 2. Conversation surrounding diagnosis and treatment are shared illness narratives of diabetes that I found particularly interesting. Ultimately, these preliminary finds contributed to this study as I became more intimately engaged in the knowledge of people living with diabetes and their strategies to treat and manage diabetes in Genadendal.

People living with type 2 diabetes: Selecting the ⁴participants/ respondents

The study participants or respondents were males and females who were between 40 and 70 years of age. All of them had been diagnosed with Type 2 diabetes. I specifically included people who used plant/herbal medicines in their treatment and daily management practices. Key participants/informants included clinic staff, herbalists (*bossiesdokters*), and care providers who assisted in treatment and management. I worked alongside the Home Based Care Unit doing their daily visits every morning. This put me in contact with more people and made others aware of my research, including access to the clinic.

Estimates of diagnosed diabetes individuals who attend Genadendal clinic, are about 60 persons who regularly seek treatment. Although I initially aimed to include an equal number of males to females, in the end more female sufferers were willing to participate. The information of 30 females and 7 males (diagnosed with diabetes type 2) who became my study respondents/ participants, formed the basis for this research study.

I found my participants through a simple snowball method (Noy, 2008). I began by talking to the local shopkeeper (Aunty BT) and with Aunty Wilma. I had met both on my first day in

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⁴ I decided to use the term respondents or participants rather than the more common term 'informant' because the latter has many negative connotations related to South Africa's apartheid history.

Genadendal. They advised me to introduce myself and my research objectives to people at the Home Based Care Unit, the clinic, the Victoria Centre for the Aged and the Library, and then to talk to individual people living in Genadendal. The medical staff (nurses) and women at the clinic introduced me to potential participants in-between examinations. Genadendal is a fairly small community, and soon, when people saw me they would greet me and ask "are you the girl doing the diabetes project?"

'Snowballing' is when the initial participants provide contact details for other participants (Heckathorn, 2011). For example; a *Rasta* referred me to a diabetes sufferer who bought herbal remedies from him. According to Noy (2008) snowball sampling assists the researcher in the initial stages of the research process. However repetitive this process has become, it still allows exposure to participants who may become vital to the research. I also wanted to spend time at the Genadendal clinic where most people living with diabetes seek medical attention and collect their medication. In this regard the nursing staff were very helpful and provided me with valuable information about the clinic as an institution.

I soon came to know the scheduled days for medical specialists, and realised that the most common medically diagnosed conditions included diabetes, hypertension and high cholesterol. More importantly, I was able to gain insight into diabetes patient care and treatment within the clinical setting. I observed the spaces in and around the clinic such as examination rooms, waiting areas and reception where I had my initial interaction with patients. For example, the most important information (treatment procedures, instruments and advisory steps to maintaining a 'normal' blood glucose level) on diabetes was in the consultation rooms and took place in English.

"Doing" the diabetes Ethnography

My focus is on how diabetes is enacted through practices, e.g. of people living with diabetes, of health care providers and/or of diagnostic tests and procedures, through herbal management – all of which have effects. Mol (2002) calls this ethnographic "praxiology" (2002: 4-5) and argues: If the practices are foregrounded, there is no longer a single passive object (i.e. diabetes) in the middle, waiting to be seen from the point of view of seemingly

endless series of perspectives. Instead, objects (e.g. diabetes) come into being—and may disappear—through the practices in which they are manipulated, such as the diabetes test that I discuss in following chapters. Nonetheless there are relations between these practices. Such an ethnography of practices locates knowledge mainly in activities, events, treatments, instruments and procedures. Therefore diabetes is both object and subject, situated in the 'doing' or practicing of disease. It always also has local meanings (Mol, 2002).

By doing an ethnography I gained insight into and could detail the experiences and subsequent realities of a person living with diabetes. The definitions and understanding of diabetes from individuals/clients, herbalists, medical practitioners, epidemiologists and other key players differ in their aetiologies. Each person with this condition also medically presents diabetes somewhat differently. This insight was raised initially by Kleinman (1999), who argued that ethnography, especially in medicine and health, is an exploratory strategy to educate academics about the illness and its role as a human experience. In this study I learnt about diabetes as it moves within the body but also demonstrates the narratives of people living with diabetes in Genadendal. Their stories captured diabetes as an illness and disease that influences and is influenced by the knowledge domains within their environment and that contribute to their livelihood.

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As part of my investigation I utilised a mix of qualitative methodological tools for this study. In this regard Greene (2008) argues that such a design provides a multiplicity of dialogues of inquiry and understanding of the social phenomena being investigated. Using multiple qualitative method approaches display various facets of a single phenomenon, such as diabetes. This approach is demonstrated in the coming together of various perspectives. For the purpose of this study, a multiple method approach rigorously explored the experiences and local understandings of diabetes among the individuals but also in accordance with the aims and objectives of the research.

I triangulated between a number of methodological tools such as semi-structured and in-depth interviews, observation (and participation as much as possible) and material semiotics i.e. scrutinising texts (from the library, clinic) and materials utilised. Semi-structured interviews, while not as intense as in-depth interviews, enabled me to collect a diversity of information through its 'open-ended' nature (DiCicco-Bloom & Crabtree, 2006). Semi-structured interviews in the form of conversations with patients and medical staff explored their various

understandings and the manner in which they influence activities and practices of diabetes i.e. its treatment and management. Subsequently it was in-depth interviews that opened up a detailed and more particular dialogue with patients. I listened and immersed myself in their life histories as community members but more importantly individuals living with diabetes.

Observation gives a rich definition to the manner in which the individuals we as researchers study live everyday lives (Jones & Somekh, 2011). There usually exist patterns of behaviour which can be observed but also experienced by the researcher. Therefore, observation is also defined broadly as ways of seeing the world. My observations and ways of seeing diabetes entailed gaining a deeper understanding to the physical but also emotional and social processes of living with and 'doing' such as prevalent metabolic condition (i.e. diabetes).

According to Jones & Somekh (2011) the range of human emotions, experiences and other details of the everyday are complex, and therefore it becomes impossible to give a full demonstration of the population being investigated, despite reaching saturation. However I strived to reach for accuracy of the data through methods that enhance interaction between myself and participants. The type of observation used in this study is a combination of participant observation and simply an observation from the 'outside'. Participant observation is unique because as the researcher I, to an extent, became immersed in the environment and its people. Daily activities and behaviour were absorbed and practised to gain an in-depth understanding of my 'research population' (Savage, 2000; Dewalt & Dewalt, 2002; Jones & Somekh, 2011) as reflected in my fieldnotes below.

My presence has quickly become appealing and interesting to the people here. However, I find myself stuck between doing my research and building a meaningful relationship with Uncle S as I always feel so sorry for him and the way he lives. I give him some money for something to eat even though I have a feeling it may have changed our relationship dynamic in an instant. (Fieldnotes, November, 2013)

Although I ran a risk of becoming too immersed in the lives of the people who participated in the study, it had advantages as well as disadvantages for me in relation to reporting and representation (Jones & Somekh, 2011). Observation on the other hand, assisted me at times when access to time and patients knowledge were not explicit. It also helped me to identify

which specific events required a more detailed measure of attention in answering my research question (Jones & Somekh, 2011).

In gaining an understanding of how people in Genadendal made sense of what diabetes is, how exactly it was affecting their bodies and how it was discussed among other considerably vulnerable groups in places like clinics, households and social spaces, I made use of focus group discussions. A total of four focus groups were held in the clinic waiting area, Victoria Centre for the aged, and at the home of Aunty S. My initial discussion concerned their definitions of diabetes, experiences of their bodies and other questions related to its management and treatment. These discussions progressed from aspects like physiology and definition toward treatment procedures and management techniques which include allopathic medicine, alternative remedies and the use of medicinal plants.

In this study, I accordingly explored diabetes from various perspectives including the manner in which it is treated. I spent time in observing its management – in the clinic, through the interaction with the Home Based Care Unit, and in the home. I followed the treatments (e.g. insulin therapy, herbal management through plant medicines), discussed and observed these as part of the daily life of an individual's living with diabetes, e.g. the clinical setting where the initial diagnosis was made and where medication was dispensed.

I try to capture the sensorial experience of both observing and participating in patient visits with the Home Based Care Unit, assisting at reception in the clinic, singing hymns at Victoria Centre for the Aged and walking with participants during their daily activities as examples of how both intensive and enriching my presence (body and mind) became to conducting the respective study. In understanding the materiality of diabetes, I try to present a kind of multispecies ethnographic detail (Kirksey & Helmreich, 2010; Rose *et al*, 2012; Smart, 2014) to understanding the relationship between people living with diabetes and medicinal plants as herbal therapy for treating this medical condition. In recognising the complexity in relationships between people living with diabetes and their use of herbal treatments, this approach proves fruitful in evoking local knowledge in Genadendal. However a level of intense mental awareness and consideration was required to understand how this medical condition is understood locally.

I also had to be alert to the use of texts (notices, patient cards, measurements, patient case studies, information posters etc.) and materials (plants, medicines, diagnostics tools etc.) because material semiotics challenges the classic subjective/objective divide in practice. Indeed Mol (2002) argues that there is a mixture of both subject and objects in practice (Mol 2002). As indicated above, in my own study, this approach made it necessary for me to also focus on objects (needles, monitors, folders) in medical settings, treatment and management as part of the practices of diabetes management. I developed an awareness for objects in practice and how they were maintained, engaged and utilized. A material semiotic approach in ethnography (as both a method and tool of analysis) was especially useful to help me understand the process of diagnosis, detection and management of diabetes in Genadendal.

My analysis of interviews and field notes were done concurrently with the research (DiCicco-Bloom & Crabtree, 2006). I used a method of categorisation based on four respective broad themes, which I later delineated into the individual themes discussed in this thesis. These were: defining diabetes in various environments (medical and other), experiences of diabetes by various individuals, procedures and processes diabetes and its sufferers adhere to and treatment and management strategies. Coding and categorisation assisted in identifying the similarities and variances in the process of making sense of the data. Similarly Basit (2003) also states that this method of categorisation divides the raw data taken from conducting interviews for example, to allocating categorical labels to this data. For example: codes for various religious beliefs, attitudes and behaviour with regards to treatments for diabetes, but more importantly, the larger research question, assisted in sorting through what I considered significant to answering the ultimate research question. I discovered overlaps and interconnected themes in the experiences and knowledges provided from various participants, indicating the complex nature of the information explored.

Process of reflexivity

The process of conducting a study of this nature made me acutely aware that a metabolic disease such as diabetes reflects a sense of discomfort, uncertainty and liminality (further discussed in chapter 4) at times but also acceptance and adaptation. Initially, I was given the role of a therapist or 'doctor'. At times I was providing comfort and 'answers' about what diabetes is in my field, and the other ways these individuals could have acquired the disease

for example. There were moments in which I become the 'interviewee' and questions centred on my family and interaction with other individuals living with diabetes. Although I felt sympathetic to their experiences by listening to their profound and intimate narratives, I was also challenged by the process.

Many of the people living with diabetes were welcoming and excited to contribute to this study. I was often invited to attend prayer meetings, to share meals in their homes and was shown the containers and spaces where their *kruie* was stored. I initially experienced some difficulty in speaking to people who are particularly knowledgable about plants. These *bossiesdokters, dokters van die natuur* and *Rastas* as they were called, were somewhat suspicious of my role in the community. They were also doubtful about my own knowledge of medicinal plants. Over time, though, they were willing to participate and to talk about medicinal plants and how their knowledge and practices form part of the everyday management diabetes of their 'patients'.

Genadendal was once a Moravian mission station and the majority of the local people are of the Christian faith. As a Muslim female, I often felt 'out of place' during, e.g. the Sunday morning service at the Moravian Church. I was often told that I 'look' Muslim and people seemed to find my presence in church surprising. I was at sometimes mentally and spiritually challenged about my own faith. However in discussions, I used this challenge as a mechanism to have meaningful conversations. My own vulnerabilities became a basis for reaching people like Aunty Katherine who struggled to speak about her diabetes.

Intersubjectivity can be understood as a 'space' or 'moment' in which the researcher and participant interact and through such a process 'co-provide/produce' or bring to consciousness (and thus to text) understanding of subjective experiences (Tankink, 2007). Intersubjectivity is a process, as I discovered when doing research among people living with a medical condition such as diabetes. I could not immediately relate to the experiences and knowledge of the study participants about living with their medical condition. I was not a person living with diabetes' nor a regular 'patient' in the clinic in Genadendal. Instead I was labelled as 'researcher' or 'meisie van die diabetet projek (girl doing the diabetes project)'.

Lindegaard (2007) argues that intersubjectivity is always present and does not only exist in explicit moments. Anthropologists can never be fully cognisant of others and their

experiences — even if we are co-producing research with them (Tankink, 2007). For Lindegaard (2007) intersubjectivity is a shared reality that assists in the interpretation and understanding of the other individual's emotions and actions, which determine the reactions by the other individual. The experience of intersubjectivity can be demonstrated in various examples that draw on the researcher's subjectivities of becoming a subject, resembling the individuals being researched (Tankink, 2007; Lindegaard, 2007 & Akello, 2007). For example, at one moment I chose to immerse myself by becoming a 'patient' at the Genadendal clinic and had my own diabetes test administered by the medical staff. My intersubjective experiences revealed that I could not assume an authoritative position and was challenged by every response in the waiting area with other patients, their emotional and physical expressions and the experience which they brought forward.

The impetus for a making of the 'subject' and subjectivity within ethnographic research stems from the development of how the local experience of living with diabetes, for example, is constantly re-produced and re-made (Biehl, Good & Kleinman, 2007). Subjectivity is an organisation of feeling and self-expression in experience of the everyday life of individual-both the people being studied and my position as the ethnographer. For example in this study diabetes is, as Mol (2002) illustrates, different things for different people. For example, diabetes affects the individual's quality of life and influences their experiences in their everyday worlds. My experiences of observing and following diabetes within various spaces alerted me to the fact that these understandings are products of subjective experiences and reflections of individuals living with diabetes as both a physiological medical condition and a subjective experience of living with this particular metabolic disorder.

Being able to immerse myself as the researcher within Genadendal clinic for example - where individuals were restricted to expressing a sense of physicality of their diabetes - forced me to push the methodology of ethnography to its limits but eventually brought a greater understanding of the people I was working with and whom I was trying to assist. Porcello *et al* (2010) claims that the senses are a gateway for grasping the ways in which culturally informed ideas, beliefs and experiences expressed and produced and also gives insight into predispositions, embodiment and sensory experiences. This study is no different. I had to touch, smell and see my way around various interactions and practices. I had to live, to eat, to feel and engage my own body in the lives of individuals living with diabetes but also the landscape of various interesting spaces in Genadendal.

Negotiating Barriers: Language and Communication

In the Western Cape area the dominant languages are Afrikaans, isiXhosa and English, Afrikaans is the predominant language used in Genadendal (Theewaterskloof Municipality Report of 2013/2014). I speak the language fairly fluently and most of my interviews, discussions and conversations were conducted in the language. There were nevertheless slang and jargon which made reference to particular places, situations, people and activities. For example a female mentioned: *ons gaan nou vlei toe*! (We are going to dam). At the time, the vlei was not the only social space were people gathered during weekends but was specifically referring to the dam in Genadendal. This simple example meant I had to become accustomed to speaking like a *Genaler* and know the spaces where they engaged, in order to understand my participants more thoroughly.

As I considered myself capable of speaking the Afrikaans language (my second language) I did not require a translator. However, in particular situations in which code switching between Afrikaans to English would occur, communication became complex at times. This happened especially when I was thinking and writing in English and was doing research in Afrikaans among people living with diabetes who were first-language Afrikaans speakers. But I quickly learnt to move with the *language rhythm* of my participants.

Ethical consideration: ethics, access and procedure

I have at all times adhered to the ethical guidelines as set out by Anthropology Southern Africa (ASnA) and by international guidelines to sound ethical research by International Ethical Guidelines for Biomedical Research Involving Human Subjects (CIOMS) and Ethical Guidelines for Social Science Research in Health which state that:

"Clinical research has a potential risk of harm, and therefore sound standards of ethics must be observed. Research involving human subjects is based on a moral commitment to advancing human welfare, knowledge and understanding, and to exploring cultural dynamics." (http://www.sahealthinfo.org/ethics/ethics.html).

