



Arlena Siobhan Liggins

MAKING DIABETES

The Politics of Diabetes Diagnostics
in Uganda

[transcript] + Medical Humanities

From:

Arlena Siobhan Liggins

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The Politics of Diabetes Diagnostics in Uganda

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Diabetes is regarded as one of the most challenging global health issues of the 21st century. Especially countries with weak health infrastructure are struggling to deal with the increased demands this chronic disease entails.

Tracing the effects of a diagnostic device, the glucometer, this book examines how it contributes to the making of diabetes in contemporary Uganda. Arlena S. Liggins demonstrates that depending on who uses the glucometer, the outcomes may go far beyond diagnosis. The book draws a complex picture of hopes and misplaced expectations, of trust and mistrust in a technology to which access in the first place is all but a given.

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Contents

Abbreviations	7
Introduction	9
Traveling tools, traveling methods	14
The matter with numbers.....	17
Spaces of diabetes - the fieldsites	21
Sketching Uganda’s health care system	23
A roadmap to visibility - outline of the book	26
1. “If you are lacking insulin” - Diabetes Mellitus	29
Not just about sugar	30
The mysterious illness: one (hi)story of diabetes	34
A disease without (hi)story?	39
From urine to blood	41
Testing matters: diagnostic tests and diagnostic criteria	44
2. (Un)measured yet (un)seen	51
Number business.....	55
Data in transit? A status quo of NCDs in Uganda	61
(Un)measured but seen - diabetes in Uganda	66
3. Thinking beyond the evident	73
Technologies without borders?.....	73
The rise of evidence-based medicine	77
Infrastructures or “Stuff, staff, space and systems”	84
Translation(s) in a technologized world	89
4. A ‘simple’ technology and its translations: the glucometer	97
Know it, get it started and “make your life easier”	101
Not for diagnosis?	108
Keeping the testing going	115

5. Diagnostic detours and a logic of chance	119
Diagnostic (un)certainties	124
Private Diagnostics	129
Survival of the richest	133
Pending diagnoses and “technological flowers”	137
Diagnosis as a logic of chance?	141
6. My numbers and my-Self	149
“Numbers don’t lie”	155
Knowing the good number	160
“Who shall I trust more, the number or myself?”	166
Numbers against uncertainty, numbers for a hopeful life.....	171
7. Seek and you shall find: Medical Outreaches	177
The crowd pullers	184
“An act of giving without receiving”	189
“The money is totally worth the experience”	196
Desired tests, undesired outcomes?	203
Concluding Remarks	209
Contesting the global health agenda.....	210
Trajectories of a fluid technology.....	211
Re-visiting (in)visibility	214
References	217

Introduction

It happened on June 5th in the year 2009¹. A Friday, 26 degrees Celsius. The wind was blowing lightly and the average humidity measured that day was 78%. A thunderstorm would be looming over Kampala, the capital city of Uganda, later in the day. It was also that very day in June, when a 42-year old man, whom I will name George, died only a few hours after he had been seen by a medical doctor. The newspaper article in the Daily Monitor, one of the two biggest national newspapers in Uganda, reports that George was a painter living with his mother. Only one week before he died, George started to become restless and began drinking huge amounts of water. He and his mother were thinking that it was likely that he had developed a heat stroke, which would surely pass. However, instead of improving, George's condition worsened and culminated in a state of confusion, lethargy and stupor and "his speech was incoherent". His mother discerned that her "son's breathing was erratic and his eyes were sunken and his breath had a queer smell". One day before his death, on June 4th at 5.50 p.m., so the article says, George's mother consulted a health care worker who knew about George's history of depression. She sent for a doctor because his condition was worrying. George's mother would later tell the court that "the doctor did not have any equipment on him" when he attended to George. The doctor's diagnosis: depression. He gave the advice to visit his general practitioner the following day in order to receive medication. The last time his mother saw her son alive was at 1a.m. Five hours later, when she wanted to check on him again, her son "had died in bed". After George's death had been investigated by the police, the case finally ended up in court. One of the expert witnesses, a medical professor, explained that he had concluded that all of George's symptoms, the "state of confusion, thirst, sunken eyes, peculiar breath,

¹ This narration is freely told following the newspaper article "Wrong diagnosis lands doctor in jail" published in the Daily Monitor on December 11th 2016, by Dr. Sylvester Onzivua. The quotes in the narration are taken from this article. The emphases in the quotes are mine. The original article can be found here: <http://www.monitor.co.ug/artsculture/Reviews/Wrong-diagnosis--doctor-jail/691232-3480400-wtljvzbz/index.html>.

and inability to speak [were] classic symptoms of diabetic keto-acidosis²". He continued that it would have been the obligation of the doctor to check the sugar levels in the "patient's blood and [he] should have immediately had the patient admitted to hospital where he would have been treated and saved". Another medical expert ascertained the doctor should have measured the blood sugar levels with a glucometer, which would not even have taken one minute. "The *failure to diagnose* the patient's condition was the main cause of death", he concluded. After considering the body of evidence, **the judge pronounced his sentence:** "The nature of your offence is too serious for anything other than a custodial sentence. You failed to *recognise* the patient's condition despite the fact that all the *classic signs* of a diabetic condition were present. You opted for a diagnosis that was *contrary to all the evidence*. This was a gross breach of your duty of care. An expert called your diagnosis appalling. I agree. It was clearly criminally negligent and a wholly preventable death." The doctor who had failed to diagnose George with diabetes was sentenced to two and a half years in prison for manslaughter.

Why did George have to die? Is his medical history of depression to blame, blinding the doctor to consider any other disease as the reason for George's ailments? Or because the doctor who attended to him was not able to interpret and "recognize" the "classic signs" of diabetes? Perhaps the doctor would have been able to diagnose George with diabetes if he had had the equipment to test him, which was seen to be his obligation and "duty of care"? I am afraid these questions will have to remain without clear answers. Conceivably, it is a bit of everything. No matter how much effort we will put in understanding what has really happened to George and especially why it has happened or why it became a legal case in the first place, we do know that the doctor failed to diagnose him with diabetes and instead chose a diagnosis that was "contrary to all the evidence". A diagnostic act hereby appears to be not only critical and essential in clinical practice in the encounter between a patient and a medical practitioner. But a diagnosis is also a political and economic³ issue, dependent on functioning (health) infrastructures, the availability of and access to tools like diagnostic devices and the knowledge when and how to apply them. I shall utilize George's story to mark the course this book will pursue.

