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### **TIMELINESS AND CHRONIC MEDICATION: KNOWLEDGE ABOUT HYPERTENSION AND DIABETES IN UGANDA**

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# Timeliness and chronic medication: knowledge about hypertension and diabetes in Uganda

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Hypertension and diabetes are commonly called ‘new diseases’ in Uganda. The names *pleša* (pressure) and *sukari* (sugar) are cognates of English words, suggesting that they derive from biomedicine rather than earlier folk categories of illness, affirming their status as ‘new’. Despite the lack of reliable national prevalence figures, both medical professionals and lay people assert that they are a widespread and growing health problem. In different ways they are linked to transformations in political economy. Health policymakers say they are caused by the changing patterns of eating and exercise following on economic development. Many lay people associate them with the difficult conditions of contemporary life: poverty, worry, violent conflict, hard work, heavy burdens of care for dependent relatives.

In this paper I examine knowledge about medicines for these two conditions. Because they are chronic diseases needing chronic treatment, time and timing are fundamental to knowledge about their medication. I will relate knowledge about medicinal timeliness to health institutions and technology. People form knowledge about illness and medicine through experience with treatment. When the formal organizations that are meant to frame treatment are insufficient and the conventional rules meant to guide practice are impracticable, then health workers and patients creatively develop other knowledge and patterns of dealing with problems.

The time of hypertension and diabetes has many dimensions (Whyte 2012). In his monograph on healing the modern in Yogyakarta, Steve Ferzacca (2001) describes the discourse of modernity deployed by Javanese health workers and patients with hypertension and diabetes. They relate these diseases to historical time and the changing conditions of life brought about by such –zations as Westernization and urbanization. Elsewhere, comparing the temporality in US and Javanese understandings of diabetes, Ferzacca distinguishes ‘circumstantial’ and ‘vital’ time. Circumstantial time is the frame of historical change in which social and cultural progress are linked to economic development. Vital time is the biomedically inspired perspective on the event history of pathology and the mechanically derived time cycles that organize diagnosis and therapy (Ferzacca 2010, 159). Vital time is based on an organized plan for control and self-management; as a time of individual pathology, it is linked to mortal time, ‘the endgame of death’ (ibid., 172). This distinction is useful, but for my purposes it must be supplemented with the dimension of institutional time, timing and rhythm, which is shaped by historical changes in political economy and which in turn shapes vital time with its measurements and medication. If the blood pressure measures and glucometers that should organize diagnosis and therapy are rare, if institutional clinical care is intermittent, then how do people come to know and practice the medicines for sugar and pressure that would dictate a rhythm for vital time?

The attempt to answer this question is based primarily on material assembled in Butaleja District, Eastern Uganda, in November 2011 and January 2012.<sup>1</sup> I visited government and private health facilities, small clinics and drugshops, to inventory the equipment and medications for managing hypertension and diabetes. I interviewed patients and health workers, and with the assistance of clinical officer Michael Mwangale, obtained brief case histories from 23 patients. With staff of the District Hospital at Busolwe, I helped to establish a weekly clinic day for these two conditions. A short study visit to Kasese District in Western Uganda and exploratory research on NCDs in the Acholi sub-region of northern Uganda provided a wider picture.

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## Measuring for medication in the era of ART

Use of medicines in Uganda is very often presumptive. Whether a patient presents with aches and fever at a government health unit or a customer seeks remedies at a local drug shop, medicines are usually obtained and taken without the use of diagnostic examinations and equipment. Common symptoms, sometimes grouped under illness categories like malaria or respiratory infection, are routinely treated with common medicines (Whyte and Birungi 2000; Nshakira et al. 2002). While people certainly value laboratory tests and the use of instruments like stethoscopes and thermometers, such clinical investigations are by no means necessary for initiating treatment. However, the history of Ugandan health care has been deeply marked by new clinical practices to deal with the HIV epidemic.

One of the many health care innovations of the response to HIV was the imperative of testing before starting treatment. Media messages emphasized that HIV was invisible, and people accepted the principle that only the ‘machine’ could reveal the truth. Not only was treatment (together with other benefits) dependent on a positive test; laboratory investigations of CD4 counts were used to monitor the progress of the disease and the effectiveness of the medication regime. A pattern was established for diagnosing and managing a chronic disease through measurement and persistent systematic medication. Antiretroviral Therapy (ART) linked knowledge and use of antiretroviral medicines to digital biotechnical information about disease. Exceptional control of the medicines and affiliation of clients to fixed treatment sites gave a new social dimension to medicine, knowledge, and managing a sickness for life. It made possible, for some at least, the kind of ‘vital time’ that Ferzacca saw in US patient’s experience of diabetes.