Similarly, this study has considered the well-being of the participants, whilst providing an exploration of knowledge about diabetes within the respective context of Genadendal. The ethical concerns I faced during this study centred on informed consent, confidentiality and the anonymity of participants. In this thesis some participants wished to remain anonymous whilst others expressed no need to be presented as anonymous.

I presented participants with an information sheet and simultaneously gave a verbal explanation of the purpose of the study. I explained that they did not have to participate if they did not wish to do so. If they chose to participate, I gave them a number or pseudonym, ensuring that only I would know their identities. I emphasised that they could withdraw at any time of the study without any consequences. If a person did not wish to give written consent I probed them for their verbal consent and audio recorded the consenting process. I also asked for consent from respondents to use photographs of them in the thesis, to which they agreed.

I ensured that the information provided would be protected and handled appropriately. Documents were kept safe at the University of the Western Cape and locked away from any individual besides myself as the key researcher of this study. The health care staff (nurses) of Genadendal clinic were very accommodating and supportive of this study. However, ethically they were not allowed to provide any information about the diagnosed individuals who were and are currently being treated for type 2 diabetes. In order to protect their positions as professional medical staff but also integrity of the Genadendal clinic as an institution, I provided a verbal and a written consent procedure schedule after my initial visit to the clinic.

The collection of plant knowledge as part of treatment and herbal management of diabetes also requires ethical consideration. Although this study was not an ethnobotanical research project in which plants specimens were collected and processed, I found the knowledge embedded in plant practices were as valuable, and in need of protection. Therefore, a memorandum of understanding was discussed with Rastafarians and herbalists in the study. This document was an ethical step toward the distribution of information to the broader research community. In this study most of these individuals (Rastafarians and herbalists) were accommodating and forthcoming in explicitly providing their knowledge about medicinal plants, although some did not want to participate due to fears of exploitation.

Limitations

The process of conducting research among what is considered a vulnerable population (Flaskerud, 1998, Garfield et al, 2003; Berkowitz, 2013) presented as a challenge. The main limitations I experienced in this study were in the study's initial stages. However, I dealt with them whilst conducting this study on diabetes in practice. Time was always a constraint in conducting a multiple method type of research. Conducting this type of study required that I consider distinct yet complementary types of procedures which can be approached by and include various individuals in Genadendal. The combination of focus group discussions, interviews, observations and participation made it difficult to attend to and be aware of everything all the time. Therefore I acknowledge that this study is not representative of all the people living with diabetes in Genadendal.

Accessibility to spaces was initially challenging, for example at the clinic, homes etc. However through proper ethical consideration and documentation I was invited into participants' homes, examination rooms in the clinic and Victoria centre for the aged. Initially I would observe from a distance in the clinic for example, or remain in the lounge at a patient's home as she collected her medication from the bedroom. Soon after, my relationships with these individuals became more meaningful, these participants became more comfortable in my presence and allowed me to 'see' and experience their daily lives.

Conclusion

Methodologically as a researcher and at times an 'insider' looking out, tracing the lives of people in Genadendal, offered a unique conceptual understanding of how as a disease and illness such as diabetes is captured as part of everyday life. My interpretations and attempts of representing a somewhat 'holistic' but deeply complex understanding of diabetes proves the "unpredictabilities of bodies with a disease" (Mol, 2008:12) as practised or enacted. The diabetes research process was daunting but sufficiently documented through the lives of its patients and others who are represented in Genadendal.

Chapter 4 – An ethnography of the clinic: The case of diabetes in Genadendal

Introduction

Diabetes as an illness is experienced by the people who have been diagnosed with it as a disease: an object for scrutiny by medical knowledge and for providing treatment and health care. As an illness it has a subjective, intimate familiarity and embodies particular practices concerning personal choices about treatment, of self-care and/or being cared for (Mol, 2008). These experiences and practices also include relations to other patients in a clinic, with nursing and medical staff, as well as frequent interactions with objects (needles, A1C monitor etc.) that make diabetes an ontological reality.

The practices of disease become particularly apparent in the environments where health care is sought and provided: hospitals and clinical settings in South Africa. Ethnographically, as Long *et al* (2008) describes, hospitals and clinics are sites or places where many vulnerable groups congregate. These clinical institutions also represent complex connections made between movements and changes in identities (a person living with diabetes becomes a 'patient' or a 'diabetic'), circulation of information about and for patients, the sick or ailing people (and sometimes their loved ones), nurses, doctors, technicians and others in these environments.

Therefore, this chapter focuses on a specific clinical setting in Genadendal. The clinic as a social space, demonstrates how people live with diabetes, as well as their interfaces with various clinic staff, treatment opportunities, diagnostic tests and knowledge about diabetes. Ultimately I will demonstrate how diabetes is 'done' in the Genadendal clinic (Mol, 2002) in medical practice.

Primary Health Care in South Africa

A number of authors have argued that the primary health care system in South Africa still is in a transitional process as the state tries to provide services across large geographical spaces and in equitable ways (than in the past) (Gibson, 2001; Tanser, 2006; Mayosi *et al.*, 2009; Harrison, 2009). The repercussions of former apartheid legislation, which enforced separation based on socially and legally constructed racial categories, still presents the health care environment with difficulties. Among them are, for example, short-staffed and underfunded medical settings. Moving into post–apartheid (Gilson, 1995; Coovadia *et al.*, 2009; Naledi *et al.*, 2011; Visagie & Schneider, 2014) the process of change was aimed at making health care more inclusive through economic, political and structural changes by the state. However in Genadendal, primary health care (PHC) still remains in a 'liminal' state (Turner, 1969), judging from my experiences with people living with Diabetes, service delivery and clinical practice, especially among the chronically ill.

First introduced by van Gennep in 1909, the term liminality or liminal period as used in this study, is described by Turner (1969) as an ambiguous state, a period of transition. However in relating this concept to PHC, I connect liminality to describing how the Genadendal clinic is in a constant process of development within the larger social structure of health care. 'Patients' describe experiences as not negatively affecting their medical condition, nor overly positive when they speak of matters such as waiting time, lack of clinical staff, lack of diabetes education and medication. I use the concept of 'liminality' to denote how in these moments people living with diabetes in Genadendal are neither 'sick' nor *gesond* (healthy); their position as clinically perceived 'chronic' patients is uncertain until their consultation with the medical practitioner or other clinical staff. Until the moment when, for example Aunty J sees the nurse for her blood glucose test procedure, she is considered in a period of transition. Aunty J could either be diagnosed as 'sick' (high blood glucose above 6.6 mmol/L) or *gesond* (healthy with a 'normal' blood glucose level of less than 6.5 mmol/L).

A 'chronic' condition, in relation to medical practice and within the clinic, is defined as a medical disorder that lasts for more than three months. Chronic illness is a burden in many countries and for the South African health care system and its staff, it is exacerbated by the high prevalence of tuberculosis (TB), HIV/AIDS and non-communicable diseases such as cardiovascular conditions, cancer etc. (Goudge *et al.*, 2009). In Genadendal clinic chronic diseases include diabetes, hypertension and high cholesterol. People living with diabetes are also influenced by the South African transition in health care practices and it is not always possible to provide high quality care. According to Benatar (2013:1) health care infrastructures are sometimes rundown or dysfunctional – especially in rural areas. Staff are

not always skilled, motivated or efficient and services provided not necessarily effectively managed. These challenges in turn impact the practitioners who have to work in and around these constraints.

PHC systems are not always consistent in meeting the needs of chronic patients. Two main reasons are accessibility of services and understanding of, e.g. diabetes and its everyday realities for sufferers, by health care staff themselves (Goudge *et al.*, 2009). People attending the Genadendal clinic reported that e.g. the visiting physiotherapists and dieticians are not always available, they often cancel their routine visits or only see their 'patients' once a month. These practitioners are also not necessarily knowledgeable about the real life circumstances and experiences of the 'diabetic patients' who have to consult them. People who live with diabetes in particular, are expected to regularly attend the Genadendal clinic, yet they do not always do so. "Patients' do not always adhere to their treatment, or understand staff, and find the 'science' of diabetes communicated to them very complex and perplexing. People living with diabetes express an inconsistency in their own management of diabetes due to lack of formal communication or consideration by clinic staff of how much diabetics are able to read and understand about their medical condition.

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In the Genadendal clinic the challenges for patients and staff involve occasional shortages of personnel, equipment, and periodic unavailability of certain medication and information about prevalent non-communicable diseases. Areas such as Greyton and Caledon offer private medical services and medication outlets (pharmacies, grocers), but these facilities are out of reach for locals because of financial and transportation constraints. The Genadendal clinical staff do however have good insight into their community and have specific 'patient expertise' in relation to the diabetic people they see on a regular basis. The receptionists and other local people who live with diabetes similarly act as support and sources of information within the setting of the clinic.

According to Bradley & Puoane (2007) community health workers have a significant role in understanding how diabetes (and hypertension) knowledges are produced and executed within medical settings. In Genadendal the nursing staff and also assistants (members of the community who started as volunteers in the clinic) who connect with people living with diabetes, know the latter's socio-economic position and histories. Therefore, a focus on a non-communicable disease such as diabetes brings to the forefront the practices which

represent context-specific 'expertise'. In essence, the above makes visible the messy and complex web of the socio-political and economic environment in which health care exists in South Africa today (Gibson, 2004). This is especially visible in Genadendal and its clinical setting. Patients live in and through ever changing medical environments and practices that influence how they do (Mol, 2002) diabetes within their homes, but also the clinic.

The Genadendal clinic

The Genadendal outpatient clinic is situated in Strydom Laan and resorts under the Theewaterskloof Municipality. The services offered include HIV rapid tests, TB, diabetes (blood glucose) and blood pressure tests as examples. There are various other services offered at the Genadendal clinic. These, however, depend on the availability of the particular health care practitioners and their allocated days of the week. The permanent in-house medical staff consists of two female nurses and ten specialists (a dietician, psychologist, physiotherapist, general practitioner, dentist, paediatrician, dermatologist, an orthopaedist, a counsellor and an occupational therapist) who visit the clinic on specific scheduled days of the month. For example the orthopaedist only visits Genadendal clinic once a month. Other staff include two receptionists (one male and one female) and a female nurse assistant who works between 8am-4pm from Monday-Friday.

The 'chronic patients' arrive at the clinic Wednesdays at 8:30am. They sit in the waiting area until nursing staff arrive for their respective shifts. When I began my study I soon realised that the people who live with diabetes also have and medical conditions such as hypertension and high cholesterol – they visit the clinic for all of these. I observed and talked with the staff, receptionists etc., as well as the diabetes 'patients' (as they are called and call themselves in this setting). I also had my own blood glucose levels tested and accompanied others who did the same. With the necessary consent, I watched nursing staff. Over time I started to see, feel and communicate differently, following, observing and participating in the procedures of the clinic. The sensorial, social and psychological impact of being in this setting powerfully demonstrated diabetes in practice within a medical setting.

Translating diabetes in the Clinic

The medical staff in the Genadendal clinic rely on a number texts which provide indicators (in the form of medical charts provided by the Department of Health see Figure 3) to guide clinical practice for diabetes. The following is an example: taken from Primary Care 101: Symptom-based integrated approach to the adult in primary care 2013/2014.

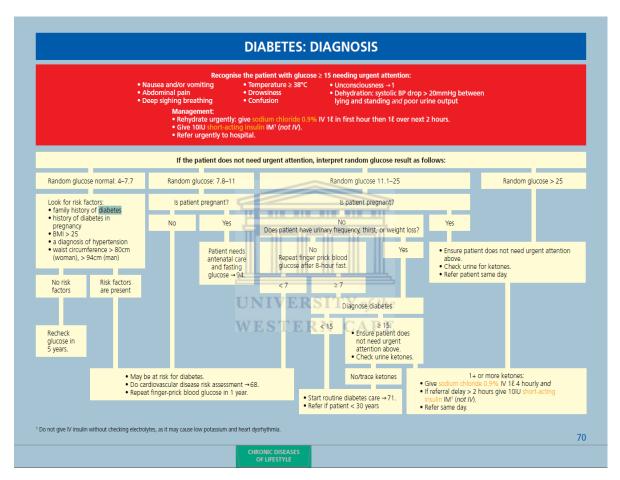


Figure 3: An example of a diabetes testing chart

The diabetes testing chart is located on the notice board in the examination room. This chart is used by nursing staff as a reference to make a prognosis of diabetes before official medical practitioners make the final diagnosis. This chart (Figure 2) communicates diabetes as a metabolic condition with chemical imbalances, from the nurse to the 'patient'. Already I start to see through practice, how diabetes is being 'done' differently.

The manner in which the nurses in the clinic address and communicate with patients and their bodies in the examination room is particularly interesting. Their intersubjective, "shared"

understanding of diabetes (*suiker*-sugar) transcends formal clinical jargon in the same Afrikaans language. Although the information exhibited in the clinic does not sufficiently explain diabetes to patients, nurses rather display the various 'diabetic realities' of various persons living with diabetes, in conversations during consultation and of testing *suiker*. This is evident in the questions patients are asked by Nurse R and Nurse W, their articulation and ability to mediate between "scientific" jargon and the language of Genalers.

In a conversation with a diabetes and hypertensive patient, Aunty Anne (53), Nurse R wants to evaluate the progress of Aunty Anne's diabetic treatment. According to recommended protocols Nurse R should ask: How effective is the treatment in helping with the symptoms you have experienced? But Nurse R instead asks:

Hoe voel Aunty Anne nou? Is Aunty Anne nog altyd soe dors? Is daar miskien n jik gevoel in die hande of die voet? (How does Aunty Anne feel now? Is Aunty Anne still thirsty? Is there perhaps a tingling feeling in your hands or feet). (Transcribed notes, December, 2014)

Communication of the nurses in the clinic and patients always entail repetition of the previous visit: the reasons for it, symptoms and outcomes experienced. The patient's body is evaluated according to past and present symptoms. In this regard the 'diabetic' bodies in the clinic arguably are active agents in their own diagnosis, measurements and treatment. However and more importantly, they represent themselves in a messy but coherent manner. For example in a monthly visit to the clinic Aunty S who had a diabetes test done, shows Nurse D, 'which finger' to prick to receive blood. She explains that when she does it at home and that particular finger, and part of her body, is most receptive in doing her diabetes test successfully. Aunty S thus enacts diabetes as part of her being but simultaneously attempts to reject this prescribed label of being a passive 'patient'. Instead she actively seeks treatment, diagnoses her own symptoms and evaluates her own progress.

Aunty S' body is an object in medical practice: Nurse D pricks and squeezes her finger to extract blood and then cleans the remaining blood off with sterilized gauze. Aunty S simultaneously is an experiencing subject – she tells the nurse which finger to prick, feels the stab of the lancet, sees her own blood well up on her finger and senses the quick discomfort of her finger afterwards. Aunty S 'is' her body - subjected to the scrutiny of medical practice

in the clinic examination room, and even the pharmacy, as she waits to collect her prescribed medication. One could say her body is 'active' and 'performative' Goffman (1959) of this disease called diabetes. However bodies in clinic do something more than passively perform diabetes. Bodies also challenge medical staff (advising medical staff on which finger to prick for example) and/or transform when taking insulin or maintaining a high fibre, low sodium diet.