This book examines diagnostic and testing practices in the case of diabetes in Uganda. What seems to be the story of a single individual, 42-year old George, can in fact be seen as part of a larger problem: Matters of diagnoses especially for diabetes are relevant more than ever in the face of growing numbers of individuals

2 Diabetic ketoacidosis (DKA) is an acute life-threatening complication of diabetes (more frequently in type 1 diabetes) characterized by a severe lack of insulin in the bloodstream (cf. Srinivas et al. 2016).

3 And it may become a legal issue as well, as we have seen.

affected with this disease globally. Opposed to the long-held assumption that diabetes is predominantly a concern of countries in the minority world, especially the majority world⁴ is now struggling to deal with this chronic disease. Compared to the number of deaths due to HIV/AIDS in 2016, five times as many people died as a consequence of diabetes worldwide – of which three quarters occurred in the majority world (Al-Lawati 2017; Moran-Thomas 2017). In this 21st century, many scholars are warning, a growing “epidemic” of diabetes is dawning (e.g. van Crevel, van de Vijver and Moore 2017; Rodriguez-Fernandez 2016; Herman and Zimmet 2012; Assah and Mbanya 2009; Tabish 2007; Boutayeb 2006; Marshall 2004).

Matters of diagnosis have clearly climbed up on the global health agenda. The appreciation of diagnostics as an integral part of care for the health of the global public has expanded: from a former focus on access to essential medicines in the early years of this millennium, by the question of access to diagnostic tools. As a result, the development of innovative and inexpensive point-of-care devices – allegedly easy to use, mobile devices, applicable even outside of hospital settings – has gained momentum, seeking to enable the rapid detection especially of infectious diseases in resource poor settings (Street et al. 2014 et al.). This is not the case for the glucometer. Compared to humanitarian point-of care devices, specifically designed to meet the needs of under-resourced settings, the glucometer has not been designed to tackle urgent diagnostic issues for places where essential laboratory infrastructures are lacking. As the first and often only choice technology to diagnose diabetes, glucometers, however, take on a significant role in the diagnosis of diabetes particularly in these settings. In a way, glucometers are emblematic for how the access to suitable diagnostic devices for this pressing global health issue is erratically distributed across the globe (Moran-Thomas 2017). While glucometers are seen to be part of the basic health care package in large parts of the minority world, the access to and maintenance of these point-of-care devices may be hard to attain in large parts of the majority world. Yet, since diabetes is a chronic disease, which can be managed but not cured, continuous testing is an essential part of the long-term care needed to determine the amount of medicines in order to keep the glucose levels at bay (Heurtin-Roberts and Becker 1993). Unlike other point-of-care devices the glucometer serves as both, a diagnostic as well as a continuous testing tool. As Moran-Thomas (2017) puts it straight in a recent article, the role of the glucometer “in frontline diagnosis also hinges on a painful irony: glucometers’ metrics help to make visible an enormous population of people living with diabetes

4 Throughout this book I will avoid using terms such as “Global South”, “developing country” or even “third world”, unless they are part of a quote. Instead, I prefer the terms “minority world” and “majority world” to focus on the demographic distribution rather than the economic development.

in contexts of poverty, many of whom cannot consistently access the same meters then vital for day-to-day care.”

The glucometer is yet part of another predicament. It serves not only as a diagnostic and glucose testing tool, but it is further an epidemiological tool that has a great stake in making diabetes visible and quantifiable in Uganda and beyond. Evidence and the visibility of a disease are interlinked with the diagnostic possibilities, like the story of George has demonstrated and as this book intends to show. Evidence, especially in the form of numbers, is further needed in order to stand up to the regimes of global health. Numbers will be adduced when health priorities are set, when agendas are formulated and action plans for global health interventions are planned and implemented. The equation is simple: the visibility of diabetes stands and falls with the access to appropriate diagnostic technologies. I therefore argue that the restricted availability of glucometers is one reason for why the widely spreading global health claims of dramatically increasing numbers of diabetes are only slowly translated into action on a global scale as well as on a local level in Uganda.

In this regard this book asks: How does the glucometer contribute to the making of diabetes in Uganda and what does the device actually render visible on a local scale and beyond? In seeking to answer this question, a number of other questions emerge. What are the circumstances under which diabetes is diagnosed and tested in Uganda? Which trajectories do individuals with diabetes and their caregivers pursue to access diagnostic devices for diabetes and when do they fail? Who are the actors involved in diagnosing and testing this chronic disease, what are their agendas and how do they deal with the outcomes of these tests? And finally, in which ways does the glucometer help to solve or create new problems in Uganda?

I will approach these questions through the conceptual lenses of evidence-based medicine, infrastructure and translation. Linking these concepts, I suggest, reflects the interwovenness of the technological, infrastructural and scientific apparatus that determines diagnostics and in turn frames care. The global travel of biomedical technologies hereby offers a platform to understand how certain techniques and technologies come to work together in specific infrastructures and under certain premises. Technologies are important constituents of individual and collective practices ordering lives and bodies in health and illness. Therefore, the value of medical technologies and the practices in which they are involved cannot be neglected or simply taken for granted. What happens when a biomedical technology like the glucometer travels to a context distinct from its country of origin (cf. Müller-Rockstroh 2007; Hadolt et al. 2012)?