Like HIV, diabetes and hypertension are made visible by diagnostic instruments. While people may treat some of the symptoms with various medicines, the use of diabetes drugs and anti-hypertensives is not presumptive – at least not in the first instance. Treatment of these specific conditions is seldom initiated without testing blood sugar or blood pressure, although continued medication is often haphazard. Unlike HIV, they have not been the object of donor generosity and government policy. There are no large-scale programmes for diagnostic testing, monitoring and medicating diabetes and hypertension. In these circumstances, how does knowledge of the invisible conditions and their specific medications emerge?

In some ways the situation resembles that described by Livingston for cancer in Botswana. She writes of how scientific objects take on ontological status as distinct entities. ‘It takes an array of technological, intellectual, social, political and economic circumstances to perceive these entities and make them widely acceptable as facts’ (Livingston 2012, 52). Without the diagnostic and therapeutic possibilities that are common experience in the global North, cancer does not have a clear collective image or set of expectations. People in Botswana must learn about tumors, scans, chemotherapy, and radiation through their own bodily encounters. Livingston shows how the first oncology ward in the country creates and embeds cancer as a reality in the lives of patients.

As substantial things, medicines help make illness tangible and communicable (Van der Geest and Whyte 1989). In the same way, cancer treatment and scans, blood pressure meters and insulin make certain chronic conditions real for the suffering individual, for the health worker, and in time, for a wider public. Symptoms and attempts to alleviate them may be real enough without these technologies; suffering and distress, presumably from HIV, were experienced before the diagnosis became common and the AIDS industry was established. But the affliction of HIV and AIDS, as medical conditions, depends upon the array of circumstances of

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which Livingston wrote. HIV emerged as a social figure through the deployment of massive resources, while there has been little investment in other chronic conditions. The question is to what extent an aura of facticity can be created in circumstances where measuring devices, medications, and clinical care are unevenly available.

Another way of putting this issue is to ask under what conditions people with hypertension and diabetes might experience vital time as a duration starting with diagnosis, and punctuated by mechanical monitoring of biological values and the daily rhythm of adjusting and taking medicines.

Measuring blood sugars, recording blood glucose levels, measuring weight on a daily basis, and monitoring food consumption using various methods are advised and used by sufferers to varying degrees. These self-measurements, which are to occur at home, are meant to establish therapeutic rhythms, which as embodied mnemonic devices, acknowledge the presence of chronicity in the everyday lives of sufferers (see Ferzacca 2000). These measurements and the therapy itself enable a mechanical accounting of the progress of the biomedically defined chronic health condition (Ferzacca 2010, 162).

Ferzacca sees this experience of vital time as far more pronounced in the US than in Java, where the experience of circumstantial time dominates and mortal time is downplayed. But he does not consider what infrastructures of institutions and technologies make possible this kind of vital time.

### **The real Neglected Tropical Diseases**

Health workers in Butaleja District unanimously affirmed that hypertension and diabetes are on the rise and were concerned at the lack of attention to them. The former District Health Officer called them the real Neglected Tropical Diseases (as opposed to parasitic diseases like bilharzia and onchocerciasis, which are objects of a donor funded programme by the same name).

In international policy organs, there is growing attention to the global increase in non-communicable diseases (NCDs), which have been declared 'the new pandemics of the 21<sup>st</sup> century' (Alberti 2001, 907). The World Health Organization has emphasized the rapid spread of lifestyle diseases in the wake of urbanization and modernization. With focus on cardiovascular disease, cancer, diabetes, and chronic respiratory disease, WHO proposed preventive interventions in the form of structural regulation as well as health education targeting individuals. It also affirmed the importance of making treatment available. In September 2011 a UN General Assembly meeting was dedicated to adopting a global agenda on NCDs.

In Uganda infectious diseases have long dominated the health policy agenda. It was not until 2005 that non-communicable diseases were explicitly given a place in the national health sector strategy and an office within the Ministry of Health. Since no figures existed on prevalence, a nationwide survey was planned to measure body-mass index, blood pressure, cholesterol, and blood glucose. However, the survey had yet to be carried out by early 2014.