As indicated in the Introduction, my own analysis is much informed by the work of Mol (2002; 2014). She, in turn, draws on Goffman's (1959) idea of performance and ultimately focuses on the term 'enactment'. This move is what is often referred to in the literature as "the ontological turn", where social scientists increasingly focus on how social acts, which include physical realities, are performed, or done, or enacted (Mol 2014):

The idea was that there are not just many ways of *knowing* 'an object', but rather many ways of *practising* it. Each way of practising stages – performs, does, enacts – a different *version* of 'the' object. Hence, it is not 'an object', but more than one. An object multiple. That reality might be multiple goes head on against the Euro American tradition in which different people may each have their own *perspective* on reality, while there is only *one* reality – singular, coherent, elusive – to have 'perspectives' *on*. To underline our break with this mono-realist heritage of monotheism, we imported the old fashioned philosophical term of ontology and put it in the plural. Ontologies... (ibid)

Similarly in my own study, diabetes is arguably a medical condition enacted in the manner in which the body (like Aunty S) lives in and through diabetes and adheres to treatment through practices. However although making diabetes visible, enacting or following the practices of this medical condition, is a complex analysis. By focusing on practices in this manner, Mol (2002) also interrogates Goffman's (1959) approach - she does so by looking at the individual and investigating how people "do their selves" and not simply perform themselves (37:2002).

For Mol (2002) her approach extends the 'framing' of the stage performance, for example. In this case, diabetes is then more than just the increase of blood glucose levels; it becomes the body positioning itself to be examined and placed under medical scrutiny. In the examination room and also the clinic in its larger physical orientation as a space, 'enacting' or 'doing'

diabetes depends on a patient like Aunty S, but also other patients experiencing disease in the clinic. 'Diabetes' is an extension of this disease in practice, by the people who experience it, and the stimuli and surrounding spaces. However, diabetes also becomes a reality through people who assist in its progression (treatment and management) within the clinic. This is similarly related to another formal clinical institution, the Home Based Care Unit.

My days spent with the women of the Home Based Care Unit (or simply *Die Unit*) entailed walking through Genadendal and visiting the homes and areas in which diabetic and hypertensive patients⁵ lived. The medical histories of patients who required such assistance was provided to the Unit by the clinic and staff of the Centre for the Aged. Detailed information such as sex, age, addresses, previous medical diagnoses, prescribed medication and place of care were provided and had to be taken into consideration. However, this somewhat formal and seemingly rigid process was open to reinterpretation and improvisation by the "care ladies" (this is what they were called, as Aunty Susan explains:

Daar is baie diabete hier in Genal, maar nie almal van hulle soek behandeling nie. Nou gaan ons (women of the Unit) ma na dardie mense wat help wil he. Dis nou eers die ou mense wat nie kliniek to kan loop nie en die mense wat baie siek is. Jy weet mos hulle kannie so lekker loop nie (There are a lot of diabetics in Genadendal but not all of them seek treatment. So we (women of the HBCU) go to those people who want help. This is firstly the elderly who cannot walk to the clinic and people who are very ill. You know they cannot walk very well). (Transcribed notes, July, 2014)

The role played by the Home Based Care Unit appears to be standard and routine at first glance. The women receive their patient information, pull out their flip files, check which patients need to be seen for the day, go to them and provide them with "care" services -bathing, grooming, testing blood glucose and checking blood pressure. However in my experiences of walking with Aunty Susan, Aunty Bernadette and others, and assisting these women with their patients, I discovered the multifaceted relationships the "care ladies" created, produced and maintained with patients and other individuals in Genadendal.

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⁵ As in the clinic, the people based at the HBCU call their clients, the people living with diabetes, patients.

The women of the Home Based Care Unit are intertwined in an inter-related network of politics, procedures and duties. Unsurprisingly most of the patients they visit and provide assistance to, view them as powerful players because of their knowledge and practices of health care. Nonetheless Mol argues that professionals (medical practitioners, and in my study, the carers) "have a lot less power over their patients" than it seems (2008: 40). In this study and conversations with people living with diabetes, family, friends and neighbours were also seen as important knowledge 'keepers' – the interaction between a network of community members including the women who work with the Home Based Care Unit appear unstable due to power relations of professionals among this semi-rural population. However the manner in which these individuals interface when discussing their insulin therapy for example, demonstrates how in certain moments professional and 'non-professional' binaries fold together.

The women of the Home Based Care Unit demonstrated that good interpersonal relations are important in the kind of work they do when in patient homes. I saw how Aunty Susan was 'directed' by a patient (person living with diabetes) as she minutely detailed her embodied experiences of an elevated glucose level, for instance. I experienced patient anger, disappointment, and anxiety directed at Aunty Susan because, for instance, medication was delayed or not available. Although Aunty Susan was not at fault, she had to really 'care' and give and 'do' care. According to Kleinman & van der Geest (2009) care involves not only physical medical care but also empathy, social and moral care: it is an art. Mol (2008:1) stresses that the care is not only about activities such as "washing, feeding, and dressing wounds that are done to make daily life more bearable", it also involves interventions in the course of a disease: in practice (caring) food and (curing) drugs may have similar effects on a body. Caringly dressing a wound may help its cure (caring) food and (curing) drugs may have similar effects on a body. Caringly dressing a wound may help its cure.

The Home Based Care Unit and its carers communicate to their patients about personal and exposed moments of their health. They teach as well as learn from these people how disease is not always visible and accurate. The Home Based Care women often explain to their 'patients' how blood pressure may be high but not shown through explicit symptoms or common symptoms (headaches, as experienced by previously diagnosed individuals); this does not mean hypertension is not present. People living with hypertension and diabetes begin to learn the importance of diabetic procedure and consistency regardless of symptoms.

This interaction also shows how the movement of knowledge and alternative medicines are used for illness and disease treatment and management (discussed in detail in Chapter 6). These women and their patients joke about illness experiences and sympathise within one another but more importantly interact on a level different to any other health care professional I have seen. Their application of 'care' for diabetic patients in Genadendal, is a collaborative (Mol, 2008) effort and illustrates how health care professionals move between 'knowing' and 'doing' and practicing.

Sensing, seeing and surviving: Genadendal clinical encounter

As a space - where the smell of dusty patient folders in the reception area, drops of blood on the sterilized gauze and chatter in the waiting area about medication dosages intertwine and are in constant motion - the Genadendal clinic demonstrates how a medical condition like diabetes moves from one continuum to the next, from one space to the another. From feeling uncertainty about symptoms and medical procedures, to curiosity, despair and ultimately survival, patients progress through a sensorial experience that intervene in their physical and psycho-social experience of diabetes. This process identifies the objects and subjects that are crucial to understanding how they *are* diabetes, not only how they (as well as the nurses etc.) 'do' the disease.

Patient and procedure

The clinic was often bustling with patients and their families throughout the day. The sombre fluorescents against the off -white walls often appeared to make patients anxious as they waited to be examined, for test results and medical attention. According to Mrs K, early in the morning and late in the afternoon, the clinic:

Dit lyk soema soe creepy (she giggles a bit). Jy weet nie wat gaan gebeur vandag nie....maar daai is hoe sieke in die hospitale and die kliniek lyk nè (It already looks creepy (eerie, disturbing) you don't know what is going to happen today but that is how sickness looks, in the hospital and the clinic). (Interview transcription, August, 2014)

Gibson (2001) argues that "waiting time" reflects power relations in the clinic/hospital. The Genadendal clinic was no different and patients always waited. Waiting time produced feelings of frustration, anxiety and sometimes desperation. In Genadendal clinic, the ill are labelled as 'patients' within this medical setting. Waiting time (periods between roll-call (attendance) and anticipating medical attention) have influenced these persons and their experience of PHC. In addition, as Strathmann & Hay (2009) argue, the receptivity of medical care. Patients' identification cards and symptoms did not necessarily ensure immediate medical attention in accordance with their embodied experiences of being ill. It rather followed a well-established triage system followed in all state health care facilities in South Africa. However the reception area was the starting point of the journey to seek medical attention and treatment.

In my attempts to map the physical spaces within the clinic - as people moved through them throughout the day (from the waiting area, to the examination room, to the reception area for follow up appointment) - I also consider the imagined spaces, the meanings attached to them and the reasons why these spaces are understood in this manner. Street & Coleman (2012) argue that real and imagined spaces are present themselves in ethnographies of the medical setting (hospitals and clinics). For example: In the Genadendal clinic the waiting area was a space for social banter, or expressing concern about the financial circumstances of Aunty M, or of somebody misusing drugs. However the moment an individual moves into the examination room (a smaller queue is formed directly opposite the room), dialogues quieten and people become 'reserved'.

In the clinic the examinations rooms are the most important spaces. They are spaces of uncertainty and doubt, but also of displays of hope and expressions of fulfilment (e.g. when blood sugar levels are 'normal'). These rooms are liminal spaces of 'good' health (*gesondheid*) and 'bad' health (*siekte*). I watched the expressions of patients change as they were called into the exam room. In an instant their expressions shifted from being impatient to anxiety, fear and, at times, despair.

Other spaces in the clinic are also representative of making diabetes visible as a disease. I was particularly interested in the reception area where patient information was stored. For patients, it represents the 'first' procedure and point of contact with medical staff when

entering the clinic. It is a space of recognition, where a patient's personal details and reason for the visit is noted. Then his/her folder is pulled from the stacks and placed among those of the patients who *will be* receiving medical treatment. However, it is also a space of disappointment and frustration when folders are not found or medical attention cannot be provided due to staff shortages and/or lack of the necessary equipment for example.





Fig. 4: Patient folders in reception area of the clinic.

Fig. 5; Next to and opposite examination rooms, additional files are stored for the attention of specialists.

The clinic represents diverse complex understandings of space and the meanings attributed to them. For the clinical staff it is a working environment where medical practice is routine and formalised; however, for the individual seeking medical attention it represents how her body as physical entity enacts and is acted upon through clinical procedures of medicine. However *multiple* (Mol. 2002) these spaces in both their real and imagined capacity are, they are inclusive of procedures, relationships, moments of continuity and discontinuity but simultaneously interconnections between a patient and technology.

In this regard Street and Coleman's (2012) use of *heterotopia* by Foucault, is a meaningful attempt to explain my experience and that of the patients in the clinic. Foucault (1976) argued that "space is not an empty void in which individuals and things are located but rather consists of multiple heterogeneous sites that are defined by their relationship to one another." In the clinic, practices in various spaces do not necessarily correlate, but come together in a process of creating order and procedure. For example in the Genadendal clinic, I observed how patients interacted with nurses, the visiting doctors and each other before and after consultation in the examination room. This space was not only for testing, reporting and

treatment. Patients also 'directed' the staff about handling and treating 'their' bodies. Therefore, I argue that the examination rooms, waiting area and even toilets - where patients collect their urine samples to produce to medical staff - are all representative of patient self-consciousness, their emotive responses to knowledge, acceptance but also contestation of practices in the clinic.

In this clinical setting (Genadendal clinic) these 'patients' contest the practice of consuming 'all' their medication. I see how persons who leave the examination room after consultation, often look to their familiars in the waiting room and display the medication packet (*pille pakkie*) they receive often saying: *Dokter het gese, ek moet almal die drink*..(Doctor said I must take all these) however also responding with: *ons sal sien hoe ek voel om almal die te neem* (ill see how I am feeling in consuming all these)". These 'patients' in the clinic explicitly argue for the feelings and symptomatic experiences of their own body rather than solely relying on what the medical practitioner advises. The ability to experience the body while also exposing the body to medical scrutiny represents a movement in, in-between and outside of medical practice.

The blood glucose test: Making diabetes visible

To avoid ethical concerns within the initial stages of this research study, I did not accompany my research participants when they went for their blood glucose tests. Instead I decided to attend the clinic and to have my own blood glucose level tested. I was experiencing some unusual symptoms that I had assumed were associated with a decrease in blood glucose.

WESTERN CAPE

Seated in the examination room on a Thursday morning, I notice the equipment - A1C monitor and its strips, needles and gauze that are placed in a sequence of priority. First is my new file, the patient history booklet, then a packet of sterilized gauze and on the far end of the desk, the needles and A1C monitor. Nurse R, who is seated, ensures me that the procedure would not take very long. But first I need to weigh myself as part of the test done within the clinic. I hesitantly get onto the scale. Nurse R seems surprised by the result and says: "You look really small to be 81.1 kilograms". I immediately felt the need to explain to her my own health issues to 'justify' the result of my weight check. As I speak Nurse R makes notes and looks up

once in a while to acknowledge my responses. She is then called to reception and instead asks the clinic assistant, Miss V, to administer my blood glucose test (Fieldnotes, November, 2013).

Miss V holds my finger and starts squeezing and rubbing as she stands over me. She ensures me that this practice helps with the circulation of blood and simply to "see". She is told by Nurse W that the injection pen (which automatically shoots out a small lancet that pierces or 'pricks' the skin) does not have any needles. Instead Miss V says she will manually prick my finger for blood. She advises me that it may hurt a little. As she proceeds in a stab-like motion, I close my eyes and hope it does not hurt. I open my eyes and Miss V starts squeezing again. I see the drop of blood expanding on my finger as she is squeezing. She quickly takes my finger and drips it over the stick (test strip). She then inserts the stick into the AIC monitor and waits for the machine to process my result. Miss V looks at the 6.7 mmol/L, it indicates that by clinical standards that my blood glucose level is considered 'above normal' but still acceptable. Miss V Smiles at me and says:

Die is toets is klaar, jy is gesond. Ek kan niks fout kry nie, so jy hoef nie bekommerd te wees nie (The procedure is complete. I cannot find any fault, so you do not have to be worried)" (Fieldnotes, November, 2013).

The test appeared 'normal' by biomedical standards: however, I was uncertain about her observation of the results and labeling me as healthy (*gesond*). My body felt different, I felt strange and unwell. My self-diagnosed symptoms of feeling light headed and having constant headaches were a motivation to get myself tested, since my family has a history of diabetes.

To Mol (2002), the practices that subjects and objects engage in are "thick, fleshy, and warm as well as made out of metal, glass, and numbers —and that are persistently uncertain" (31:2002). As a subject to the medical procedure, I was still unsure about my overall health. In my experience, the procedure of administering and also experiencing a blood glucose test, was more than an action of extraction and analysis through medical objects. Similarly Mol (2002) - who departs from Latour's (1993) escape from the subject/object divide - suggests that, although we live in a world that has both quasi-objects and quasi-subjects; 'practices' are more complex than 'action'. What Mol (2002) is indicating and demonstrating by this

statement is that diabetes, for example, is a complex arrangement of practices that depend on and is depended on by the stimuli situated in the clinical environment.

In an interview Mrs Barnes (56) a diabetic, recalled her consultation for testing as well as its results:

Sy (nurse) het net vir my gese dat my suiker baie hoog is. Dat ek dalk a diabeet is, tewyl ek daar gesit het en die res van die bloed van my vinger affee (The nurse told me that my glucose level is high. That I might be diabetic whilst I am seated and wiping the remaining blood from my finger). (Transcribed interview, July, 2014)

Doing the blood glucose (diabetes) test, demonstrates a particular interface between technologies of medicine and the bodies it engages with in a process of extracting blood, information concerning diabetes testing and (for the patient) the possibility of having diabetes as a medical condition. The needle plays an important role in extracting the blood containing the plasma of glucose. A drop of this blood sample drawn from an individual containing high glucose levels determines the absence or presence of diabetes: the former as within a 'normal' range and the latter as elevated. The AIC monitor detects this glucose level. The numbers reflected on the monitor shows levels of glucose in the blood. If the monitor reading measures above 8 mmol/L then diabetes in visible, reflected and present in the body of the patient. However if the measurement is below 4 and 7 mmol/L, diabetes is not present and the patient is considered to be *gesond* or 'healthy'.

Ferzacca (2000) argues that, for the individual living with diabetes, this condition is also a symbolic experience of the self within dominant discourses of clinical socialization and an idealized normative self in medical practices (Ferzacca 2000). However, for patients in the Genadendal clinic, diabetes equally is an identity *die pasient met suiker* (the diabetes patient) that moves in and out of medical knowledge practices. These practices change and intervene in their lifestyles, but more importantly provide the clinician with information –results that speak to their medical condition.

'Knowing' diabetes among 'patients'

The medical staff I communicated with demonstrated that their relationships with patients extended to the outside of the clinical setting, even while they maintained their professionalism. While nursing staff have to follow prescribed procedures and objectively produce outcomes in patient care, in the interface with the latter, reality is continuously being negotiated, as object and subject, disease and illness are mixed together and become almost indistinguishable.