In 1981 Allan Young made the case for the notion of embedded knowledge, which cannot be deduced from peoples' talks or stories alone but is incorporated in nonverbal schemes, clinical procedures and technologies. Unraveling medical knowledge also requires to look at practices and apparatuses and not only into

minds and cognitive operations (Young 1981: 324). In the process of translating and appropriating a technology in a novel context (be it a glucometer or a new policy), neither biomedicine nor its new context stays the same. As they travel and are put to use in diverse environments, biomedical practices and artifacts shape their receiving societies. They do so for example by altering existing practices, bodies, identities, and institutional structures. Simultaneously, the technology itself is formed and created by the cultural, political, economic, and sociocultural dynamisms expressed in these environments. The extent to which biomedical practices and artifacts stay the same or alter in the progression of their appropriation and translation – at home, in clinical settings, global and public health interventions, or in policymaking (Granado et al. 2011) – hence is an empirical matter.

In order to critically employ the legislations of global health (Biehl and Petryna 2013; Adams 2013, 2016), diagnostic and testing practices in the case of diabetes can be a crucial step to get an ample picture of the dynamics within the (re)organization of health care services on a local level, but also the need for a reorganization and reframing of chronic diseases on the global health agenda. Chronic conditions in general and diabetes specifically in Uganda and elsewhere in the majority world can be a crucial entry point to understand how an ‘emerging’ threat like diabetes is and can be approached and how it is handled. Since diagnostics are not only essential in uncovering disease on an individual level, but contribute to the visibility of diseases in epidemiological terms, I intend to highlight the complexities in which the glucometer is entangled in Uganda. Scrutinizing matters of diagnoses does not only highlight local embroilments, but may allow insights into broader structural and global dynamics that have to be addressed when tackling diabetes as a pressing global health issue. The way diabetes is diagnosed marks what will be made visible and what remains hidden. Therefore, this book ultimately deals with how a biomedical device like the glucometer alongside its consistency and rationalities, contributes to the (in)visibility of diabetes. And this in the light of a setting deprived and curtailed by resource shortages, weak health infrastructures and an alleged lack of global interest and investment.

Up to now, a range of studies on diabetes and other chronic diseases within anthropology and related fields in the social sciences have mainly been conducted in the minority world. For instance, focusing on health beliefs, coping strategies and the day-to-day suffering of individuals affected by diabetes (cf. Lynch and Cohn 2016; Mendenhall 2010; Manderson and Smith-Morris 2010; Guell 2009). Others have highlighted the chronicity, long-term, aspect of this disease (Weaver and Mendenhall 2014; Whyte 2012). I do not question the merit of these studies for they have yielded valuable insights especially for what it means to be chronically ill. The diagnosis of diabetes in weak health infrastructures, however, has not yet been adequately captured. Without attending to the ways in which diagnostic practices are enacted in a setting like Uganda, the daily hazards of dealing with diabetes as

a public health issue as well as the struggle for visibility in the vortex of the global diabetes epidemic, will remain unseen.

Accordingly, I see the main contribution of this book in the critical examination of diabetes as an emerging global health problem. The days in which HIV/AIDS, Malaria and Tuberculosis were the major killers in Uganda and elsewhere seem to have passed. Against the odds this shift has not led to a decrease of global interest in these matters but the contrary is the case: the global market for the so-called ‘Big Three’, HIV/AIDS, tuberculosis and malaria, is flourishing as ever. On the downside, actions taken to tackle diabetes and other chronic diseases do not match the claims of an arising diabetes epidemic. The battle against diabetes surely is an individual and local one, but it is not less a global one. I argue that the faith and hopes towards a technology like the glucometer may obscure the far-reaching implications intrinsic to such a diagnostic device. In the face of the long-term care and continuous testing an individual will need, the glucometer will not be able to serve as a panacea. Instead it raises larger questions about the prioritization of certain health conditions over others. The glucometer hereby is illustrative for the struggle to provide and maintain diagnostic access for diabetes while having to deal with rising numbers of people affected by this disease.

The following section will foreground my research questions on visibilities of diabetes in Uganda in a methodological reflection. I will illustrate the role ethnographic field research may play especially in the evidence-based world we live in today. We will have a closer look at the emergence of the new global health (chapter two) alongside the rise of evidence-based medicine (chapter three) in more detail – ethnographic evidence consistently “*dies* within the dominant conceptual paradigms of global health” (Biehl and Petryna 2013: 16; emphasis in the original).

Traveling tools, traveling methods

“Put aside the camera, and join [...] in what is going on” — Malinowski 1984 [1922]: 20.

This book is based on approximately 14 months of anthropological fieldwork. In 2012, when I came to Uganda for the first time, I conducted three-months of research collecting illness narratives of individuals affected by diabetes for my M.A. dissertation research. Two years later I returned to Uganda as a research assistant for the DFG-funded project “Translating Global Health Technologies: Standardisa-

tion and organisational learning in health care provision in Uganda and Rwanda⁵. The following year, in June 2015, I joined this research project as a PhD candidate, and undertook another nine months of fieldwork in three consecutive research phases⁶. Coming back to Uganda on these different occasions after the initial stay, meant that I had a solid basis on which I could ground my research activities. In a way, it was like continuing from where I had stopped, rather than starting anew when I came back for my official PhD research. Many of the contacts I had established back in 2012 were fruitful also for the current research. For example, I continued my research in two of the three health centers where I spent large parts of my fieldwork. Further, some of the individuals I had worked with before became part of my PhD research again, including diabetes patients and their health care workers.

Semi-structured interviews (Bernard 2011; Medjedovic and Witzel 2010), focus-group discussions (Pérez 2017; Witzel and Reiter 2012), numerous informal conversations and participant observation (Paxson 2017; Robben and Sluka 2007; Lüders 2004) were the main tools that helped me approach my research object and track places and people who were, in one way or the other, involved in making diabetes visible in Uganda. In total I collected 57 formal interviews with diverse actors in the field. These included members of the Ministry of Health of Uganda; employees of the National Medical Store (NMS), responsible for the distribution of medicines and medical equipment in Uganda; I met district health officers as well as biostatisticians; I visited different medical equipment distributors in Kampala; and of course, I worked closely together with laboratory technicians, nurses, doctors and with people affected by diabetes. Next to the formal interviews, a large number of interviews were informal in nature, where I took extensive notes.