A few district level population-based studies suggest that hypertension is widespread. A crude prevalence rate of 30.4% was found among people age 20 and older in Rukungiri District in 2006 (Wamala et al. 2009). Another research group (Maher et al. 2011a, 2011b) conducting a survey in southwestern Uganda in 2009 found a prevalence rate of 22% for hypertension in people age 13 and older. For diabetes the prevalence of probable diabetes and probable hyperglycemia were 0.4% and 2.8%. Strikingly, 96% of men and 86% of women were not aware that they had hypertension, while nearly ¾ of those with probable diabetes did not realize it. It is

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evident that these conditions are not being diagnosed although they are common. Even those who were aware of their hypertension diagnosis were apparently not receiving adequate care since only half of them had controlled blood pressure.

The lack of diagnosis despite high prevalence, especially in the case of hypertension, is reflected in the near invisibility of high blood pressure and diabetes in the records of public health care facilities. In a small exploratory study in northern Uganda, we examined the out-patient registers for one month of the year 2011 at six health units. Less than one per cent of patients age five and above was diagnosed with hypertension, except at the one private-not-for-profit hospital, where prevalence was 2.5% (Whyte et al. forthcoming).

Diagnoses of hypertension and diabetes were similarly low in Butaleja District. At the Out-Patient Department of Busolwe, the district hospital, they accounted for less than 1% of cases seen in October 2011, while they constituted 3% in the 'Grade A' wing, where out-patients pay a small fee for consultation. In the Health Management Information System, which collects statistics on new cases seen at public health facilities, hypertension and diabetes figure minimally in the annual reports for Butaleja district. Still there is some evidence that health workers are right in their views that these 'new diseases' are on the increase. In the five years from 2005/6 to 2010/11, diabetes cases more than doubled (from 265 to 693) and hypertension increased almost twofold (from 852 to 1638), while new AIDS cases grew only by half (304 to 492).

In order to understand the low visibility of these conditions at the public health facilities where people commonly seek treatment, we must consider the process and timeliness of diagnosis, monitoring, and chronic treatment.

### **Making the unseen visible**

On a private clinical laboratory in a provincial town was printed the motto 'Discover the unknown', an invitation implying that testing can reveal a biological truth hidden in the body. While the 1980s saw the expansion in range and quantities of pharmaceutical medicines in Uganda, the decades since have been marked by an increasing appreciation of diagnostic tests. In public health units, attempts have been made to strengthen labs and train technicians. Some private clinics have laboratories, and in larger towns, private laboratories often cluster around hospitals, providing the services that lab strengthening programmes have failed to muster. As with medicines, so with diagnostic procedures: what is not available in the nominally free public health sector must be sought in the private sector for a price that often excludes poor patients from accessing them.

While people in the global north consider the merits of genetic testing, even the simplest diagnostic instruments are often missing in Uganda. In government health units, which are under-resourced and under-staffed, clinicians routinely check children for fever by placing a hand on their foreheads. Even if a thermometer is available, they may not take the time to measure temperatures when the waiting room is full of patients. Health Centres level III and IV, as well as District Hospitals, should have functioning laboratories, but reagents and equipment are often missing, especially at Health Centres.

In late 2011, blood pressure meters were not commonly used in district health facilities. Many were broken and the donor programme for equipment maintenance had ended. One In-Charge remarked that the quality was just poor; he had two working meters, and ten broken ones. At the 100-bed district hospital in Busolwe the only one that functioned was in the

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male ward. Digital machines had been given by visiting Danish medical students but there were no more batteries. Of the 7 health centers I visited in Butaleja district, five had working manual BP meters and stethoscopes; three of these five were private not-for-profit units, not fully dependent on government supplies. Several of the health centers had BP meters only because AIDS programmes had supplied them to the antenatal units as part of the Prevention-of-Mother-to-Child-Transmission efforts. While some units were quite conscientious about checking pregnant women, especially first time mothers, they were extremely selective about screening out-patients. If they had meters, they used them only if there were strong grounds to suspect hypertension.

The situation with respect to glucometers and strips was even more difficult. Government health centres did not have them at all. At the district hospital, Danish medical students who rotated through, routinely brought them, but the strips usually got finished before the next visitors arrived. Glucose testing was a problem throughout the country. Visiting pharmacies, public and private health units, I easily found 29 different models of glucometer, each requiring its own type of strip. In some instances, well-meaning visitors had donated meters for which the strips were not available in Uganda, or could be found only at one distributor in Kampala. In any case strips are expensive.