The waiting room is one of the most interesting places to observe and communicate with patients. As I sat among the waiting people, I saw patients often come in and immediately recognise their neighbours, friends and even co-workers seated and waiting to be assisted. Their conversations often revolved around their responsibilities at home, work and money. However most concerns and discussions in this setting emphasised illnesses and disease. Patients talked about and demonstrated how they self-diagnosed, how they had acquired an infection, virus or pain before they were diagnosed by nursing staff and through medical tests and diagnostics. For example, Aunty Mina (62) is seated next to Aunty Sarie (58) and explains in a conversation:

WESTERN CAPE

Ek kan dit voel, daar is iets nie lekker nie. Nou wonder ek as dit nie die koue is nie, want my bene pyn so baie in die nag. John (Aunty Mina's husband) sêe vir my miskien is dit my suiker wat nou my bene pla, maar ek dink nie soe nie. Hy sê mos alles is van die suiker (she giggles). Maar ek se jou die pyn is iets anders (I can feel something is wrong. Now I am wondering if it is not the coldness, because my legs are paining a lot at night. John tells me that maybe it is my diabetes that is affecting my legs, but I do not think so. He says everything is because of my diabetes (she giggles). I am telling you, this pain is something else). (Transcribed interview, December, 2013)

Aunty Mina is a diabetic. She was diagnosed more than ten years ago and also suffers from hypertension and chronic undiagnosed pain. My conversation with Aunty Mina and with other patients revealed an important characteristic of their understanding of their illnesses and diseases: the manner in which patients self-diagnose and make sense of diabetes through the

embodied, incoherent and at times inexplicable experience, as well as their own knowledgeable embodiment of their medical condition.

Diabetes mediates between the mind (knowledge) and physical body (symptoms) and in their coming together within the body; a disease condition like diabetes is enacted. The embodied experience is also pre-symbolic, and as Merleu- Ponty (1962) adds, pre-linguistic. Patients in the clinic produce particular aetiological explanations and experiences about diabetes and how it exists in its entirety: a physical, emotional and psychologically challenging medical condition. It is within these experiences that people who live with diabetes in Genadendal may not always explicitly communicate their embodied experience of diabetes but transfer their physiological experiences into 'their' knowledge of 'their' bodies.

Patient aetiologies provide an interesting insight into the knowledge that originates from patients, e.g. Aunty M's ideas and assumptions. At the same time it is influenced by the clinical setting and the medical practitioners they interface with during their visits. In a dialogue with Aunty Mina (a diabetes and hypertensive patient) I notice how she identifies with being a self-proclaimed 'diabetic'. However what appears more interesting is the manner in which she speaks about her diabetes. She claims that her experience of her emotional or physiological state is unique because only she *knows* her body. When she leaves the clinic her body becomes her own again, in which she is able to move to its ebb-and-flow and does not solely rely on her medication.

In an instant Aunty M slips in and out of her patient role and in moments 'becomes' the practitioner to which diagnosis is made. She questions the medication prescribed and asks questions surrounding the management of diabetes. People living with diabetes in Genadendal ask: if the medication makes them drowsy, will they be able to perform daily activities (labour), and how will they know when their blood glucose is elevated without a test? What would happen if they should miss a dosage? These are the issues patients like Aunty Mina raise in the clinic before they follow the treatment prescribed. For clinical staff who diagnose the presence of diabetes, patients move through "multiple" levels of experience and imagery that influence their knowledge and understanding of "their" disease.

From knowledge, to diagnosis and diabetes treatment: An interlude

The blood glucose test administered at the Genadendal clinic follows a standard systematic procedure regardless of patient status. As I enter an examination room I notice all the instruments and equipment (scales, vials, blood pressure monitors, needles, sputum jars and more) placed all around the room. Although the examination room is small Nurse R assures me that it is ample for the kinds of procedures they administer regularly. I suddenly feel overwhelmed by a wall on the far left. It is entirely covered with posters about TB, HIV prevention and standard codes for conducting sound clinical practice. However, I notice that there is no information on the subject of diabetes even though staff had assured me of its high prevalence in the town.

I ask Nurse R about the lack of non-communicable disease information in the clinic and she simply responds: the government only supplies the clinic with information of 'certain' kinds for these displays (posters, pamphlets, readers etc.). The information covers what is deemed "more dangerous" in terms of symptoms and long-term damage to the body. (Fieldnotes, December, 2013)

WESTERN CAPE

So, I begin to question: How much is actually 'known' and 'understood' by people living with diabetes and how does it relate to how medical staff are 'prescribed' to know and understand its physiology and the formal practices related to its diagnosis and treatment? What and how is communication surrounding diabetes in the clinic mediated, articulated and translated?

From diagnosis of diabetes to ek het suiker

The process of detecting diabetes in the blood of the individual through the objects, encounters with staff and clinical procedure that assist in diagnosis, is marked by a significant moment. This moment represents the difference between a 'healthy' body and an unhealthy body. I discovered from stories of initial diagnosis of diabetes that this moment (after diagnosis and before treatment begins) was significant in understanding how patients see, feel and understand this transition after being diagnosed as a diabetic, to being a patient of the

clinic. According to Mol & Law (2004) "People whose body-images are not coherent, who do not feel their bodies to be integrated, are diagnosed as deviant". In the case of diabetes, bodies are not always co-operative and people living with diabetes stress the bodily incoherence they sometimes experience.

Mrs S described her experience of being diagnosed with diabetes:

Ek het n gevoel gehad dis seker suiker maar ek het nie verwag dat dit waar moet wees nie! Hulle (medical staff at the clinic) het my bloed getoets oor twee weke. Na die eerste week het ek begin bekomberd raak. Ek moes gereeld my suiker getoets het voor hulle my kon se as dit nou chronies is of nie. Nou..is ek ma n suiker mens soos hulle sê. (I had a feeling it's probably diabetes but I did not expect it to be true! They (medical staff at the clinic) tested my blood glucose over the period of two weeks. After the first week, I started to worry. I regularly needed to check my blood glucose before medical staff could determine if it is chronic or not. Now I am just a diabetic like they say). (Transcribed interview, November, 2013).

Aunty M talks about her feelings after diagnosis with both diabetes and hypertension:

WESTERN CAPE

Ek was nie verbaas nie. Dis in my familie, my ma en pa het suiker gehad. Maar net my ma het hoe bloed ook gehad. Maar ek was a bietjie ontsteld wanneer ek by die huis aangekom het. Ek meen ma, niemand will siek wees nie en pille vat and kliniek toe gaan nie (I was not surprised. It is genetic, my mother and father also had diabetes. However I was a bit disappointed when I came home. I mean, nobody wants to be sick and take pills and go to the clinic). (Transcribed Interview, November, 2013).

Uncle J shared his experience with me too. However, for Uncle J it was an overwhelming experience because it encapsulated so many elements of his daily life. In an interview he very intensely explained:

Being sick in a place like this, everyone knows, you know. You can't just walk to the clinic or fetch your pakkie (medication), hulle weet (they know). When I first found out of my diabetes. I was shocked! The first thing I thought about was; how much is

this gonna cost me? how long will I have it? must I change my lifestyle now? I just panicked for a bit. (Transcribed notes, December, 2013).

The responses above present a particular dialogue between bodies and disease - which is located underneath the skin and in the blood in this case. However it is also the process of diabetes 'coming into being' through objects in the examination room, as well as active bodily responses – including symptoms such as dizziness, headaches, frequent urination, thirst and reactions to medication such as changes in weight, nausea, rashes, upset stomach etc. - and the clinical experience. The aftermath of being diagnosed with diabetes reveals the practicalities and impracticalities of living with it in everyday life. People who live with diabetes in Genadendal are concerned about treatments options and expenses, they become anxious about change and routine, they are pressured about issues concerning their role and status in their community as a diabetic, being able to continue with their work and lives. In Genadendal having diabetes is understood as somehow representing poor health care practices and/or blatant disregard for the body and "heathy living". People consider this moment of diagnosis as the positioning of their bodies and disease among others in Genadendal.

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This is also because a chronic disease makes "life even more difficult than it already is." (Mol, 2008: 25). The foreseen events and procedures that follow the diagnosis of diabetes affect the body and mind of the patient at that particular moment. The body in the moment (of diagnosis), is labelled, tested, pushed and pulled in various directions because it is now part of a larger 'product' of both disease and illness. This does imply that a patient like Aunty Mina or Uncle J are passive recipients of these procedures, they are creatively active in shaping their specific diabetes, even though they acknowledge the chronic condition that is diabetes in the clinic setting.

Dit gaan oor die pille, die inspuiting, die behandling

Diabetes medication for the Genadendal clinic is supplied by Caledon Hospital every second month. Collections for medication are done from the clinic itself, or from the Community Hall located opposite the Hester Dorethea Conference Centre. I regularly went to the Genadendal clinic with people who sought medical attention or just dropped in to collect their

regular prescriptions, or *my suiker pille* (diabetes pills) or *my hoë bloed pille* (high blood pressure pills). The most common allopathic medication given to patients who suffer from type 2 diabetes is Metformin and Insulin injections. Cholesterol and pain medication are also used by many diabetics, as I observed in their medication packages or *pille pakkies*.

Allopathic treatment options used for diabetes vary between patients, depending on the Type (1 or 2 diabetes) and diagnosis of diabetes. Patients like Uncle John, use Metformin 500mg pills. Others, Aunty Katie and Uncle Paul, consume Metformin 850mg because of the decreased level of absorption of the hydrochloride agent in their bodies. Insulin injections are prescribed to patients whose pancreas, over time, produces less and less insulin. They are used among patients with Type 1 and Type 2 diabetes. These injections are dependent on the patient's body weight. For example: every kilogram of weight requires 1-2 units of insulin. Additional medication is prescribed to use with diabetes medication, such as Disprin (which I was told lowers blood glucose levels but can also be used for pain).

Diabetic persons (the individuals in this study) in Genadendal are all above the age of 40 years. Among the diabetics in this study some also suffer from other illness conditions. Therefore medication is often delivered to their home by the Home Based Care Unit. Medical staff in the clinic, who reside in Genadendal, will often take medication to the homes of people on their own way from work.

While medication is everywhere in the homes of people with diabetes, these material things are not 'passive' objects in patient homes. The knowledge acquired about these medications: what they do, how they work, the diseases and illnesses are they used for, all stem from the shared knowledge of medical practice of people living with diabetes. Aunty Mina explained to me that she never quite understood the "weird" names of her medication and how they actually helped her body until she discussed her concerns with others – including a doctor, but also her friends and neighbours.

Die pille wat ek kry is nie die selfde soos daai wat Bette gebruik nie, maar hulle (medical staff, neighbour) se enige Diabeet kan dit gebruik (The pills that I receive, are not the same as those of Bette, but medical staff tells me any diabetic can use them). (Fieldnotes, June, 2014)

Chronic 'patients' in Genadendal not only consider medication (pills and injections) as vital to treating and managing their diabetes, but evaluate its efficacy and substance, and are constantly aware of its presence. As Mol (2008) argues, patients have the opportunity to acquire detailed knowledge that is suitable for their individual needs. Medication in its physical form, i.e. white or orange in colour, small in size and texture, smooth or 'bumpy', is an important indicator of diabetes within the home. As a form of medication, these pills indicate that a diabetic patient lives in that home. Medication is important as it is placed in exposed areas within the home as a reminder and that pills have to be taken regularly and thus are a source of surviving diabetes every day. However patients understand that this pill being digested or insulin being injected into their bodies does not necessarily correlate with "good" health or even cure. It remains always a chronic condition.

The constant surveillance by patients of their bodies and objects such as the pills or injections and the regular self-administered blood glucose level tests that interact and intervene with their daily practices (in some instances reflecting subconscious routines and in others reflecting coping mechanisms) is all aimed at the goal of being in good health in the eyes of medical staff and individuals in the Genadendal community. The experience of bodies and surveillance for diabetes is discussed in the following chapter in relation to the experiences of an individual living with diabetes.

Conclusion

I have striven to provide a detailed insight into diabetes as it moves through various spaces and practices and affects patients who experience and enact it in their daily lives. The many objects I described - although presumed to be passive things in relation to which active patients act - play a significant role in the diagnosis, treatment and ultimately attempting to survive a chronic condition. Patients are active in diagnosing and enacting their disease beyond the tangible or visible measures of the clinic. The "players" (nurses, assistants, Home Based carers) of the health care system are understood, act and practice disease and illness care differently to what is prescribed under biomedical standards.

Chapter 5- Living with *Suiker* (diabetes)

Treatment of diabetes mellitus is not located in the body but in hospitals, information leaflets and people's homes. It is in the daily lives of people who suffer from diabetes mellitus (Mol & Law, 2004:46).

Introduction

Anthropological insights to diabetes have shifted from an emphasis of diabetes and culture, the individual's emotional distress and the impact of the public domain in which diabetes exists (Ferzacca, 2012). Although these elements are highly theorised and relevant to investigating experiences of diabetes, this seemly singular medical condition in Genadendal represents the fluidity of an individual moving from the clinic as a "patient" to a "person living with diabetes' within the home. Instead, I argue that the focus is re-directed toward the presence of diabetes as it is situated in the bodies, spaces and materiality in which it exists and is reproduced. For Mol & Law this "epistemic shift" (2004:44) is valuable to understanding how diabetes, for example, is not a disease but more a "condition" of the body.

WESTERN CAPE

The body in itself, as a living organism, is unpredictable (Mol, 2009). Diabetes in this chapter will closely examine how a medical condition such as diabetes becomes a coherent (and at times incoherent) collection of social and clinical practices done by and to the body. This approach proves invaluable to understanding diabetes, especially through persons who live with diabetes, the material and the non-physical stimuli in their immediate environments which make this medical condition visible among actors. It is imperative to conceptualise diabetes as part of the everyday for individuals living in Genadendal. The most important aspect I discovered lay in the intensity in the relationship between the person living with diabetes and the medical condition as it documented in the day-to-day lives of people living with diabetes and their bodies. Essentially, this chapter attempts to demonstrate in both narrative and theory how diabetes is understood through a sensorial, but more importantly, a conceptual and material manner where bodies of the individuals like Aunty J and others negotiate in and around having what she labels as *suiker* (sugar) or diabetes.

Narrating, internalizing, experiencing disease

Dit is nice om te hoor dat jy hierdie projek doen, Genalers kan baie praat van hulle self en hulle siektes (Transcribed interview with Oom (Uncle) Sunny Boy, July 2014)

Defining *illness* as a term in Anthropology and within this paper focuses on a subjective experience of having a medical condition or disease (Wiley & Allen, 2009). Illness narratives specifically, which have been discussed within and alongside Medical Anthropology, are used as explanatory models for expressing distress, as well as illness experiences that have been extensively researched in medical anthropology (Helman, 1981; Kleinman, 1988; Garro, 1992 and Lock, 1993). Such narratives are also useful in detailing how chronic illness interrupts and changes the individual's lived experience. I argue that similar narratives of diabetes that follow, such as the experiences of Aunty J, both as an illness and disease reveal the intersections of diabetes and its various understandings, and help demonstrate how biomedical and lay perspectives play a role in positioning diabetes within the individual experience.

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Throughout my stay in Genadendal I was invited into many households where I engaged with people who were either living with diabetes or other medical conditions such as hypertension, hypoglycemia (low blood glucose), cholesterol, fibromyalgia, chronic and diabetes type 1. Their detailed descriptions are the stories/narrative that depicts the movement and experience of disease within this space. For some patients, their diabetes was a consequence of reckless and irresponsible behaviors and a conscious self-harming of their bodies. This was related to the consumption of "bad" foods, negligence in following diabetic treatments as prescribed by medical staff at the clinic and simply misunderstanding of the illness. For others, it is "just one of those things" as Aunty Augusta puts it. Diabetes as a disease and illness is internalized as part of the everyday although this does not imply that it is taken for granted, as a serious medical condition with grave consequences.