I also engaged in participant observations for which I spent a large part of my stay in three governmental health facilities, which I will further specify in the next section. In these settings, I mostly commuted between the examination rooms and the laboratories, following patients and glucometers. I assisted in some of the activities that were going on there. One of my tasks for instance was, to assist in the registration and documentation of the individuals who were seeking care at the governmental health facilities. Especially when a health worker or a laboratory technician was working alone, this meant a small relief for her or him, considering the large amount of paperwork required. At times, there were up to four different books in which the same information had to be written. I noted down patients'

5 DFG is the abbreviation for "Deutsche Forschungsgemeinschaft", the organization for science and research in Germany. You can find more details on the research project here: <http://www.spp1448.de/projects/translating-global-health-technologies/>.

6 The first phase took place between July and September 2015, followed by another phase from January to March 2016. The final research phase was from July to September 2016.

names, their villages, their age and sex. Sometimes I also wrote down the testing results – depending on the health center not only for diabetes, but also for other tests that were performed in the laboratories. I called patients by their names when it was their turn to see the doctor or health care worker, which very often ended up in bouts of laughter, both in the laboratory and the waiting area, since I was apparently not very good at pronouncing the names correctly. At the end of a clinic day I would help to clean the examination room, assist in filling up the shelves with medication. I often gave health workers a ride from the villages back to Kampala. An additional and welcome possibility to ask more questions that had come up during the day, or simply more time to chat about other things.

Though all interviews and focus group discussions were recorded with a digital voice-recorder after obtaining the consent of the interviewee and consequently transcribed verbatim, I took extensive notes. This was also the case if recordings were not possible or unwanted. My field diary was my constant companion fed with information, thoughts, ideas, worries and sketches whenever and wherever possible. This was a welcome routine especially in the evenings after I had returned home and had the time and quiet to reflect upon the day and prepare for the ones to come. Most interviews were conducted in English, however, especially interviews and group discussions with individuals affected by diabetes, even more so in the villages, required the assistance of a translator. Though I had attended a Luganda language class, the language widely spoken in central Uganda, my proficiency remained very limited. Despite my limited vocabulary and grammar, which merely allowed me to engage in simple phrases like saying ‘hello’ and ‘good bye’, ‘thank you’, or ‘diabetes’, this was nevertheless important to establish a good rapport with people. My informants enjoyed it very much when I tried to speak Luganda and appreciated the effort on my part. My language skills would have not been enough to conduct a whole interview, not to mention grasping the fine nuances and details this language has to offer. I therefore worked very closely with my interpreter Lucy, who is an anthropologist herself. Her support was of indispensable assistance not only during the interviews when translating, but also when debriefing thereafter or arranging the next ones⁷.

My aim to study diabetes in terms of its visibility, required me to move around and search where it was made visible, how and by whom. The glucometer is one of the main actors, contributors and facilitators that makes diabetes visible. Since this device is mobile and not fixed or bound to a certain place or actor, it required me to

7 At times, I had two interpreters. While Lucy was conducting the interview or leading the focus group, the other interviewer was sitting next to me translating simultaneously. This convenient possibility made it possible for me to ask follow up questions immediately. That I partially had two interpreters was due to the fact that Lucy had a family member whom she was teaching interviewing techniques.

be mobile too. I had to maneuver between different locations, engage with different people and join diverse activities. The empirical chapters of this book (chapter four to seven) reflect this mobility and flexibility, where in each of these chapters different actors engage in (testing) practices for different reasons and with different outcomes. Since the glucometer is a traveling technology this opened up the field to do what Marcus (1995) framed a multi-sited ethnography. As suggested by Marcus (1995) and Hannerz (2003) shadowing a traveling technology and to observe its alterations makes it necessary to study a particular technology or object in different places. Multi-sited ethnography “defines as its objective the study of social phenomena that cannot be accounted for by focusing on a single site [...]”. The essence of multi-sited research is to follow people and objects, connections, associations, and relationships across space (because they are substantially continuous but spatially non-contiguous)” (Falzon 2009: 1f.). Multi-sited ethnography the way Marcus (1995) suggested, should nevertheless not simply be understood as a proliferation of different sites, stacking one on top of the other. Instead it should rather be perceived as a practice deriving from the object of study, because if “our object is mobile and/or spatially dispersed, being likewise surely becomes a form of participant observation [...], it is ‘fieldwork as travel practice’” (Falzon 2009: 9). Hence, ethnography itself emerges to a travelling practice following objects like glucometers, other technologies, ideas and people (ibid.).

Depending on the actor, and dependent on the agendas, a certain part of diabetes may become visible or it may remain hidden. Studying the visibility of diabetes in Uganda therefore meant to hunt for the different actors who contributed to it in one way or the other. Especially in the beginning of the research I caught myself being a ‘detective’ on the trail of diabetes and the glucometer. I could not take it for granted that I would find one in every health facility. Even if the device was said to be at a certain place, for instance in a specific health facility, this did not necessarily mean that it was (still) there. At the same time, it was possible to find the glucometer in places where I would not have expected it. One time for instance, a glucometer fell out of the pants pocket of a passenger who was sitting next to me in a minibus in Kampala. It could neither be taken for granted that diabetes was captured in numbers in policy documents or at the Ministry of Health of Uganda. Especially in the beginning this made it hard to grasp the scope of this chronic disease until I understood that the fragmented or missing numbers were part of its visibility and invisibility.