National Medical Stores should supply equipment to district hospitals and government health centres. But no blood pressure machines, glucometers or strips had been received for the past few years. In October 2011, when the storeman at the district hospital rang NMS, he was told that they had none of these items in stock and did not know when they would be able to supply them.

Given the shortage of glucometers and strips at government hospitals, it often happened that health workers referred those they thought should be tested to private clinics. In Busolwe, the small urban centre where the district hospital is located, there were two such clinics that offered glucose tests. One (owned by the hospital medical superintendent) charged 4000 shillings for a test, while the other took 5000 shillings. These fees are about twice the retail cost price of one strip and many patients find them too high.

People in Uganda say that sugar and pressure are for the rich, or at least for the 'working class', that is people with salaried jobs who are relatively well off compared to everyone else (Whyte 2013). Whether or not this holds, it is certainly the case that better off and better connected people are more likely to be tested for these conditions and thus to get a diagnosis in the first place. Health workers or their relatives or those with some link to a health facility figured prominently among 'known' hypertensives and diabetics. Haji Habanga, chairman of the hospital management committee, was on a casual visit to the hospital when he saw the doctor checking a patient's blood pressure and asked to be checked as well, just out of curiosity. It measured so high that the doctor admitted him on the spot. When some visitors donated a glucometer to the hospital, they demonstrated how it worked on a nurse, only to find that she had diabetes. There are many stories like this, illustrating that position significantly affects chances of 'discovering the unknown'.

Some people learned their diagnosis when presenting to health units with acute or unexplained symptoms. A secondary school teacher was riding his bicycle to town when he felt pain, fatigue, dizziness, blurred vision and pins and needles in his legs. He went to an NGO clinic thinking he had malaria, which they tested for and confirmed. They also checked his blood pressure. Five years on he still remembered that the first number (systolic) was 200.

Because screening is rare, people often have grave symptoms before they ever find out that they have hypertension or diabetes. Malik, a truck driver, was trading cattle in another district,



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when he collapsed and was taken to hospital by other drivers. When they checked his sugar it was so high the meter gave no precise reading. Isak, a builder, was going to mourn when he had to return home because his left arm and leg had gone weak. Next day his family took him to hospital where he was found to have had a stroke.

### **Medicating by numbers — once**

Those whose blood pressure or glucose values measure above the normal levels are prescribed medicine. Health workers in Uganda, like those in the global North, prescribe by numbers (Greene 2006) — at least in the first instance. Blood pressure under 140/90 is considered acceptable as is Fasting Blood Sugar under 6 mmol. Above these levels, and depending on how much above, health workers write a prescription for one or two weeks and ask the patient to come back when the medicine is finished.

The district hospital has the widest variety of medicines. For hypertension, they dispense: lasix (frusemide), propranolol, aprinox (bendrofluazide), captopril, atenolol, amlodipine, nifedipine, and cardiac aspirin. For diabetes, the hospital has oral hypoglycemics: glybenclamide and metformin. Usually it also has three kinds of insulin in stock: lente, soluble, and mixtard. The dispenser is thoughtful about his list and the need to work within the hospital budget. 'Instead of filling a prescription for 30 days, we sometimes give for two weeks in order to make supplies last.'

The hospital could 'pull' drugs, that is, it could order from National Medical Stores according to its own budget priorities, as could level IV health centres. Not so the lower level government health centres, to which medicines were 'pushed' in Essential Drug Kits. They had no choice. The Kits contained three medicines for hypertension: propranolol, lasix, and aprinox (bendrofluazide). There was nothing for diabetes because it is supposed to be treated only at the higher level units to which patients are referred if diabetes is suspected. Health units with NGO support, such as that run by the Catholic church, were able to order the drugs they chose, and had slightly different selections, though seldom more or other drugs than those stocked by the district hospital.

Almost all drug shops I visited had at least some anti-hypertensives, and a few had oral medications for diabetes. When the government units were out of stock, or when patients wanted a refill without waiting in the queue at the public clinic, the drug shops supplied the tablets they wanted. Shops selling drugs take a variety of forms, from proper pharmacies in the larger towns, to clinics run by trained health workers, which offer examinations as well as medicines for sale, to small shops manned by assistants to the owner, who only sell drugs. The difference between a drug shop and a private clinic is not always clear, since both sell medicines and give advice. Those that are more like clinics may measure blood pressure, and as I have mentioned, two located near the hospital offered glucose tests with glucometers and strips.