These stories of a metabolic disease in practice depict a life where diabetes is a reflection of the past and present. However I argue that diabetes in certain moments, no longer exists as just a chronic illness dependent on the prescribed prior 'facts'. According to Ferreira & Lang

(2006) conventional medical anthropology is shifting presentation of illness narratives. Among the patients, instead of engaging with "face value" experiences of diabetes as a widespread disease and illness in Genadendal, there lies an extension of the self that makes diabetes different and complex in every encounter.

The manner in which people speak about their illness, especially considering their self-evaluating of diabetes, is important in revealing their coping strategies. A patient indicating "I am living with diabetes" differs from one who says "I am suffering from diabetes". Their self-internalizing medical identity is forged not only from their experiences, but becomes a product of the networks and relationships that result from practicing and enacting diabetes as a disease. This could also be argued to be a performance of a medical identity. For Goffman (1959) performances hang together and unfold from various patterns (in the case of metabolic condition of diabetes rather practices) that lead them. In my own study, these performances of practices formed part of a broader system such as the clinical setting (Mol, 2002).

A patient in Genadendal living with diabetes moves between realms of self-management and care and their lives are determined by routine associations and relationships in various spaces such as the clinic. Unlike scholarly discussions of diabetes that emphasize the cultural and psychological effects or psychosomatic symptoms that affect the everyday life of an individual living with diabetes (Mendenhall *et al.*, 2010; Ferzacca 2012, Schoenberg *et al.*, 2005), diabetes in this study is demonstrated by its unstable and unpredictable nature. In narratives of self-management and adherence -but also what appeared to be ignorance and at times noncompliance by medical staff toward managing and treating their diabetes- these individuals are in a constant negotiation with their environment and their bodies.

Patients emphasis their dependence on the government/state (for state contributions, social grants, medication transferred to them via the clinic), the clinic (for diabetes treatment, insulin therapy, advice, diagnosis) and family (for social support, assistance in daily tasks and staying socially connected, as well as interventions (medication, clinic cards for access to institutions, grants, food, and housing for example). My conversations with the men and women who include these associations in their stories and narratives, also rely on the Moravian church for spiritual interventions to assist the treatment and "healing" of their diabetes.

This interdependence network in providing physical and material of living with diabetes, also revealed something more. These 'service' and support providers also disrupt, re-arrange and at times shift experiences, judging from their stories and narratives. The manner in which people living with diabetes communicate and converse about their illness condition, is reflective of their illness experience and in this study, Ross (2010) similarly emphasizes the importance of language in constructing social institutions. In conversations these contexts move beyond a preoccupation with describing experiences: they also demonstrate the impact resulting from the broader community. Individuals in Genadendal living with diabetes although labelled as 'chronic' patients are transformed by their experiences, in addition to the language and stories by which they are expressed. According to Mendenhall et al (2010) making sense of, or 'sense-making' of illness, are revealed in this manner.

Language in the form of stories or narratives creates an imaginative space where fantasy, idealism and reality are blurred, and at times create a diversion from everyday life. Techniques of living and managing diabetes do not always project a visible/explicit and positive result. For example: Aunty J mentions how medication takes a while to move through the blood stream, A1C monitors malfunction, patients experience distress or can't walk to the clinic because of pain. However, when these practices within and around the body do eventually "co-operate", patients consider themselves and their bodies "healed", "cured" or "fixed" for that particular moment.

The life and mind of a diabetic patient: The case of Aunty J

It is nine on a cold Wednesday (July 2014) morning in Genadendal and I arrive at the doorstep of Aunty J. She is already dressed in her "going out" clothes as she labels them and about to have a cup of coffee before collecting her diabetes and chronic pain medication at the clinic. Aunty J had previously reminded me that Wednesdays are allocated for chronic patients: the diabetes, cholesterol and high blood pressure "regulars" as she calls them....

As we are walking Aunty J (who is a first language Afrikaans speaker but occasionally speaks English) starts to express her "other" disease (defined as a biological and pathological condition in this case), in which she experiences pain in her joints, because Aunty J also suffers from fibromyalgia. Having diabetes and

"another" condition often leaves her feeling anxious and at times depressed. Yet she has to acknowledge her diabetes and live with it, she argues. It makes up her reality every day. She follows routine medication times to take her Metformin, Insulin and Voltaren (pain) pills, "it's all about the medication and keeping with the prescription *most* of the time," she tells me....(Fieldnotes July, 2014)

In listening to her story, I realize that the materiality of her disease precedes her symptomatic and sensory experience of diabetes. Katzenellenbogen (2008) argues that the demands of living with diabetes are multifaceted and often incapacitating. At the same time, living with diabetes is not only about following a treatment regimen and monitoring blood sugar levels, it is also felt and experienced. Rhys-Taylor (2010) speaks to this idea of "sensory awareness" which came through in my analysis and helped to identify the usage and importance of sight, sound and smell as primary senses in describing how diabetes exists both in its physical and synesthetic forms (Rhys-Taylor, 2010). According to van Ede (2009), individuals also act as 'consumers' when engaging in various experiences and therefore unconsciously use their senses in recognising and evaluating events such as treating diabetes.

A person like Aunty J is not only self-aware of her medical condition but also sensitive to the stimuli surrounding it and the medication she chooses to consume as treatment. Diabetes medication in the form of insulin therapy (injections, oral medication or "suiker pille" as it is referred to in Genadendal) is a vital demonstration of how the physical body of a diabetes individual endures and transforms or rejects and contests this biomedical intervention that is prescribed for their diabetes.

Diabetes medicine: 'enacting' insulin and its objects

Aunty J expresses her experience of diabetes through a prick of the finger, and pain in the joints and head which helps her assess sugar levels but also the efficacy of medication. In this regard, bodies are sites of the 'clinical experience' of diabetes but simultaneously a sensorial and physiological indicator, producer and control mechanism of disease. In her initial visits to the clinic to test for diabetes, Aunty J's results were compared with the diabetes test levels chart (see figure: 4), which determines whether she is diagnosed as "normal", "diabetic" or "likely to become diabetic" (pre-diabetic).

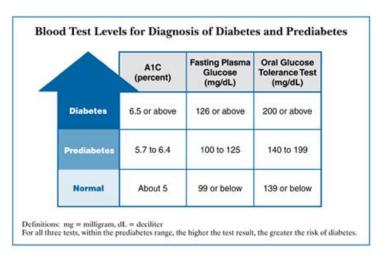


Figure 6: An example of diabetes control chart

Aunty J usually tests her own blood glucose levels at home. To do so she uses her A1C monitor. She bought it a couple of years ago from the pharmacy at Greyton. However today she wants to get tested and weighed in the clinic as part of her monthly routine check-up. When her name was called, she told me to accompany her into the examination room. For a medical practitioner, the presence of diabetes is a blood sugar level above 7/8 mmol/L. For Aunty J, it is in telling the nurse how diabetes feels within her body. She describes her symptoms with light-headedness and at times intuitive sense that her blood sugar level may be elevated. At times the physical symptoms of diabetes may not be present but the condition is still present, therefore diabetes in certain moments exists beyond the realm of instruments, medical tests and patient histories (July, 2014).

The clinical experience

The materiality of everyday life for a diabetes patient is encapsulated in network, or as Latour (2005) argues a "work-net", of medication and medical technology of diabetes control and management. Aunty J like many other diabetic patients, who may not share and understand their disease based on dominant aetiological or even ecological knowledge, still connect and experience their diabetes in multiple ways that are material and immaterial. Latour contends that "To believe in the existence either of individual or of society is simply a way to say that

we have been deprived of information on the individuals we started with; that we have little knowledge about their interactions..." (2011:10): the interactions between patients but also patients and their interaction with the medical objects, their bodies, technology or diabetes information vary, but connect and interface in medical care. For patients in Genadendal, this can be visible in the clinical experience.

Whilst sitting in the examination room with Aunty J, I am reminded of the capacity of patients to incorporate material and non-material entities into their experiences of being and performing their role as a diabetes patient. Aunty J is constantly aware of her physical contribution (a drop of blood) as she sits and waits for the A1C monitor to reveal her blood glucose level. She does not speak but watches every single movement: from the initial prick, the squeeze of her bloodied finger onto the 'stick' until the reading on the machine is being processed. For many diabetic patients in the clinic, their role appears coherent and passive. However this is the misconception. Diabetic patients like Aunty J are subconsciously involved in an active and collaborative effort to monitor and assess their bodies, their diseases and illnesses. In this regard Mol and Law (2004) contend that it is the living body as a subject that enacts disease; however it is this 'private' body that exists beyond language. Although patients in the Genadendal clinic make visible their diabetes through action, this does not necessarily demonstrate explicitly the experience of the body and influence of its surroundings that contribute to making it reality.

On the way home, Aunty J and I discuss her visit to the clinic. She constantly reminds me of her feelings of anticipation, curiosity and relief that her blood glucose level was well within range of being considered 'normal' (according to biomedical standards, a blood glucose level of 6.5 mmol/L). Aunties J, like many of the other participants, constantly interact with medical technologies that assist in making Diabetes visible. In the clinic their bodies become objects from experiencing medical scrutiny- control of one's limbs, blood glucose level, medical diagnosis and scrutiny. Medical technologies and knowledge 'translate' experiences of patients but as an actor in his/her own right, interact with other objects to inform a medical practitioner of symptoms (Lupton 2012). However this creates an awareness of the body in all actors (Aunty J, the clinical staff).

I agree that diabetes as a medical condition can be controlled through a healthy diet, weight loss and exercise (Katzenellenbogen, 2008). However the complexity in terms of

management and care entails persistent education and surveillance by the individual/patient and health care practitioner.

Diabetes Care

Food and nutrition in glycaemic control

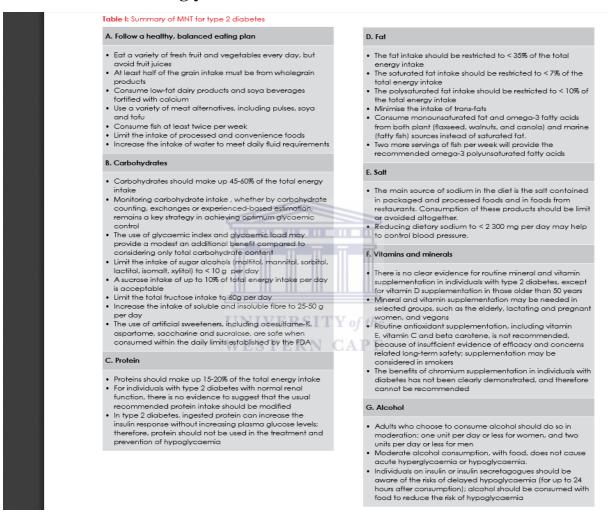


Figure 7: An example of the dietary requirements for diabetic individuals.

It is 3pm as Aunty J and I enter her kitchen. She wants to begin with the preparation of the family's supper, but she does not want to appear impolite. I immediately assure her that I am fine she can go ahead. In the kitchen, I see the brick walls, off-white coloured cupboards and containers filled with tea, dried herbs, flour; scattered all over. I then focus on the food Aunty J is making. She explains that she does not follow a 'completely' healthy and routine (for somebody with diabetes) diet as

prescribed by the clinic. Depending on what is available at the nearest grocer she shifts her dietary practices and modifies what it means to be or live 'healthy' within her own setting and circumstances and also for her own diabetic condition (Liburd 2003). Aunty J believes in "moderation" of any food group. She emphasises the difficulty in maintaining a healthy lifestyle for herself and her family. According to Aunty J:

I like vegetables and fruit, I don't mind eating it. There's times when I won't even lus (crave) to eat luxuries but you know how it goes when you alone watching TV or you go out with family and friends. Say to a birthday or a lunch, you just eat and make sure you take your medication. Two pills before and two after.. (Transcribed notes, November 2013)

The shops around here don't always have nice, fresh healthy stuff. I wait for the end of the month then me and Nita will go to Caledon and do the grocery shopping. Otherwise I wait for Thursday and pick up some squash or butternut suma by Aunty BT. (Transcribed notes, November 2013)

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Although Genadendal lies within a farming community, the availability of 'good' food that meets the nutritional needs of a diabetic is minimal because of access and financial constraints. Clinic staff insist that diabetics should eat fresh produce every day, but this is simply not possible in Genadendal. Instead Aunty J improvises, by using canned vegetables and reducing her fat and sugar intake. Similarly Aunty Sarie, whom I met at the Victoria Centre for the Aged, tells me that she just 'adapts' and will 'make-do' with what she has in her household, which she purchases with her pensioner's grant.

The Victoria Centre for the Aged (Genadendal's only Senior Club facility) supplies the diabetics with a nutritious meal (equal parts protein and carbohydrates) every Monday, Wednesday and Friday. These pre-packaged food plates are loaded with fresh produce that are donated by various firms (Woolworths, other food stores in Caledon). In a semi-rural community like Genadendal, food for individuals represents security, survival and sustenance. For others, like the diabetes patients it also includes a step in the treatment and healing of their bodies.

Nutrition and the consumption of 'healthy' food also reflects a material but simultaneously immaterial demand for treating this metabolic condition in practice. On the one hand, diabetics are advised to be aware of dietary requirements (reading labels and identifying sugar/glucose and fibre intake presented on packaging). On the other hand, it forms part of a cultural and ritualistic practice within the home and among friends and family and it is very much a part of establishing and maintaining social relationships (Liburd, 2003). The aspect of dietary requirements i.e. food in the life of a diabetic is then translated as more than a condition for the treatment and management of diabetes; it also reflects a representation of identity, good management of diabetes and ultimately survival in Genadendal for the diabetic.

In 'caring' for one's diabetes, nutrition and food represent an individual's choice to manage and care for their diabetes (Mol, 2008). Diabetics in Genadendal are advised to eat regularly; medical staff in the Genadendal clinic are always concerned about their patients' poor adherence to dietary prescriptions, not only in terms of nutritional value but also as regards quantity. Diabetic patients do not consume enough protein, vitamins and "good" carbohydrates. Although patients are advised to follow a healthy diet (for diabetics), the process is complex in a setting like Genadendal, where diabetes is very much an expression of unequal access to health care, poor socio-economic environments and marginalization (Mendenhall et al 2010).

Managing and 'caring' for one's diabetes becomes "a matter of attending to the balances inside, and the flows between, a fragile body and its intricate surroundings" (Mol, 2008: 34). Similarly, the diabetic body itself is influenced by the environment within which it exists. Diabetes goes beyond being overweight, not getting exercise, smoking, or drinking. While some people may have a genetic predisposition to diabetes, inequality adds to the risk of developing it – poor nutrition, unequal access to health care services, unequal quality of health care services, being socially marginalised – all heighten the possibility of developing diabetes, as is evident from people living with diabetes in Genadendal.

Aunty S makes this apparent in her discussion with me in the waiting room:

Daar is nie geld nie. Die mense moet ma kliniek to kom as hulle siek is. Maar is jy iets van die apteek makeer, moet jy ma 'n plan maak. (There's is no money. People have to attend the clinic if they are ill. However if you need

something from the pharmacy then you have to make a plan. (Transcribed interview, July, 2014)

I had many similar conversations with other patients in the clinic. Their responses highlighted the extent to which disease can affect the everyday well-being of the individual through its ebbs and flows. One moment diabetes or disease in general is manageable and can be treated. In the next, diabetes patients have to resort to buying medication from the pharmacy in Greyton because of the urgency and treating symptoms of co-habiting illnesses such as hypertension and cholesterol. But this form of treatment is not the only way people in Genadendal response to their medical condition (diabetes): spiritual healing is seen alongside medication as a form of treatment.

Om te bid (to pray), om te glo (to believe)

The well-being of diabetic individuals such as Aunty M and Aunty J exist through practice and the materiality of everyday life: they also demonstrate the inter-relations of different objects, subjects and knowledges. There are many networks that influence and are influenced by the struggle of diabetic *Genalers* and their relationship to the world. One of these is the manner in which individuals live within and alongside aspects of divinity (God). The role of religion is profound within the everyday lives of people living with diabetes in Genadendal. The Moravian denomination is considered a central and prominent representation of the Genadendal community. Their spiritual beliefs have long influenced the manner in which disease is understood and practiced, in their attempts to 'heal' and understand diabetes. Other co-existing religious believers who are members of the local New Apostolic, Old Apostolic and Anglican congregations hold similar belief ideologies that they rely on to guide and intervene in daily practices of diabetics, within their bodies and in spaces such as their homes.