The matter with numbers

Diabetes has a lot to do with numbers. From a global health perspective and in line with what evidence-based medicine (see chapter three) tries to reach and convey,

disease is inherently bound to numbers. Diabetes is about numbers from an epidemiological point of view, concerning the prevalence rate of the disease in different settings. Individuals become numbers as soon as they are diagnosed with a disease – number 11 in the registration book of a health center, or individual ‘number 3789’ with diabetes in Uganda.⁸ Diabetes itself is expressed through a number, the glucose level that makes a diagnosis possible in the first place, and will be part of the lives of individuals from the day this diagnosis has been declared. Getting a clear picture of these numbers and gathering quantitative data on diabetes, however, appeared to be a difficult undertaking in my research and the information I received varied substantially. The national prevalence rate of 3.3% for diabetes in Uganda had been generated and published in a report from 2016 (MoH 2016; see also chapter two), the first and only study assessing the burden of non-communicable diseases in Uganda. However, it was a lot more difficult to receive localized information on the number of patients having diabetes in the districts, respectively to find what these numbers were based on or how they had been generated. It was further not easy to track down, which health facilities in Uganda were able to diagnose and offer testing and medication for diabetes, for instance as part of functioning diabetes clinic days. On an official level, such as in the Ministry of Health of Uganda, where I expected to find this information, I was looked at with skepticism and suspicion. They wondered, why I would be interested in where or how diabetes was diagnosed or which facility had a diabetes clinic, if the national prevalence rate was finally known? Was it not enough to know *that* diabetes was diagnosed instead of knowing *where* this was? Or, as I was once asked “But what is it more you need to know? The numbers, they are now there.” Indeed, numbers, or numerical evidence, are one way to account for the visibility of a disease. But what happens if these numbers are highly localized and in other parts (e.g. other districts of Uganda) fragmented or lacking or not the ones you were seeking for? Or what happens, if numbers cannot express what words can?

Ethnographic methods are often not as valued as data from disciplines that predominantly work with a quantitative methodology and numbers, as is common in many global health studies. Qualitative methods here often have a reputation of not being objective, and therefore not qualified to establish generalizations, which is usually the aim of statistical and numerical evidence that biomedicine and related fields usually operate with. I had sent a chapter of this book to one of my friends, a laboratory technician, working in a laboratory of a governmental health facility in Uganda. A week later he replied in an email that he liked the paper, *but* “I

8 There is a registration system partly in place for diabetes in Uganda. Yet it is not, or cannot be used in every health facility across Uganda, which leads to a fragmentation of data in Uganda and a lack of data focused on diabetes in specific areas of Uganda.

think some numbers should be included to make it more meaningful". This statement, adding numbers for more meaningfulness, is not only an expression of the encounter between two individuals with different disciplinary and methodological backgrounds. Instead, rationalizations, numbers and metrics are taken to be the most reliable and trustworthy entities and indicators. They are regarded as the necessary foundations on which (political) actions and considerations about the world can unhesitatingly be grounded. Yet the narratives and stories we come to hear and note down, and which we use to add lived experience are unique ways of dealing with, understanding, and conveying certain phenomena in our ethnographies.

Nevertheless, medical anthropology feeds on biomedical evidence in many ways. As Ecks (2009) highlights, in our funding proposals, or as in my case in the introduction to this book, we use epidemiological data to show that our object of study is urgent in one way or the other. When moving in the realm of the global health today we more than ever before need to ask how medical anthropology is connected to biomedical practice and global health. Ecks (2009) argues that

the two fields are not as far apart in how they gather evidence as is usually thought. Biomedicine is not a passive object of the anthropological gaze. Instead, biomedicine defines most of the parameters within which we are working. Biomedicine informs anthropology on all levels of inquiry, from the definition of what we aim to study, to the way we write field notes, and the way we stake our claims in arguments with medicine. On each level, questions of 'evidence' are crucial. (ibid.: 82)

Like the story of George in the beginning has shown, there can be evidence and 'visibility' of disease even next to or as a substitute for numbers. It is visibility through stories. As human beings, and perhaps even more so as anthropologists, next to the observations we make and the interviews we conduct, we listen to the (hi)stories of the individuals we come to meet. People with whom we work and share parts of our lives and from whom we want to learn. Each story – the way it is told and what individuals decide to tell – is unique. Stories cannot be captured as a number. While we carefully listen to these (hi)stories and while we spend our days living small parts of these stories with them, new worlds unfold. Hereby, as Mol (2002) states "[m]ethods are not [only] a way of opening a window on the world, but a way of interfering with it. They act, they mediate between an object and its representations" (ibid.: 155). Though numbers count especially in evidence-based medicine, stories like the one of George can enrich these numbers. As Merry (2016) beautifully encapsulates, ethnography is essential

to counter the homogenization and stripping away of the social world inherent to quantification. Without that, one misses critical dimensions of the texture of social life and reinterprets the loves of the nonelites around the world through

the lens of the cosmopolitan experts who design indicators and their concepts of social problems and interventions [...]. Quantification has a great deal to contribute to global knowledge and governance, but it is important to resist its seductive claim to truth and to recognize it as only one form of knowledge with its own distinctive limitations. The narrative ethnographic account provides an important complement to quantification. We rely on numbers alone at our peril. (ibid.: 221f.)

With stories like George's, we can get noticed, make someone politically aware of a problem, attract the attentiveness of possible donors or "justify sweeping ideas and large-scale interventions" (Biehl and Petryna 2013: 17). Who, if not an anthropologist, is better positioned to capture these stories? It is empirical and not numerical evidence that arises when individuals seek to express their worries or other feelings, their hopes and angers or their happiness. Narratives, "which then open up to complex human stories in time and space. Life stories do not simply begin and end. They are stories of transformation, linking the present to the past and to a possible future" (ibid.: 19).

The way how anthropologists work has changed in a way. It is no longer a stepping in and stepping out the way Hortense Powdermaker insinuated back in 1966. As anthropologists we step in, into novel settings and new situations. When we step out by leaving our 'field', when we go back home, we often times stay connected. We are aware that not only we have changed, but the 'field' has changed, too. Though we might not any longer be present in person, the connected world of today allows us to stay in touch with the individuals we have met and with whom we have built a relationship. We might be thousands of kilometers apart, yet we are always only one message away. "Fieldwork thus emerges as process rather than event, a 'spiralling' cumulative progression which borrows on a number of empirical strands – collaboration, the appointment of field assistants, direct participant observation, Internet research, and so on" (Falzon 2009: 16). Doing fieldwork has a different quality with the technological possibilities there are today. It is a way of working where you can always stay informed by your informants and with this have the possibility of being able to receive and convey information and fill in the gaps retrospectively. The stories we come to hear do not simply end when we leave the 'field', but they may continue through different channels in the future.