All of the patients whose histories I learned started on medicines for hypertension or diabetes only after a first diagnostic measurement. Their very first medicines were prescribed by a health worker and written on a piece of paper, often a page from the cheap school exercise books brought in lieu of the Medical Form 5 that health units are supposed to hand to the patient. Most patients did not remember the names of the medicines they were given, perhaps because they did not go back for regular monitoring and refills, as we shall see. The exceptions are those who took insulin, health workers who had some knowledge of biomedicines already, and the few who actively pursued chronic medication, persistently seeking refills whenever their medicines ran out.

Medicines were the immediate response to measurements indicating disease. But the people we interviewed remembered that the health workers who prescribed their medicines also gave them advice about diet and exercise. They should walk and dig in their gardens. They should avoid salty, sweet, fatty and oily foods. Diabetics should not eat sweet potatoes or too much cassava. In high-income societies, patients often use such 'lifestyle' discipline to improve their numbers and allow them to take less medicine. This did not seem common in Uganda; many health workers said that it was difficult for people to change their diets although we spoke to people who did try to use less salt and avoid sweet items.

Health workers were not the only source of counsel. It was striking, given that people spoke of *sukari* and *plesha* as new diseases, that so many recounted advice from neighbours and family about local foods they should eat, rather than what they must avoid, in order to control the conditions. Bitter, astringent, and sour foods were recommended, especially for *plesha*: lemons, tamarind, bitter greens (*nakati*, *saga*), varieties of bitter tomatoes (*enjagi*, *katukuma*), oranges, sesame, raw onions, garlic, and small amounts of local gin (*waragi*). Moreover, many had heard of 'native medicines' for sugar and pressure: Neem (*arubaini*), *mugi*, *muhelemba*, the roots of *misokoso* and *hawong'a*. Chinese medicines from the multi-level marketing company Tianshi were known by some, as were other commercial nutritional supplements from South African companies targeting the 'lifestyle disease market' (Whyte 2013).

Although they started on dedicated diabetes and hypertension medicines after a test of their blood values, people with sugar and pressure thus had a variety of possible measures for continuing to address their condition – if indeed they continued to do anything at all. They could use herbal medicine and/or adjust their diets to include bitter and sour items. Those few who could afford the expensive commercial nutritional supplement products bought them occasionally. Many purchased medicines for sugar and pressure in drug shops. Some visited different health units to obtain drugs. They did not necessarily have one regular source of medication or one fixed regimen of diet and exercise.

### Intermittent monitoring

Patients diagnosed with hypertension or diabetes were initially given medicines for one or two weeks and told to return for follow-up. The idea was that they should be regularly monitored to see if the medicinal regime needed adjustment. But reviews of out-patient registers in government health units revealed that the names of those given medicines for a short time did not usually reappear within the month. If patients felt better they did not trouble to go back, especially if the source of treatment was distant, entailing transport expenses. Haji Habanga, who had his blood pressure checked on that casual visit to the hospital, never went for review, because, as he explained, he never felt any pain, not even when, ten years later, he suddenly had a strange heaviness on his right side, and his family noticed that his mouth had turned to the right. It was only then that he thought of pressure and went to the health centre. Of Loyce, a woman with hypertension, a health worker remarked that 'she is fond of coming for admission, but does not return regularly for her medicine and follow-up.' Like Haji and Loyce, many experienced acute episodes and hospital admission, rather than the temporal pattern of regular follow-up and daily medication.

Those whose symptoms were pronounced were more likely to come back and wait their turn among the other out-patients. If they mentioned that they had earlier tested positive for hyper-

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tension or diabetes, or if the diagnosis or medication was scrawled in the cheap soft exercise books they were supposed to keep, the words ‘known pt. of HT’ or ‘known DM’ were entered in the patient register for the day. But since monitoring values, especially for blood glucose, was hardly done except for those who could afford to pay for it at a private clinic, the most common pattern was that the earlier prescription was simply refilled without checking values in order to see if adjustment was needed. As one conscientious and concerned health worker remarked: ‘Usually we just write medicine without testing, putting their lives at risk.’ Health unit staff thus creatively adjusted the use of medicines to the realities of weak institutions.