As soon as I first enter the home of Aunty J, I am surrounded by pictures of Jesus Christ and wooden crosses in the lounge area. I also notice framed scriptures from the bible in the wooden display cabinet. Aunty J catches me staring at her collection and assures me that although I am Muslim, the "word" (of the Christian faith) can be understood and understood

by "anyone". In a conversation with Aunty J, I begin to realise the impact of her faith on her physical well-being. *Die Here* (God) is her comfort and provides her with strength to overcome her symptoms and everyday struggles.

Religion answers the existential questions of her world as a sufferer. God is evident as a protector and healer. The reality of being 'sick' is understood as being part of God's will. It becomes testament to the spiritual stance of having a disease that can exists as part of one's body. In their everyday living it demonstrates how the diabetes shifts into the social (within the home) however differently it is regarded within the clinical setting, for example. Back and forth: diabetes is being represented as a natural order and but also spiritual disorder in which religion intervenes in the way that it is understood.

Having diabetes could be a punishment for not living a healthy and righteous religious life, Aunty M would argue. It is a consequence of "bad practices", of living too vicariously and against the will of God. However, repentance and attempts to change attitudes and lifestyle choices are commendable. Persistent communication with a "higher power" (God) and being guided in the form of heeding the advice and treatment of the carers and other medical staff meant that belief in being 'cured', or 'healed' was a subconscious projection of religious beliefs on the individuals among whom diabetics live and experience their disease. In the process of communication with God, one can *voel* (feel) the healing process taking place in the body. One patient Aunty Beth describes how prayer *om te bid* and belief/ to believe *om te glo* helps ease the pain and is effective, whilst consuming medication. Aunty Beth often prays before and after her insulin therapy, thereby indicating that prayer and a spiritual connection makes communication with God, cathartic.

Conclusion

The everyday life of a diabetic as illustrated above in the example of Aunty J and others living with or suffering from diabetes demands to made visible through their experiences. In my attempts to re-conceptualise the anticipated and experienced outcomes of diabetes as both an illness and disease, meanings associated with diagnosis, detection and treatment become unpredictable. The body of a diabetic sees, feels, hears, is ultimately immersed in his/her

disease and the context in which it exists and practiced. However, the ways in which individuals manage and treat their diabetes, are not always consistent with the expectations of biomedical procedures, clinical expectations and the knowledges and technologies brought forward by medical staff. Many patients, including Aunty J, have reported the efficacy of plants or *kruie* as medicine for their diabetes. The following chapter will attempt to provide a walking ethnography of plants, people (carers, patient, bossiesdokters and non-diabetics) and spaces. It will move along with the plant practices of these *Genalers*, documenting how medicine interfaces in this context, in attempts to 'heal' and treat diabetes.



Chapter 6- Medicinal plants: An ethnographic encounter



Fig. 8: Authors own photo Figure 5: A view from Koorlandskloof Street/Straat at midday in Genadendal.

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Introduction

In the previous chapters, I emphasised the importance of 'practices' in the lives of people living with diabetes and/or hypertension. These medical conditions are closely interlinked and many people use (allopathic) medicines and follow a treatment regimen for both. Next, I will examine this idea of 'practice' to re-conceive and re-conceptualise indigenous medical plants used in Genadendal as treatment for, e.g. diabetes. This chapter details a kind of multisensory walking ethnography (Ingold, 2010; Bachelard, 1983 & Careri, 2002). By doing so I try to reveal possible ways to ethnographically get to know medicinal plants, the people who use it and the surroundings in which these plants produce medicine for diabetic patients.

Firstly, I was influenced by Ingold (2008), a social anthropologist who explores the integration of anthropology, environmental perception and an ecological approach to development, and creates a medium for understanding the practice and influence of walking in my own study. In addition, I observed how the approach Ingold (2008, 2010) proposes,

speaks to my experiences of walking, sensing and understanding local ecological knowledge in Genadendal.

By walking with my participants and at times on my own through the landscape of Genadendal, I developed over time a heightened sensorial awareness. As I started to walk in the early hours of a winter's morning the smell of wet earth, the 'herby' odour of plants lead me into view of the cactus trees at the corner of Moravia Street. There I met the Home Based Care Nurses, or walked further along to visit the clinic. Recognising this invaluable yet deeply subconscious practice I learnt how to move within the environment, as well as how local people forged meaningful connections between, plants and their medical conditions.

Similarly, and in accordance with multisensory experiences of ethnography proposed by new developments in multispecies ethnographies (Kirksey & Helmreich, 2010; Rose *et al.*, 2012; Smart, 2014) and to ecological studies as in this chapter, I try to produce a lens for understanding the interfaces of various agents or actants and the connections made between them (Law, 2007). Mol (2002) similarly stresses that recognising the entanglements with other living organisms such as plants should be recognised to highlight the reality of 'doing' (treatment, interventions) but also 'knowing' about medicinal plants. I became knowledgeable about plant medicine treatment used not only for the medical condition of focus in this thesis but also a range of chronic and terminal illnesses that will be discussed.

An important element in this study was to consider the ways in which individuals in Genadendal manage and treat their illness and disease (diabetes) through the use of medicinal plants. This included an insight into their local ecological knowledge about medicinal plants but also the efficacy of using herbal therapy in terms of its chemical components (anti-diabetic properties that alleviate diabetic symptoms). This chapter attempts to resemble a kind of walking ethnographic experience throughout Genadendal, detailing its sights, sounds, tastes and textures, especially as it relates to medicinal plants.

The walking ethnography: Landscaping Genadendal



Fig. 9: Authors own photo taken whilst walking across the Baviaansriver at Genadendal

Genadendal has grown as community in terms of conserving its land, which residents call home. More importantly, the conservation of cultural and historical heritage in Genadendal has contributed to its development. According to van Papendorp (2009), the cultural landscape is inclusive of the environment and how the environment has transformed over time. The name is already an indication of the place itself, situated between the Riviersonderend (river without end) mountains. Surrounded by rocky hills, mountains, cultivated and uncultivated land, Genadendal is a simple yet profoundly attractive place. In looking at historical accounts of its past one can still identify what was originally the Renosterveld vegetation area in which plants used for healing were harvested by the local Khoi, long before the Mission Station was established. Although a semi-rural community with dilapidated houses and pollution arose in some areas, all of these add a particular character to what is perceived as a 'rural' landscape, including honeybush farms, livestock etc.

Genadendal is the oldest mission station in South Africa and has well-preserved historic buildings, which contribute to the old-time atmosphere of the small town. The landscape of Genadendal is peaceful, a serene environment with lush greenery and beautiful scenic routes. The smell of fresh air in the mornings and dense cold mist that covers the entire town in the evenings struck me every day as I walked, talked and soaked up the people, plants and places. When I first arrived the landscape struck me for its visual beauty – the mountains, changing

of colours, the greenness and the almost quaintness of the town and the old buildings. I had only encountered the medicinal plants of the area through my reading of articles, historical documents and the few botanical studies done there (van Wyk, 2000; Erasto *et al.*, 2005; Thring & Weitz, 2006). However, as I constantly walked throughout the area, I soon discovered how plants interacted and lived among the people of Genadendal.

I often walked with my colleague past the old mission station and up into the mountains. The scenery was beautiful. I could also it see every time I look outside my window. The greenery and abundance of vegetation had a particular smell that was in the air. It smelt grassy, herbaceous and clean. Inside my room I was also surrounded by plants and nature all the time. The water flowing past in the stream was a golden brown colour and was really cold "berg water" as the locals refer to it. To the people of Genadendal it represents purity, straight from a beautiful source, die berge (the mountains). As I walked with participants they taught me how to spot certain plants like Fig bush, Wilde Als, Boegoe (or Berg Buchu), Bakbossie and Groen Amar, which I discuss in detail in this chapter. I learnt to recognise the shape of the plants, the colour and shape of their leaves and their smell. Wilde Als for example, has a strong herby, earthy scent that I learnt to recognise even if I did not immediately visually identify the plant. Some plants are identified by their beautiful flowers e.g. Kankerbossie or Belbossie and its orange flower (see dried plants below). As I walked across the river and soaked up the midday sun I felt a sense of well-being and of being surrounded by nature. It made me feel even more a part of this community of plants - at one with the beautiful sights, sound of insects and birds, and smell of earth and vegetation.

Walking is a common activity for people in Genadendal. It represents more than routine physical exercise. People walk to see and feel their surroundings. Walking to the shop, to the clinic or to visit a friend is a sign of "gesondheid" (health) and is also an engagement with the environment. As detailed in this chapter, the practice of walking became an opportunity for me to engage with "the medicine of the earth", as Uncle James reminded me. It was important that I learned to "see": to recognise individual plants, what the plants mean to people who use them and to understand as a practice why plants are important.

The people who live with diabetes and/or hypertension in Genadendal frequently use *kruie* or medicinal plants. The practice of using plants is multidimensional. It radiates the local knowledge and provides a representation of plants as treatment strategies but also as living

organisms that intervene and mediate within various illnesses and diseases such as diabetes. In the environment of Genadendal, these plants are visible and can easily be identified by 'Genalers'. Young and old demonstrated knowledge about medicinal plants derived from stories, pictures and conversations that contributed to my appreciation of various ways of knowing, but simultaneously participating in practices surrounding plants. These stories also speak to historical accounts of medicine in Genadendal and inform plant usage in this South African setting.

A brief history of medicine in Genadendal



Fig. 10 Authors own photo: Inside the Genadendal museum depicting "illness", "disease" and "sick" bodies with various medical conditions.

The Genadendal museum in Mission Square provides an interesting but brief history of medicine in the community. I also discovered old biblical and philosophical scriptures, and Dutch medicinal influences related to disease treatment and management, describing medical conditions as a result of social "wrong doings" and exposure to diseased bodies. In Genadendal it is also seen as something bringing an individual closer to God. Through experiencing "diseases" and "illnesses" one is drawn into repentance, and afterwards the love and compassion of the Creator.

In the images presented in the Genadendal museum there is also recognition of various medicinal forms including homeopathy, reflexology, neuropathy and hydrotherapy. The

images presented that speak to medicinal plants are labelled as "herbal therapy" or "home doctoring". Genadendal people are represented as excellent "herbalists". The many displays thus recognise "alternative" medicine as an important past and modern contributor to assisting Genadendal people with their medical conditions.

Medicinal plants in South Africa: A trajectory of knowledge/healing systems in medicine

The "re-introduction" of medicinal plants through ethnobotanical research in South Africa and more importantly within the domain of knowledge studies in anthropology about plants and their practices, have provided an interesting yet challenging discussion (van Wyk, 2000, 2009; Abo, 2008; Erasto *et al*, 2005; Thring & Weitz, 2006; Afolayan & Sunmonu, 2010; Davids, 2012). In Genadendal specifically - as seen from the photograph below - botanists have already been doing research in the area on plants, including those that are used for medicinal purposes. Similarly, in other parts of the country there is also increased interest in ⁶indigenous knowledge, including herbal management through plant medicines (Oyedemi *et al.*, 2009, Cohen, 2009; Davids *et al.*, 2014).



Fig. 11 & 12: A documentation of medicinal plants and their uses sponsored by Prof Ben Erik van Wyk. These posters can be found at the Genadendal Museum situated in The Mission Square.

6

⁶ Indigenous Knowledge (IK) is described in South Africa as local knowledge that is unique to a particular society (Green, 2012). In this thesis, local knowledge of diabetes and the use of herbal therapy/ medicinal plants are the topics of focus.

Gibson and Kilian (2013) note the difficulties in localising and appropriating indigenous knowledge such as medicinal plant usage in a South African context where indigenous knowledge has been subjected to intellectual criticism. The inception of the Indigenous Knowledge Systems policy (IKS) ,while a significant contributor to national discussions of post-apartheid strategies concerning traditional or indigenous knowledge, has found itself in what Green (2012) deems a "science war" between traditional medicine and Science in South African scholarship. The result is an engagement with indigenous knowledge outside the domains of what is considered "respectable" intellectual frameworks such as biomedicine.

One of the questions (Green, 2013) seeks to investigate, is how scholars can potentially push beyond a selective account of indigenous knowledge that mimics a Western and almost singular based perspective to understanding, for example nature – or in the case of my own study, medicinal plants. In a knowledge economy, indigenous knowledge systems, including that of and traditional medicine are often perceived as lacking intellectual empiricism, which do not follow the philosophy of biomedical treatment. In contemporary scholarly enterprise, indigenous knowledge should, according to Green (2013), be recognized alongside its scientific counterparts in a production of different kinds of ecological knowledge perspectives in which each is recognized and validated. Furthermore, as demonstrated in this thesis, these systems (biomedicine and medicinal plants) can also fruitfully be seen as interconnected and intertwined in specific moments of practice.

This is particularly the case for diabetes. In this regard Oyedemi *et al* (2009) argue that, while medication such as insulin and other hypoglycemic medicinal treatments are offered by clinics and hospitals, these are costly and not always available in rural areas. Therefore attention should also be given to alternative ways of treating and managing diabetes, including the knowledges involved in doing so. One example is an ethnobotanical study in the Eastern Cape on the use of medicinal plants in diabetes management. The authors stress that various plant types utilized have anti-diabetic potential for diabetes management. These plants contain high levels of polysaccharide (starch) complexes (among other properties) which are useful for diabetes treatment (Oyedemi *et al.*, 2009).

According to van de Venter *et al* (2009) anti-diabetic agents found in medicinal plants are under-researched considering the significant biodiversity of South Africa. This also includes a focus on the diversity of local (de Venter *et al* (2009) call it "traditional") knowledge that

accompanies these plants. In Venter *et al's* (2009) study, eleven species were sampled for their known anti-diabetic properties. In Larsen *et al* (2012) the use of honeybush is considered an agent, as it increases glucose utilization.

Thus the phytotherapy used in diabetic treatments are considered to be potentially valuable. In South West Nigeria, for instance, scholarly discussions and information surrounding the local utilisation of medicinal plants are limited, as also in the broader African continent. The results of this study demonstrate that "traditional" medicine (and more importantly indigenous knowledge) is used to diagnose and treat diabetes mellitus through identification of symptoms and treatment that can assist in relieving frequent urination (a common symptom in diabetic patients) and a reduction in the presence of glucose (Abo *et al.*, 2008). Gaining much greater exposure in South Africa the last ten years, the use of commercialised medicinal plants has had a huge influence on understanding socio-cultural contexts and the people who use them. The uses of medicinal plants have also been incorporated into scientific productions and scientific processes. In South Africa some medicinal plant medicines are sold as products (van Wyk 2008): for example; *Boegoe* (Buchu) tonics and capsules, Lessertia frutescens(L.) capsules (used for mental health and vitality in Genadendal), *Kooigoed* capsules (Sceletium – used for anxiety and stress), and *hoodia* capsules (for weight loss and used as a general health tonic).

Deutschländer, Lall & van de Venter (2009) argue that diabetes mellitus has become not only a disorder of both hyperglycaemia and glucose intolerance, its treatment in terms of biologically active compounds are found in medicinal plants. In my experience with the individuals in Genadendal the use of medicinal plants and their related knowledge moves through various spaces (the clinic, their homes, walking to the shop, going to the church bazaar etc.) and in patient negotiation of diabetes, as also their simultaneous sense-making of diabetic treatment opportunities.

According to Strathern (2004: xxiv) "the world is always both one and multiply enacted – it is always both a container and what is contained. We cannot see it all at once". In the context of Genadendal, Strathern's (2004) 'Partial Connections' can also be related to the 'undoing' of the divisions of doctor- patient relationships in, for example, managing and treating illness conditions such as diabetes. In this manner, patients intervene in processes of healing by

using medicinal plants. In the context of Genadendal people living with diabetes and their realities or 'worldmakings' offer an insight into the various 'diabetes' that become visible under medicinal treatment and its scrutiny, in this case the use of medicinal plants as part of knowledge of healing. These various 'diabetes' as I argue above, are done and treated differently as in the example of Genadendal.