I do not want to denigrate fields such as global health that are predominantly concentrating and working with and through numbers. Instead this book will challenge and critically question the premises and highlight some of the consequences a mainly quantitative approach has. We may ponder about whether the methods we use should be put into a hierarchy when it is ultimately the lives of the people we seek to improve. By framing diabetes in terms of its visibility I suggest that numerical evidence might not be that different from ethnographic evidence in terms of making a disease visible. It is the way the results and outcomes are presented that

mostly differs. It is then only of secondary relevance to which disciplinary background we belong when we discuss tangible complexities of our lives or when we might render something visible which numbers cannot capture. As anthropologists and social scientists in general, we are not able to change the world for the people we work with, but we can counteract seemingly rigid regimes such as the one of global health by continuing to make the individuals visible and their voices heard by adding life to the impersonality of numbers and statistical evidence.

Spaces of diabetes - the fieldsites

I will briefly introduce the three districts and the main health centers where I spent a large part of my fieldwork and from which most of the empirical material originates. Places, where I met individuals with diabetes, laboratory technicians who diagnosed and tested them, health care workers who attended to the patients and prescribed medicine, and also places where, if available, glucometers assisted them in doing so.

My research was mainly conducted in three governmental health facilities, each located in a different district, which I will call district X, district Y and district Z⁹. In district X and district Y, I had already conducted research on diabetes prior to my PhD studies. Choosing these districts therefore also had pragmatic reasons because I knew the people working there rather well and in turn they knew me and what my research was about and facilitated access. Their proximity to Kampala, where I was based, allowed me to commute back and forth between the different field sites and Kampala. Kampala as the capital was also where the Ministry of Health is located where I interacted closely with officials. Above all I was tied to the availability and possibility of diagnostics for diabetes and therefore it made sense to continue working in these facilities.

Further, these three health facilities (HC) varied from each other in terms of the services they offered for diabetes patients. This diversity proved fruitful especially for comparative reasons: The health center in district X had no separate diabetes clinic; the one in district Z had been in its infant stage of offering a specialized clinic for diabetes; and the health center in district Y had a well attuned diabetes clinic with an experienced diabetes nurse heading it. Overall there are 112 districts in Uganda, divided into different regions, central, eastern, northern and western region. All three health centers are located in the central region of Uganda. District Y has a total population of about 2.000.000, of which roughly 1.370.000 live in the rural part of the district; district Z has 250.000 inhabitants in total, 200.000 living in the rural part; and district X finally counts 600.000 inhabitants with 440.000

9 I have changed the names of the districts for reasons of anonymity.

living in the rural areas (The State of Uganda Population Report 2016; figures are rounded). As mentioned before, two of the health centers had a functioning diabetes clinic once a week, and one facility offered testing and treatment for diabetes as part of the average outpatient medical services. District Y has seven bigger health facilities, District X two, and district Z has one¹⁰. This distribution may partially explain, why the numbers available of the individuals diagnosed with diabetes varies substantially between the districts.¹¹

Located 16 km outside of Kampala in a north-westerly direction and a roughly 30 minutes car ride, district Y, was the closest health center from where I stayed in Kampala. Though a rather small health center – recently endorsed from a HC III to HC IV – this HC IV has a separate building for its diabetes clinic, unlike many other governmental health facilities (the hierarchy of health facilities will be explained in the next section). It is a small clinic with two rooms and a floor space of about 35 square meters. Enough space, however, for an examination room and a separate waiting room for the patients. The clinic took place once a week every Thursday between approximately 7.30 and 12.00 o'clock in the morning, depending on the number of patients. The head of the clinic, Sister Joy¹², whom we will meet again later in the empirical chapters, ran the hospital on her own. In contrast to the other health facilities I visited that had a large number of patients on a single clinic day, Sister Joy examined up to 20 patients on a diabetes clinic day. The diabetes clinic was initiated in 2007 and has ever since been run by Sister Joy. Inspired by a trip to Tanzania in 2009, where she received specialized training on diabetes care, Sister Joy started a diabetes association for her patients at the clinic. Collecting a yearly fee of 30.000 UGX¹³ from her patients was and is a way to keep the clinic going even if the government fails to provide equipment and medicine.

The HC IV of district Z, 40 km and an hour's ride from Kampala on decent roads in western direction, too, has a diabetes clinic. The diabetes clinic was founded in the end of 2014. It runs every Monday from around 8 a.m. o'clock "until no patient is here anymore who needs to see me", like the responsible diabetes nurse, Sister Cathy said, which was often not before 5 p.m. She started working as a nurse in 1999, mainly in the outpatient department. Since "one year and eight months", she has now been working as a diabetes nurse after being trained "the essentials". Before that, she had never worked with diabetes patients, mainly because before

10 Based on the data from 2017. Therefore, the situation might have changed now.

11 The total number of individuals diagnosed with diabetes in district Z between 2011 and 2016 was 554, compared to a total number of 602 in district X and a total number of 3247 individuals with a diabetes diagnosis in district Y in the same time period.

12 Throughout the book, the term 'Sister' is used synonymous for nurse, since that is the term patients use and the way nurses refer to themselves. It does not indicate any kind of religious affiliation.

13 Approximately 8,20 US Dollars.

the clinic started, there was no equipment for testing. The name ‘diabetes clinic’ does not mean that the health center has an own building for it like it was the case in district Y. Instead, there is an examination room, which is reserved for the clinic every Monday and is otherwise used for the examination of patients in the outpatient department. The corridor in front of the room served as waiting area, at times endlessly congested with people waiting to be attended to. Sister Cathy at times saw up to 40 patients, a tiresome undertaking, considering that she had to document all the data into different books without assistance. Unlike Sister Joy, who tested her patients herself, Cathy sent her patients to the laboratory for testing.