Patients dealt with the absence of measurements and irregular access to medicines by developing knowledge of their bodily states. Those on insulin learned to assess symptoms and seek medicine if necessary or modify what they were already taking. Ahamed had developed ways of knowing whether to increase or decrease his dose of insulin. He props a sheet of corrugated roofing iron against a wall and urinates on it. When it dries, there is a dark stain if much sugar is in his urine. When he eats jackfruit, the sweetness lasts longer in his mouth when his sugar level is high. Another diabetic, Malik, said that when he urinates more than three times in a night, he increases his insulin; when he urinates less, he reduces it. Faisi adjusts her insulin according to how sweet her urine tastes. James, also on insulin, found the glucose tests at the private clinic in Busolwe too costly, and shared his experiential assessments with another diabetic. They discussed ways of monitoring their blood sugar levels without recourse to a glucometer: how long the sweetness of a fruit lasts in the mouth; how painful is the prick of a needle. Sometimes James stops his insulin for several months, relying on his own senses to know when he needs to start it again.

Whether on insulin or tablets, most diabetics could tell when their sugar was high. Lucy explained that she knew by the dizziness and sweating and aching in the whole body. ‘Then when I take metformin, my body clears.’ As a nurse at the hospital, she sometimes had access to a glucometer and strips. ‘But I just know and I don’t have to waste strips.’ Robinah knew that when her sugar was low, her muscles ‘twitched like a goat’s hide does when a fly lands on it’.

Likewise people with pressure learn to be attentive to sensations that require treatment. Robinah, whose muscles twitched like those of a goat when her sugar was low, described how it felt when her blood pressure was high: ‘My heart would beat as if you were asked hard questions in a court.’ Angela mentioned the signs that impel her to go to the hospital: bells in the ears, dizziness, blurred vision and pain in her arms and legs. Margret only goes for medicine when she is in pain, as was the case for others with hypertension. One health worker remarked that people living with hypertension over many years sometimes did not feel pain even when their values were very high, and thus neglected medication.

The ability of people to monitor their bodies successfully in the absence of measuring devices should not be overestimated. Tefiro, a young man who had been living with Type 1 diabetes for five years, claimed he could feel when to adjust his insulin. Because there were often no strips at the hospital and his father could not pay for a glucose test at the private clinic, he relied on his own sensations. Yet he was weakening and had such pain in his feet that he could hardly walk. It was not until I got him onto a Novo Nordisk sponsored programme in Kampala that he managed to control his glucose levels properly with the help of a free glucometer and unlimited strips and a regime of testing himself six times a day. Even nurse Lucy, who did not want to waste strips, admitted that there were times when she was confused and needed to measure herself.

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## Vital time and mortal time

In the global North, where measurement of blood pressure and glucose levels is common, efforts at their control often start before people have symptoms and before they would be medically classified as having a disease. The practice of treating risk is widespread; that is, attempts are made to reduce glucose levels or blood pressure when values are somewhat elevated but not yet within the range defined as actual disease. Thus prevention and treatment meld together, and people combine lifestyle discipline, medication and continual measurement checks. Nikolas Rose describes how prudent citizens of 'advanced liberal democracies' put their trust in numbers, and treat not only symptoms but also susceptibility (2007, 82). He writes of the importance of control: 'In the field of health, the active and responsible citizen must engage in a constant monitoring of health, a constant work of modulation, adjustment, improvement in response to the changing requirements of the practices of his or her mode of everyday life' (2007, 223). This kind of control depends on the advances in biomedical science and technology that he sees as informing somatic selves, but it also depends on institutions – organizations and the practice of rules – to which he devotes less attention.

In Uganda neither advanced technology, nor strong health care organizations, nor the regular implementation of therapeutic guidelines facilitate this kind of control. The vital time of chronic illness, with its rhythm of cyclical monitoring by measurement, and the regular daily consumption of medicine modulated according to test numbers, exists only rarely. Because screening is seldom done, the initial diagnosis – the event that marks the beginning of a stretch of vital time for patients in high-income countries – occurs when the disease is already well-established. Many with adult onset (Type 2) diabetes have such advanced disease at diagnosis that they are put directly on insulin injections, rather than on oral medication as is usually given for Type 2 diabetes.