Plant practices: diabetes therapy in Genadendal

People living with diabetes, hypertension and other illnesses and diseases in Genadendal have historically incorporated the use of *kruie* as part of their treatment regimens. For example; Aunty J is a diabetic and also suffers from chronic pain (fibromyalgia) of the muscles and joints. Although Aunty J receives her medication from the Genadendal clinic every third month, she also uses medicinal herbs and plants as part of her daily treatment schedule. Aunty J says very proudly:

The (herbs) *kruie* really helps with feeling good. You know I have very bad pain but when I drink the tea I make from the dried honeybush and that other herbs, I feel better at the end of the day...(Transcribed interview June, 2014)

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Aunty J also experimented with a few other medicinal plants since she was diagnosed with diabetes. Her least favourite was the *Wilde Als* - although it helps with the *gesondheid* (health) it is "galbitter" (bitter as gall). This interaction of people, plants and the world as dependent on one another to bring each other into being, is discussed by Cohen (2013). It is also demonstrated in the example of Aunty J. By knowing how to identify a plant like the honeybush or wilde als as medicinal, Aunty J knows how to pick it (at the stem), she knows that it is available and grows in her garden, and also in other spots along the road and in the mountains. She knows that without the presence of a plant medicine she may need to use her diabetes medication from the clinic, although the latter does not help with her vitality and strength -it simply controls her symptoms. Plants as living organisms, as well as contributors to knowledge, influence and affect not only medicinal conditions but create a sense of well-being. The liveliness in the stories of people living with diabetes form part of these networks in which the 'ecology of well-being' (Cohen, 2012) is constantly being enacted and produced.

Aunty Mina is both a hypertension and diabetes patient. Recently she has also been complaining about rheumatism in her legs. Aunty Mina's favourite medicinal plant for the pain is guava leaves boiled in water. She goes outside to her garden to the guava tree and picks the leaves in the early hours of the morning. She washes and cleans the entire leaves, including the stems – this is vital. She says that the strength of the plant is found not only in the leaf itself but the stems and to an extent the sap in the bark, which tastes stronger than the fluid in the leaves. Aunty Mina then throws these leaves into a pot of boiling water to cook for 30 minutes. I start to see the leaves, which are usually firm, start to bend and move. The smell resembles a steaming and dense grass-like odour that she enjoys sniffing. She explains to me even the smell is therapeutic, it calms her down. I eagerly await the results of her mixture and look into the container of brown liquid 30 minutes later. She says it should cool down for a bit and gives me some to taste...I do not like the weird aftertaste and Aunty laughs whilst saying I must finish it up, promising I will feel "soos a nuwe mens" (a new person) if I use it religiously.

Uncle J, another *Genaler* with diabetes and hypertension is vibrant and full of humour. He appears to be very curious as he stares at me and Aunty Susan walking toward his home. He hurries back into his home. It is 9:30am, we open the gate and Uncle John sits in the lounge reading his newspaper. When he sees Aunty Susan and myself, he invites us in. Uncle John is very knowledgeable about plant medicines and uses them actively, Aunty Susan reminds me. He immediately jumps into the conversation and asks me what I would like to know about plants and why? After providing a detailed description of my objectives and aims for the study, he tells me about his history with medicinal plants.

Uncle John grew up surrounded by the old remedies, like Dutch medicines, and the *kruie* his parents collected in the mountains and veld. Uncle J used plants not because he could not afford medicines, but because he believed in the power of plants and had confidence in the plant-related healing knowledge he had learned from his parents. His parents in turn, had inherited it from their own forefathers and -mothers. The use of medicinal plants had continuity for him and linked him to the past while also keeping him healthy in the present. For many Genalers medicinal plants have high cultural and social value because, unlike pharmaceuticals, they have been part of many family histories when treating medical conditions. They speak to the identity of the local people, their Khoi heritage, their place in nature, the history of the town as a mission station, but also a place where people value

historical knowledge and practices such as the use of medicinal plants. If he felt unwell Uncle J took plant medicines – and he constantly reminded me that these had made him feel better, made his symptoms disappear and revitalised him. It gave him strength and enhanced his sense of well-being. Although Uncle J took his pills for his 'condition' (diabetes), he stressed that *die kruie help my en het my grootgemaak* (the *kruie* helped and raised me).

Mr J, on the other hand, is a self-proclaimed *bossiesdokter*. He was born in Cape Town, but spent his childhood and adulthood in Genadendal. He stays in the Kersiesdorp region as one enters Genadendal. Whenever he speaks about the environment, plants and the movement of the Genadendal people, he emphasises the way in which these aspects come together as healing trajectories through the many stories he had previously heard from satisfied diabetes and hypertensive patients.

Mr J tells me that his first patient was his mother who lives in Genadendal and suffers from diabetes and cholesterol. He explains that he constantly had to endure his mother's complaints about headaches and her eyesight deteriorating as a result of her diabetes. Living in a household with a diabetic is challenging, he admits. Mr J often reminds his mother to take her medication and maintain her prescribed diet. As Mr J became more interested in and more knowledgeable about what he terms "natural healing", he thought of possible plant mixtures that could alleviate his mother's diabetic symptoms. He explains in his broken English:

I just give her a mixture of *Wilde Als*, *Wilde Dagga* and some *Honeybush* so it won't taste so bad. She didn't like it at first but after she started to see and feel the difference... (Transcribed interview, Mr J, June, 2014)

Currently Mr J practices a mixture of the way of Jah (Rastafarianism) and Christianity. Like many other *bossiesdokters* the "natural" way of life is important for their own well-being as well as that of their families. Mr J was introduced to Rastafarianism by a friend he met in Genadendal. For Mr J the plants are living 'things': they are alive, breathe and adapt to the environment just like human beings and they should be handled with respect and care. I was introduced to a few other 'knowledgeable' people in Genadendal through Mr J but also through patients I had the pleasure of meeting in the clinic and centre for the aged.

Unlike Uncle J and Mr J, Uncle B was initially worried that the information he provided could be used in an unethical manner and that his knowledge would be exploited by me. Over time, as we got to know each other better, he began to trust and teach me. Uncle B started to demonstrate his plant-preparation methods and to discuss plants with me. His first 'lesson' was to allow me to feel, smell and taste the plants. For him the knowledge of healing with plants was deeply sensorial. For instance, he gave me a piece of dried anyswortel. I assumed it was liquorice as it tasted very similar. The important message from him to me was to not just understand a plant in one way, e.g. through its taste; I had to get to know it in the veld, look at it, smell it, see where and how it grew, scrutinise its roots, shape and form, recognising not only the whole plant, but also separate leaves and stems, taste it, and try to discern its strength and healing power as I swallow the juices that come from it. Both Uncle B and Uncle J emphasised that by distributing plants and knowledge about its medicinal use to *Genalers*, it enriches them all with their ancestral blessings and maintains the connection between the spirit of God, Jah and plants as nature.

For some, the distribution of plants relate to an economy of medicine in which buying and selling plants as medicines are transactions of health and well-being. According to Cocks & Dold (2002:589) the trade in 'traditional' medicines forms part of a "hidden economy", largely influenced by South Africa's rapid socio-economic growth. Similarly, in Genadendal the informal trade of these plants by Rastafarians and self-proclaimed *bossiesdokters* are not purely about money, they are also about peoples' appreciation for local (indigenous) knowledge and the historical use of this form of medicine. Ultimately for people who engage with medicinal plants in Genadendal, plant practices are a connection from the past to the present.

These many people in Genadendal who use plant medicines, including the Home Based Care nurses, are blurring boundaries between biomedicine by incorporating medicinal plant usage into their everyday, as well as professional practice, transferring ecological knowledge and distributing plant medicines.

'Blurring Boundaries': When biomedicine and plants meet

During my study in Genadendal it became evident that knowledge, people and plants often overlap and intervene with each other in messy relations. This network of material and non-material entities and their respective principles change and adapt through and within the environment. An example of this change was demonstrated in the relationship of Home Based care nurses with their patients, with pharmaceuticals, as well as with medicinal plants and their related knowledge within Genadendal.





Fig. 13: Aunty Susan (Home Based Care Nurse) with Wilde Dagga (Leonotis Leonurus L.) in Volks Street/Straat.

As we are walking early in the morning, Aunty Susan (picture above) points to the plants and immediately identifies one as the Wilde Dagga (Leonotis Leonurus L.) plant. She puts her bag down and tells me to stand closer. She tells me that this plant, the Wilde Dagga is very popular in Genadendal. She advises me to look for the "oranje blommetjie" (orange flower). Aunty Susan starts to pick off the leaves, smells them and tells me to take them home to boil into tea and drink to protect me from getting colds and flu which I have been having frequently. She looks at her watch and says we must go to the next "diabeet mens" (diabetic). We start to walk plant in hand between the tall grass to her next 'patient' as Aunty Susan calls her. We reach her

home, which is located a couple metres away from where Aunty Susan picked the *Wilde Dagga*. Aunty P welcomes us into her home. She asks Aunty Susan whether we went out picking plants as she stares at the *Wilde Dagga*. Before Aunty Susan takes out her patient file and evaluation sheet for Aunty P a brief discussion ensues when Aunty P asks Aunty Susan: Nou wat maak die kruie? Ek het gehoor dis goed vir hoë bloed (what does the herb (medicinal plant) do? I heard is its good for high blood pressure). Fieldnotes, June, 2014.

Aunty Susan explains that it can be used for almost all medical conditions but people do not use it correctly. She hands the plant to Aunty P like a gift. Then Aunty Susan explains the 'proper' procedure for it use: pour boiling water over it and have it "rest" for a few hours *om te trek* (extracted from the plant into the water). She explains that when the colour of the water is a brown, it is ready to drink. She also tells Aunty P about the places in the area, close to her home, where the *Wilde Dagga* grows. This interaction between Aunty Susan and Aunty P illustrates to me the relationship that medicinal plants have to people, but simultaneously the relationships or networks forged through the use of this medicinal treatment for diabetes and other medical conditions such as high blood pressure.

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My experiences of walking through the streets of Genadendal, in the veld, the mountain, through the vlei and the in-between the spaces where the town meets the veld alerted me and imbued me with the environment in an embodied, sensual and even aesthetic way. I was constantly captivated by the number of medicinal plants that grow and sustain themselves within Genadendal and its environs. Sometimes one of the clinic or Home based care nurses would take me by the hand and show me plants. In these moments they would shift suddenly from their biomedical knowledge to that of medicinal plants. Aunty Susan in particular was an amazing source of information and discussion, as I walked with during her early morning patient visits. According to Deutschländer *et al* (2009: 349)

The use of plants in traditional medicine finds its natural expression and further development in primary healthcare. Current estimates suggest that in many developing countries a large proportion of the population relies heavily on traditional practitioners and medicinal plants to meet primary healthcare needs. Although

modern medicine may be available in these countries, herbal medicine has often maintained popularity for historical and cultural reasons.

In Genadendal there are no 'traditional healers' (i.e. diviners such as *sangoma* or *amagqirha*) but there are herbalists and other knowledgeable people – including nurses. Like almost everyone else in the community, the latter also use medicinal plants - despite the supposed "duty" to promote the usage of allopathic treatments only. For them their professional training and expectations of the health care system seemingly segue with their own belief in the power of plant medicines. I initially expected the nursing staff to be opposed to the use of plant medicines, especially when patients were "on" certain diabetic drugs. Yet, that is not how the nurses made sense of it, instead they felt that their first responsibility was to the people under their care – who like them had experience of the use of medicinal plants and believed in its usefulness for the daily management of diabetes. Being part of the Genadendal community the nurses (both at the clinic and HBCU) had also grown up with parents and family who used and still utilise medicinal plants. They knew that the people they monitored regularly for blood sugar etc. also used plant medicines.

In Genadendal, sufferers of diabetes and high blood pressure feel a sense of duty and responsibility to collect and use their pills. Although some may say that these are temporary 'fixes' for their respective *siektes* (diseases\illnesses), their practices inform a larger network of patient choice and care (Mol, 2008). The role of biomedical and pharmaceutical treatments in managing diabetes and its related illnesses- hypertension and cholesterol - are imperative to understanding the relationships between biomedicine and plants. The role of the clinic and pharmacy that assists but also intervenes in practices of medical plant usage among people in Genadendal who suffer from type 2 diabetes is also of importance.

Ek kan die pille neem, maar ek gebruik die kruie ook, dit help my op n ander manier (I can take the pills but I use the medicinal plants too; it helps me in another manner). (Transcribed interview, Uncle J, November 2013)

Prescriptions and pills as part of diabetic treatments are prescribed by medical practitioners as a 'must' for people living with diabetes, yet few restrictions are placed on the usage of medicinal plants. While dosages and prescriptions differ, the side effects of medicines are

often similar (although they can vary in intensity from one person to the next), e.g. headaches, dizziness and nausea, if taken in large dosages and/or over time. Although plants can also have negative effects when used incorrectly long term damage was less likely, I was told by Uncle J.

Plants serve as mediators between people, their medical conditions and their environment. In addition plants are a well-known, accepted and even encouraged form of treatment for locals. In Genadendal the usage of medicinal plants is not entirely linked to poor access to healthcare resources, but is influenced by peoples' experiences of it as efficacious, and as having the ability to provide a 'natural' form of relief. Medicinal plants are active 'members' or 'actants' (Latour 1990): in most households 'agents' used by people, which also heals sickness, alleviate symptoms or make them disappear. Thus, in a Latourian sense (2004) in Genadendal, medicinal plants are both actors and acted upon.

As indicated in the preceding chapters, disease, e.g. diabetes, can never be considered separate from the practices in which they are done or enacted (Mol, 2002). Techniques, from processes of diagnosis to various treatment and disease management systems, must be considered in the manner in which they make disease visible and also knowable to various health practitioners and individuals living with diabetes. What I am arguing is that in the investigations of the diabetes 'epidemic' in South Africa and the focus on diagnosis, treatment and management through pharmaceuticals, the constant interfaces between various medical/healing knowledge systems in a place like Genadendal are effaced: whether rigidly scientific and biomedical, or in relation to local knowledge to medicinal plants.

Plants used in the treatment of diabetes and co-habiting illnesses such as hypertension and cholesterol

The following are some visuals of the plants people in Genadendal utilised and incorporated into their treatment and healing regimens for diabetes, hypertension and a range of other medical conditions.

In communicating with patients (who suffer from diabetes, hypertension and cholesterol), the nursing staff in the clinic and Home Based Care Unit, the Rastafarians and *bossiesdokters*, I have been exposed to my own "discovery and perhaps a re-discovery" (Thring & Weitz, 2006: 271) of plants and their practices for diabetes but also "co-habiting" conditions such as hypertension. Far beyond simply engaging with plants as alternative to pharmaceuticals, professional and local knowledge were intertwined, with their methods and procedures of treatment mixed together. In this process, plants created new connections and brought about new relationships (Latour 1999, Callon 1999). Below are some of the commonly used plants for diabetic and hypertensive conditions.



Fig. 14: Authors own photo: Spekboom found in Koorlandskloof in Genadendal

1. Spekboom (Portulacaria Afra)

People reported that the most common part of the plant used was the sap and leaves. *P. Afra* is used in the treatment of diabetes mellitus and hypertension. Both nurses and *bossiesdokters* recommend the use of the *spekboom* for decreasing high blood pressure and blood glucose levels. The sap is drawn from the leaves by squeezing the fresh plant and consuming the

gummy liquid. The chewing of leaves is also an effective method for immediate reduction of raised sugar and blood pressure levels, I was told.