This was also the case in the HC IV in district X, 28 km and about a one-hour ride eastbound of Kampala. Compared to the other two health facilities, it did not have a specialized diabetes clinic at the time I conducted my research, though there were plans of implementing one in the future. Like the district’s health officer (DHO), Dr. Thomas said: “To be frank, we have not yet come far to NCDs [non-communicable diseases], but we are trying to work on it.” This meant, that individuals would stand in line with all the other individuals who were waiting to be tested in the laboratory for various other diseases. This also meant, there was no specialized medical staff at the facility and since there was no diabetes association like in in the HC IV in district Y (at the time I was in Uganda, the HC IV in district Z was just planning to start an association too), the number of patients coming to be tested for diabetes remained zero for a long period of my fieldwork. The government had failed to procure medicine and testing strips for the glucometer for months. Individuals who needed glucose testing were therefore sent to nearby private health facilities if they could afford to pay the fees, or remained untested, untreated and unseen.

Sketching Uganda’s health care system

The delivery of health care services is the backbone of a health system and offers one frame in which diabetes can be made visible by providing localities and a platform where diagnoses and testing can take place and care can be initiated. Yet as hinted at previously, not every health center offers services such as diagnostics or specialized clinics for individuals with diabetes in Uganda. Even where it could be expected, namely at the higher-level health facilities. Before moving on to the next chapter, I will briefly sketch out the main characteristics of Uganda’s health care system¹⁴:

14 The data that can be found on e.g. the numbers of health care facilities within Uganda varies between different documents. To keep consistency, I will base my descriptions for this chapter

The biomedical health care system of Uganda consists of governmental/public¹⁵ as well as private health facilities, whereby private health facilities can be divided into for-profit and not-for-profit health facilities (Lindelöw et al. 2003: 8). Uganda has no all citizens' health insurance scheme¹⁶, but since March 2001 the user fees at all governmental health facilities have been abandoned - in theory. Medical consultations, diagnostics and treatment should be free of charge for everybody except in the private wings in governmental hospitals (Meessen et al. 2006: 2253; see also Men 2012). In practice, however, medical care does cost money very often even in governmental health facilities. I have met several diabetes patients who told me they would have to pay for their medication and the diagnostic tests, which meant that often times they would not be able to afford going to the hospital to receive treatment.

The health care system is, both in the governmental as well as in the private sector, structured in a hierarchical referral system staggered on seven levels: village health teams (VHT) are based on the lowest level, followed by health center II (HC II), health center III (HC III), health center IV (HC IV), general hospitals, regional hospitals and finally the national hospitals. The higher the level of the health center, the greater is usually the diversity and amount of services offered, resources and equipment available, and therefore the diagnostic and specialized care possibilities that can be offered at the facility. According to the Ministry of Health of Uganda (2014) there is a total of 5078 health facilities in the whole of Uganda. The majority of which are HC IIs, namely 3549. 1188 of the health facilities qualify as HC IIIs, 188 facilities are categorized as level HC IVs, 133 general hospitals, and 12 regional hospitals. The national referral hospitals stand at the top of the hierarchy, three in total in Uganda. They have the largest target population with 10 million people and are expected to provide highly specialized medical and surgical services. Furthermore, they are the institutions where medical research is conducted and training is offered for medical practitioners in various fields (MoH 2014).

mainly on the report "Uganda Hospital and Health Centre IV Census Survey, the first comprehensive assessment of availability of and capacity to offer health care services" in Uganda (MoH 2014: 3).

15 In the following I will use the term "governmental" instead of "public" facility, as this was the term mostly used by my informants.

16 I went to different private health insurance companies in Kampala just to find out a bit more about which services they offer and to whom. Besides the fact that it was hard to get information at all, most of them offered insurances only for companies or organizations. If they offered insurances for individuals, it was especially difficult to get insurance when having a chronic disease. Individuals with type 1 diabetes for instance will not be insured at all. Individuals with type 2 diabetes if at all, then only with a very high premium. As I was told by an insurance broker "it is the same when you get in a car accident and you go to the insurance the next day expecting them to pay". But she was not able to tell me what happened if an individual fell ill with diabetes while already being covered.

The services offered at the different levels can be summarized as follows:

Uganda has three levels of primary care facilities: level II (lower-level primary care facility), III (mid-level primary care facility) and IV (higher-level primary care facility) all focusing mainly on prevention and treatment of infectious illnesses. A level II primary care facility is the lowest level of formal health care delivery. It is mostly staffed by nurse aides and qualified nurses. A level III primary care facility has provisions for basic laboratory services, maternity care, and inpatient care (often for onward referral). It is usually staffed by nurse aides, qualified nurses and clinical officers (physician assistants). A level IV primary care facility is the level immediately below a district hospital and has a target population of 100,000 people. It has provisions for an operating theatre, in-patient and laboratory services, and is a referral facility for 20-30 level II and III primary care facilities under its jurisdiction. A level IV primary care facility is staffed by nurse aides, qualified nurses, clinical officers and doctors, although the majority does not have doctors. (MoH 2014: 35)

As mentioned, Uganda's health care system functions on a referral basis. Meaning if a lower level health facility is not able to handle a disease or provide the needed care, an individual will be referred to the next higher-level facility until the facility offers the services, care and treatment required to manage the disease. The scope of duties at lower health facilities, HC II and HC III, mainly evolves around the diagnosis and treatment of medicable infectious diseases, including the flu, malaria, pneumonia, and urinary tract infections. The increasing availability of different rapid diagnostic tests for diseases, which were usually handled at higher health facilities with more complex laboratory equipment, for instance HIV or hepatitis, has facilitated the application of these tests also at lower health facilities (Umlauf 2017).