Rather than the regular measurements that establish therapeutic rhythms and punctuate the time of everyday life with chronic conditions, both measurements and medication are more intermittent. People told, sometimes quite off-handedly, of long lapses between the vital measurements that would be taken for granted in high-income countries. Samwiri, a 'known patient of hypertension' for the last five years, knew that he weighed 85 kilos two years ago but had not been weighed since. Malik had weighed himself ten years earlier when he pulled 120 kilos on the hanging scale at a grinding mill. Christine was weighed 8 years ago when she was first diagnosed with hypertension, but they never told her how many kilos she measured. Others simply shrugged and said they did not know their weight. Although changes in weight are carefully followed for HIV patients, weight measuring was not a part of clinical consultation for people with hypertension and diabetes. Many of those who did know their weight had used the scales at the grinding mills or those of the buyers who came round to homes to purchase crops.

As we have seen, monitoring of blood pressure and glucose were mostly too occasional to provide the kind of control and punctuation of vital time that Ferzacca described among US diabetic patients. Likewise, while some people took medicine regularly every day, many did not. Instead the time of chronicity was often marked by episodes of acute symptoms that sent the patient back to the health facility or to a drug shop. Sometimes these episodes were so grave that patients were admitted for a period. Azida had been diagnosed with hypertension four years earlier and given medicine for two weeks. She occasionally went back to the hospital for more medicine when she was in pain, and sometimes bought from the drug shops. For four months she had been using only herbal medicine, but then she succumbed to a throbbing headache, pain in her back and abdomen, dizziness and blurred vision. She was admitted to hospital

for two days, her blood pressure was measured at 200/100, and she was given medicine for a few more weeks. This kind of episodic time with its inconsistent measurements and medication is at odds with the vital time of chronicity posited by Ferzacca. Order and regularity in control measurements and adherence to a medicinal regime require health care institutions that hardly exist in Uganda, except in the heavily resourced HIV clinics.

Yet people diagnosed with hypertension and diabetes often expressed a sense of mortal time, with its final punctuation of death. The timing of death was uncertain but feared imminent. As Akusa, with hypertension and an enlarged heart, said 'I am expecting to die any time.' Polycarp, who attributed his hypertension to the stress of having his name deleted from the payroll of his school for two years, confided that he feared to die suddenly. When Abdallah was diagnosed with diabetes, his first reaction was fear, remembering what his late father had gone through. The next thing he thought about was dying any time, 'sooner than soonest'. Some people said that death could be held in check by treatment, but many were not so sanguine. Unlike the Americans whom Ferzacca studied, few of those we spoke to had confidence that an orderly time of well-managed chronicity would balance the danger of death.

### **Clinics and sociality**

To know chronic medication for the control of hypertension and diabetes in the way that health professionals would like it to be understood requires another kind of relationship with health care providers. We have seen how this came into being with ART treatment programs that turned patients into clients: consumers of services and dependents on a source of treatment (Whyte et al. 2013). They *belong* to a clinic, come for check-ups, are told about their disease and drugs; they are weighed and sometimes measured for CD4 count. They receive their ARV medicine from one place. They are documented in paperwork that forms a part of their care and attests their belonging. This kind of long-term relationship is found, to a lesser extent, in connection with clinics designated for other health conditions such as pregnancy, mental illness, tuberculosis, and now in some places diabetes and hypertension. At a hospital or health centre, a special clinic means a time (eg Tuesday mornings), place (a room and benches for waiting), equipment, medicine, and staff freed from regular duties to man the clinic.

The first step toward a different kind of relationship with health care providers was indicated by three letters – TCA – followed by a date. Those health centres and hospitals that had established special clinic days for mental health, hypertension, or diabetes gave appointments 'To Come Again'. Instead of loose instructions to come back when the medicine ran out, they were required to appear on a certain day.

Like the HIV clinics that exist at health centres level III and above, these other clinics register their patients. Each has a permanent number and their records are retained at the clinic, in contrast to the Out-Patient Department which numbers patients from the beginning to the end of each month in the patient register, but has no retrievable record of earlier visits. In both cases, patients are supposed to carry their exercise books from home, but these may be forgotten or lost. Only dedicated clinics keep a file folder on each patient/client/registered member.

The importance of the paperwork was brought home to me in the process of helping to set up the new hypertension and diabetes clinic at the district hospital; 100 file folders and a ream of paper were needed, and these were not available through the hospital. A nursing assistant had to be assigned to copy the clinical officer's entries from the patient's exercise book to the paper filed in the soft file folders I managed to buy in the trading centre. She was also the person

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who read out the names of those who were supposed to have come again on that day, whereas the nurse who did the tests took on the task of scolding those who had not kept earlier appointments.