Fig. 15: Authors own photo: Wilde Dagga in Volks Straat/Street

2. Wilde Dagga/Wild Dagga (Leonotis Leonurus L.)

The utilization of the leaves was said to be most effective in the treatment of diabetes and hypertension. A commonly used plant medicine in Genadendal, *L. Leonurus* has a long historical record of usage in South Africa (van Wyk & Gericke, 2000; Thring and Weitz, 2006). A decoction is made from the leaves. Boiling water is poured over the leaves for the extraction process and consumed either as a hot or cold drink.



Fig. 16: Author's own photo: Guava tree in Aunty Mina's garden

3. Guava (Psidium Guajava L.)

Leaves from the *Koejawel* (Guava) are the most utilized part of plant used for diabetes (van Wyk & Gericke, 2000; van de Venter *et al.*, 2008). The leaves are used for their antibacterial and more importantly hypoglycaemic control properties. The infusion is made with boiling

water and consumed daily. Leaves are also washed and chewed. Diabetes patients reported using guava leaves which they pick from their gardens and guava trees that are located in and around their homes.



Fig.17: Wilde Pieterselie Taken from www.ispotnature.org

4. Wilde Pieterselie / Wild Parsley (Heteromorpha Arborescens)

Wild Parsley or *wilde pieterselie* water is a common drink among diabetic and hypertensive patients. The plant's size and texture varies from very small to bigger leaves and stems (van Wyk & Gericke, 2000; Erasto *et al.*, 2005). Both roots and leaves can be used. In Genadendal, people often infused the leaves in cold water and drank the water with their allopathic medication.



Fig. 18: Authors own photo: Aloe ferox in between the rocks along the hiking trail

5. Bitter Aalwyn/ Bitter Aloe/Cape Aloe (Aloe Ferox)

As a succulent, the Bitter *Aalwyn* can be found from the Cape to KwaZulu-Natal (van Wyk & Gericke, 2000). The plant grows along the streets in Genadendal but also along the mountain trails. The sap that oozes from the leaves of the Aloe plant was traditionally, and is still

boiled and used as a cleansing/purgative agent. People with diabetes sometimes eat the leaves or put them in boiling water. Leaves are also applied externally to cuts and wounds as a skin regenerative agent.





Fig. 19: Taken from: http://www.exotic-plants.de

Fig. 20: Taken from: www.plantzafrica.com

6. Buchu/ Boegoe (Agathosma Betulina) and/or Berg Buchu/ Boegoe (Agathosma Crenulata)

Rastafarians in Genadendal reported that their biggest *verkoper* (seller) and most sought after plant is Buchu. Both species of buchu are situated in the mountain areas of the Cape (van Wyk & Gericke, 2000). Used a health tonic for general ailments, patients who suffer from diabetes and hypertension also consume buchu in mixtures that utilise both *Wilde Als* (Artemisia Afra) and *Wilde Dagga* (Leonotis Leonurus L.). Both leaves and stems are used in a decoction and consumed once a day for two to four times a week as a diuretic and digestive simulant.



Fig, 21: Taken from: www.botany.cz

7. Kankerbossie/Belbossie (Lessertia Frutescens (L.)

Known as the most multi-purpose medical plant in Southern Africa (van Wyk & Gericke, 2000; Van Wyk, 2008). The leaves and stems are mostly used in decoctions and infusions. A range of medical conditions such as cancer, diabetes and arthritis are treated using the *Kankerbossie*. *Genalers* also reported using the medicinal plant for inflammation and as an antiviral agent for colds and flu.



Fig. 22: Author's own photo: Wilde Als picked from Uncle's J'S garden

8. Wilde Als (Artemisia afra)

This grey and green leafy plant can grow up to two metres high. It is also considered one of the oldest medicinal plants in Southern Africa (van Wyk & Gericke, 2000). The leaves are the most common part of the plant used (Thring and Weitz, 2006; Van Wyk, 2008). Diabetic and hypertensive patients in Genadendal also reported utilising both leaves and stems (Erasto *et al.*, 2005). A decoction or infusion is an effective method of extraction and is mostly consumed as a warm drink. Conditions also treated with *Wilde Als* include: headaches, general stomach ailments and colds and flu.



Fig. 23: Authors own photo: Groen Amara found in a garden in Magerman Laan

9. Groen Amara (Vernonia Oligocephala)

Known for its anti-diabetic properties (van Wyk & Gericke, 2000), *Groen Amara* or *Groenemore* and its bitter green leaves and stems are consumed by patients suffering from diabetes in Genadendal. The plant is also used as a health stimulant for general medical conditions of the stomach. Rastafarians and *bossiesdokters* alike reported prescribing *Groenemore* for pain, constipation and urinary tract infections.



Fig. 24: Taken from: southeastfromcapetown.blogspot.com. Picture depicts Genadendal community members preparing *Heuningbos* for the drying process

10. Honey bush/ Heuningbos (Cyclopia)

Two species of *Heuningbos* commonly found in Genadendal are *Cyclopia Speculata* and *Cyclopia Maculata*. It is commercially farmed in surrounding farm areas of the Overberg region. According to *Genalers*, *heuningbos* is challenging farming practice, because its successful cultivation is dependent on access and knowledge on its processing as well as its care in a plantation. It is also recognised as a popular tea (*heuningbostee*), and is considered a substitute for 'ordinary' tea (van Wyk & Gericke, 2000). Among diabetic and hypertensive patients in Genadendal, honey bush tea is a regular health tonic and is consumed mostly using boiling water - incorporating both the leaves and stems.



Fig. 25 & 26: Authors own photos: *Bloekom* trees at the entrance of Genadendal and an example of *Bloekom* leaves.

11. Bloekom/ Blue Gum (Eucalyptus globulus)

Now considered part of the landscape of Southern Africa, *Bloekom* is widely used in various forms in the country - for cleansing agents and as food (van Wyk & Gericke, 2000). It is sold in Genadendal by Rastafarians and mostly used in dried form (the entire plant). The leaves (dried or fresh) are used in decoctions and taken few times a week or when necessary. As immune-stimulant agent, *Bloekom* is also used as a general health drink by locals.



Fig. 27: Taken from: www.ispotnature.org

12. Berg Seldery/ Wild Celery (Peucedanum galbanum)

This plant was reported as one of the most effective and commonly used medicines by diabetic patients. Since it sometimes grows in steep places, *Berg Seldery* is difficult to collect, but is harvested and sold locally by Rastafarians. It is consumed after being infused with boiling water. It is also drunk as a cold tonic. *Berg Seldery* is effective as diuretic (van Wyk & Gericke, 2000) for both bladder and kidneys. It is also used in general health drinks mixed with parsley. Common colds and arthritis are treated by using hot mixtures which contain this medicinal plant.



Fig. 28: Authors own photo: Bakbossie found in a garden in Madiba Laan

13. Bakbossie/ Bakbos/ Bakkerbos (Conyza scabida)

This plant was originally used to heat up ovens - hence the name *bakerbos* or 'baker bush' (van Wyk & Gericke, 2000). In Genadendal *Bakbossie* grows in the gardens and streets among residential houses. It is usually described by its narrow leaves. Although previously used to create heat and used to bake bread, the *Bakbossie* plant is used to relieve pain and stomach ache.

The use of medicinal plants in their dried form is a common visual in many households in Genadendal. As purchased and received from Rastafarians and Bossiesdokters within the area, mixtures are also provided as prescriptions to individuals suffering from diabetes, hypertension and other illnesses and diseases.



(Left): *Honey Bush/ Heuningbos/ Cyclopia maculate species found in and around Genadendal



*Kankerbossie/ Belbossie/ (Lessertia Frutescens (L.)



*Berg Seldery/ Wild Celery



*African Potato/Patat



*Anyswortel/ Aniseed Root

^{*}All author's own photos

Conclusion

The use of medicinal plants in the treatment and management of disease and illness still requires a great deal of attention. We have to consider that plants form part of a larger network, than is simply described by its ecology and scientific description. Plants as living organisms exist among other living organisms such as people (home based carers, doctors, Rastafarians, larger community etc.) and also in immaterial realities such as indigenous knowledge systems. The use of medicinal plants among people living with diabetes speaks to these 'linkages' or assemblages (Katzschner, 2013) in describing how human (people living with diabetes) and nonhuman elements (medicinal plants) co-exist but simultaneously relate to one another. A new kind of relationship is constantly being re-introduced through every story and encounter among these forms and ways of knowing about plants, sickness and its care and treatment. Although these 'knowledges' are produced in specific spaces and under particular conditions, they produce a *practice* (Turnbull, 2009) that embodies and engages with the environment. Similarly in this thesis, people in Genadendal have produced a local insight to the ecology of medicinal plants but have ultimately demonstrated how productive these relationships (plants and people) have become within their own realities.

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Chapter 7- Conclusions

Diabetes and local knowledge is best understood in its definitions, management and healing practices within Genadendal. This includes a focus on immaterial and material realities as shown through procedures in the clinic, in the home and in practices of treatment of diabetes. In this investigation of diabetes I illuminate its encounters within various knowledge systems by showing how its actors - for example medical staff and people living with diabetes - interface. Similarly medicinal plants intersect in diabetes with the knowledge of nurses, bossiesdokters and people who use plants as well as allopathic medicines. I argue and try to prove that theoretically and ethnographically diabetes knowledge among people in Genadendal moves between orthodox biomedical explanations to an emphasis of practice and local knowledge. Local knowledge is embedded in practices surrounding diabetes. From the moment of diagnosis to treatment, diabetes is 'done' differently by medical staff, people living with diabetes and those who seek herbal therapy as examples.

Practices are essential to understanding diabetes; however it cannot be holistically researched and understood, as I discovered. Knowledge of diabetes is complex and is best understood and enacted by the bodies experiencing its symptoms and treatment. I draw on Strathern's (2004) partial connections to describe how knowledge about the world and its connections (including knowing about diseases such as diabetes) cannot be completely understood. In an attempt to making sense of diabetes, acknowledging and understanding local indigenous knowledge is vital to understanding how this study attempts to make its contribution. Through a theoretical but similarly ethnographic lens this study demonstrates how diabetes moves in and through various spaces whilst emphasising the importance of the local knowledge.

Conceptually tracking diabetes within the everyday lives of diabetic patients proved a challenging methodological task. The 'objective vs subject' divide translated into a messy yet intricate perspective in which both ethnographic and material semiotic approaches, I argue, were necessary to understanding diabetes in Genadendal. This methodological approach revealed that as a researcher I was able move from providing a holistic and often reductionist understanding of diabetes, to detailing the spontaneous nature of disease and illness. It is this spontaneity and unpredictability that demonstrated how bodies, objects, subjects and the

environment are a process of practice and enactment instead of a definitive reaction to diabetes.

My aim was to present and represent the lives of people living with diabetes who consider their medical condition a negotiation of knowledge and practice through everyday engagement with their respective environment. Obtaining this information and the process was a negotiation for the researcher. According to the extant literature (Flaskerud, 1998, Garfield *et al.*, 2003; Berkowitz, 2013) diabetes is considered a sensitive issue and diabetic patients, a vulnerable population. Through daily observations and interactions with these individuals, I discovered that diabetes in Genadendal is not constant in particular institutions (the clinic) and activities but rather throughout daily practices, seen in various other spaces (the home, walking in Genadendal) and embedded in social understandings of disease, despite each space being an important representation the 'multiplicity' (Mol, 2002) of diabetes.

The clinic proves particularly interesting as it shows how connections and often misconnections are made within the clinical setting. Objects within this space, are often assumed to be passive; however, in this study, a result from a blood glucose test for example, means more than its face value. It means for the 'patient' that the body is 'sick', the body is considered 'diabetic'. In attempting to reveal the agentivity of patients and objects within the environment, I discovered the roles each play in managing and treatment of non-communicable disease such as diabetes. More so, the role patients or people living with diabetes are productive because of their enactments in monitoring their diabetes as a disease within their bodies.

I argue that the formal healthcare system (PHC) within which the Genadendal clinic is recognised, is demonstrated to work alongside other knowledge systems (local knowledge about diabetes), which produce different diabetes with each patient that is assisted. Diabetes is entangled in a web of social and political environments. However, it is within these environments where patients living with diabetes re-produce their own knowledge about diabetes, which differs from biomedical explanations. Similarly this re-production is a sensorial experience where making diabetes visible incorporates various practices such as the consumption of medicinal herbs/plants within the home for example.

The process of understanding diabetes includes a focus on the detailed day-to-day experiences of the diabetes patient that I describe. I use the example of Aunty J as a focal point to describe and illustrate how a body that suffers from diabetes is immersed in experiencing the disease but more importantly the context within which a patient like Aunty J and others make sense of this medical condition. I argue within this chapter that people and their interactions with the healthcare system, medical environments inside and outside the home AND knowledge that stems from these sources, are essential to understanding the meaning and practice of diabetes within Genadendal.

Diabetes knowledge among patients in Genadendal are more unpredictable than a simply symptoms-diagnosis-treatment procedure. This unpredictability for example can be witnessed in moments where despite medication the body living with diabetes still experiences headaches, medical technologies appear to dominate or there is miscommunication, and additional medical treatments are used alongside clinically described medication. I take a closer look at the agentivity of diabetic patients and their role in self-medication and management, which presents a demonstration of people living in Genadendal and their ecologies of well-being. This understanding of well-being incorporates various organisms within the environment such as food and medicinal plants, as a means to live with but also negotiate around having diabetes.

I postulate that medicinal plants use in the treatment and management of diabetes is an important practice in Genadendal. Medicinal plants form part of a larger social and biological network. In this study this form of treatment for diabetes is more than that simply described by its ecology and scientific description. Living organisms, add to which medicinal plants as described, live among others such as people in Genadendal. However these plants also demonstrate how connections/ linkages are made between material and immaterial realities i.e. people and plants.

The role of medicinal plants is receiving a re-introduction into medical anthropology and currently incorporates a larger interdisciplinary connection to other fields of inquiry, which has subsequently assisted in understanding its role; in this case, as a diabetes treatment. Medicinal plants are also involved in practices by various actors, including formal medical staff who engage and transfer their own knowledge about herbal therapy. The driving force behind the usage of the medicine for diabetes patients in Genadendal lies within the local

knowledge that often becomes lost within more formalised definitions and methodology. The impetus and overall argument of this study is a re-focus on the importance of a rapidly growing metabolic disease that has silently threatened the well-being of many individuals living in the Western Cape. As illustrated with patients in Genadendal, diabetes and local knowledge surrounding this medical condition has interestingly demonstrated how it can be treated, understood and managed. Ultimately this study plays out as a *multiplicity* of knowledge and practices, vital to conceptualising disease within its context.



Illustrations

Landscaping Genadendal



The infamous dam where many "Genalers" visit.



The Khoi- kraal situated along the hiking trail behind the Mission Square



Along the hiking trail situated behind the Mission Square

Spaces between...



Information centre and guest house in Mission Square

The Genadendal clinic



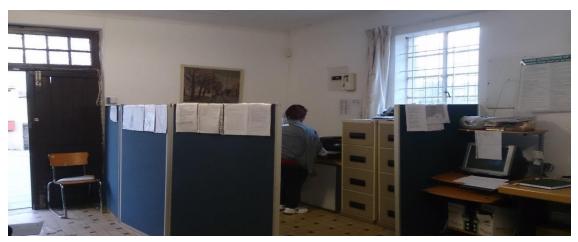
The Moravian Church located in the Mission Square



Genadendal library



Victoria centre for the aged



Home Based Care Unit office

Diabetes and Hypertension: Patients and Procedure



A Diabetic patient who also chronically suffers from hypertension, has her blood

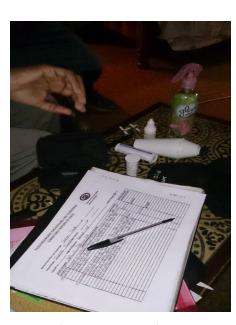


Oom "Sonny boy" having his blood pressure tested by Home Based Care Nurse Aunty Susan

pressure tested regularly although she UNIVERSITY of the administers her own blood glucose test. WESTERN CAPE



The results of Aunty S's random blood glucose test



The patient sheets on which Home Based Care Nurses record patient results

^{*}All author's own photos

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