The descriptions so far depict the ideal case. In practice, the referral system and the services offered at each level health facility are not always functioning according to their scale. This holds true for infectious diseases, but especially for chronic disease like diabetes, where symptoms of diabetes have to be recognized as such in the first place. The glucometer can aid and confirm diagnoses. Further, the glucometer is a point-of-care device, which can be used also in settings where a laboratory is absent, such as at lower health facilities in Uganda, it can rarely be found in governmental health facilities lower than HC IV. Like I was told by an employee of the Ministry of Health responsible for the procurement of medical technologies:

“Now, those glucometers we have. They are there in the districts. But sometimes it is a challenge where to find them and that makes referral complicated, because where should they refer the patients if they cannot be sure the device is there in the other facility? Diabetes has been one of the diseases, which has not been

top in terms of ranking when they do the surveys to see the prevalence and all that. Diabetes has not been a big issue until recently. That is why I would say at all hospitals you would get glucometers and some HCIVs. HCIIIIs I don't think so."

In Uganda's health care system, which is characterized by underfunded and weak health infrastructures, guidelines and regulations for diabetes care, including the handling of glucometers, are still missing. Diabetes care in governmental health facilities remains haphazardly available. While health care is said to be free in Uganda, especially individuals with diabetes face costs when seeking care: stock outs of medication, including oral agents and insulin for the treatment of diabetes, and absent testing equipment frequently requires individuals to pay for their treatment and testing at private facilities and pharmacies. Contrary to government policy, some governmental facilities often only test and provide medication against a fee in the face of resource deficiencies.

A roadmap to visibility – outline of the book

The book you are about to read comprises seven central chapters, nestled between this introductory part and concluding remarks. Hereby each chapter intends to shed light on a different aspect, which either contributes to or hampers the visibility, perceptibility and the making of diabetes on different levels and by diverse actors. Since each of the chapters has its own theoretical introduction and argument, each chapter can be read independently of one another. At the same time the overall picture expands and becomes more nuanced the more chapters you decide to read. The more of this book you will read, the more you will delve into the complexities and entanglements of diabetes. The more you will read, the more you will understand the diagnostics of diabetes and what contributes to the struggle for its visibility and its making.

The next chapter intends triple-fold: firstly, diabetes will be defined from a biomedical perspective, staging this disease as a chronic condition without prospects of cure and without a predictable course of disease. The longevity of the disease has consequences for its understanding as well as for the provision of resources and care. Secondly, you will be taken on a medical journey from past to present understandings and perceptions of diabetes, and its transformation: from a formerly mysterious, puzzling and deadly disease into a chronic condition achieved through technological intervention and progress and advanced knowledge. On the flipside, the (hi)story of diabetes as it is noted down in textbooks is a strikingly localized disease where hardly anything can be found on the history of diabetes in the majority world. This in turn may explain the invisibility of this disease in contexts such as Uganda and why diabetes can repeatedly be reframed

as a “new” and “unseen” disease. Finally, chapter one will outline some of the diagnostic possibilities there are to diagnose diabetes including recommendations and (contested) diagnostic thresholds.

Diabetes is not a disease, which transcends national borders. It is not a disease that endangers the health of the global public the way infectious diseases do. I therefore suggest that non-communicable diseases are caught in a vortex of suspense provoked by the rigidity and partially inflexibility of the regimes of global health in this 21st century, which is dedicated to global health security and humanitarian biomedicine. Though global health intends to improve the health outcomes on a global scale, it might be at the expense of conditions that do not fall in either of these two categories. As a possible result, global actions are only slowly taken up and donor funding of any kind is pending, local policies and guidelines remain stagnant. Further the lack of comprehensive numerical data is one major reason for why diabetes receives little attention in Uganda’s health care system and beyond. Different types of evidence, such as narratives and ethnographic evidence, or “real-life evidence” as an informant once called it, then become ever more important to make diabetes, and the individuals who are affected by it, seen.

Subsequently, chapter three lays the conceptual fundament on which the empirical material for this book is built. I propose to look at diabetes and its making through the conceptual lenses of evidence-based medicine, (health) infrastructures and translation. By linking these different concepts to the study of diabetes – and to one technological object, the glucometer – I want to picture how diverse actors engage in its use and how each different practice brings about a different kind of knowledge and visibility. Whereas the technologies travel ‘borderless’, the borders they might face are the borders created for instance by the rigidity of other technologies, such as evidence-based medicine, as well as the borders built by weak health infrastructures and resource shortages that limit the radius of operation.

Starting from chapter four up until chapter seven we will immerse ourselves in the empirical body of this book. As hinted at before, in each of these chapters we will encounter the glucometer – sometimes more explicit, sometimes less explicit – as strikingly multidimensional actor: it will present itself as a tool to deliver (numerical and epidemiological) evidence contributing to the prevalence rates of diabetes in Uganda. It will be the diagnostic device producing and revealing more individuals who will then be labeled “diabetic”. I will appear as a contradictory object that limits uncertainty, while it is at the same time being the source that creates this uncertainty. The beauty but also the curse of this technology is neither dependent on a predefined group of people who may engage in its use, nor is it bound to a specific locality, we will find ourselves in health centers and laboratories, in people’s homes, on a roadside or in a primary school. No matter where we will find ourselves and who the actors are we will come to meet, they all in one way or the other, with one intention or another, make diabetes and related aspects of

it visible. The conclusion, finally, will offer a platform to discuss the main findings of this book.

Before we proceed, a final note: the names of the individuals you will come to meet are aliases. As mentioned I have also changed the names of the districts in which I have worked. I have, however, retained the names of organizations. Further I have, where suitable, merged several occurrences or interviews into a single one to ease the readability and avoid confusing enumerations. I have hereby not changed the content. Finally, I am well aware that I have made many certain choices throughout this book. I have for instance chosen which stories to include or to exclude, or I have decided in which way I would like to retell them and the wording I use thereby. I know there are other stories I could have told, there are different conceptual paths I could have taken, other references I could have included. There is always something you could have done differently afterwards. Nevertheless, if Geertz, as he is quoted by Wendland (2010), was right and the true purpose of anthropology is to increase the number of stories out there, then we may simply read the following book as *one* possible story about glucometers and the making of diabetes in Uganda (Wendland 2010: 221). A story told from the vantage point of a small device, the disease it renders visible and about the people who use it.