Not only do these special clinics within health units have a different temporality with their regular visits and institutional memory; they have a spatial dimension in that a separate room and waiting area bring together people with the same diagnosis. They have the possibility of talking to one another as they wait. Most important, the character of their relations with health workers is different. Special clinics have a responsible nurse and/or clinical officer who get to know the regular patients. Consultations are longer than in OPD, if only because it takes time to measure blood pressure and blood glucose.

The new diabetes and hypertension clinic at Busolwe District Hospital, like the others I visited in Mbale and Gulu Hospitals, had to solve the problem of measuring devices in order to 'prescribe by numbers.' Since the designated source of equipment, National Medical Stores, could not deliver, they improvised. At Mbale Hospital, the local branch of the Diabetes Association had arranged to purchase glucometer strips from a supplier in Kampala who sent them to Mbale on the Elgon Flyer bus. Patients paid for their tests, but only 2000 shillings, much cheaper than the price at private clinics in Mbale. So an NGO, a patient group, was doing the work of the government health system. At Busolwe, the strips were sometimes available as donations from the Danish medical students, but otherwise had to be bought in Kampala. At first the hospital administration agreed that glucometer tests could be sold at 3000/- in order to have money in a fund for the clinic. But the Hospital Management Committee was critical; all treatment is supposed to be free in government health units. So the price was reduced to 500/-, which is sustainable so long as some of the strips continue to be donated. Finding ways to supply the strips, make sure the medicines were available, and motivate the staff to do the extra work was part of the improvisation necessary in circumstances of scarce resources.

Of course, the existence of clinics with their measuring instruments, files, time patterns, consultations, and prescriptions does not necessarily create these diseases as cultural and social phenomena, just as it does not necessarily produce biosociality. But special clinics are a foundation, often overlooked by researchers and projects that tend to focus on patient support groups as examples of biosociality.

### **Knowing through treating**

Knowledge about hypertension, diabetes, and their medicines is emerging in the shadow of the response to the HIV epidemic in Uganda. It is useful to reflect on how the responses compare, and on how the one has influenced the other.

For HIV, prevention campaigns were the first response, long before treatment was available. Awareness spread through a combination of massive propaganda and direct experience of the disease. Then came voluntary testing and counseling; only later did treatment become a real possibility. In stark contrast, hypertension and diabetes are coming into social existence through treatment rather than prevention. Generally speaking there are no consistent prevention campaigns for 'lifestyle diseases'—indeed the very concept of lifestyle is associated with prosperity and the elite who can afford 'style'.

For hypertension and diabetes, there is hardly voluntary testing, and no routine screening. Most cases are diagnosed when people come for treatment of something else, or when they seek help for severe symptoms, or by chance. In the case of diabetes, diagnosis often depends on

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whether they can pay for a blood glucose test. (Practically no diagnoses are made on the basis of urinalysis.) Without the necessary numbers, they will not be initiated into treatment for diabetes.

Whereas donors finance the great majority of AIDS activities, the little that is happening in the area of hypertension and diabetes is initiated by commercial interests, patient organizations, and, to a very small extent, researchers. In contrast to the routine Test and Treat approach, which entails rapid HIV tests of in-patients and out-patients no matter what their symptoms, screening for diabetes and hypertension happens only under special circumstances. Suppliers of testing equipment or medicine sponsor screening on Diabetes Day or at rare ‘camps’ arranged at Kampala hotels and publicized on radio. Several research projects have involved testing of a few hundred people and referral of those found in need of treatment to government health units. But these screening efforts are random and uneven – drops in the bucket of a 30 million strong population.

In Denmark people with hypertension and diabetes often have their own measuring devices to monitor themselves at home. In Uganda, the few with their own equipment had received it from their children working abroad or in well-paid positions in Uganda. Like health workers, they had connections that gave access to meters.

In a country where prescription medicines are not very effectively controlled, it is impressive that ARVs have little presence on the open market. ‘Exceptionalism’ characterized not only AIDS (Smith and Whiteside 2010), but also its medicines in that it was, and is, difficult to buy them without a prescription. Medicines for hypertension and diabetes are far easier to acquire and people buy them from one source and another, at their convenience, if they are not able to get them free from a government health facility. ARVs are regulated in another sense as well. People say that ‘they have their rules.’ Those starting on ART are made to attend counseling sessions ‘to study the medicines’. They learn when to take them, how to eat while on medicines, what to do if they miss a dose, and most of all they learn that they must keep on taking them for life. By contrast, those starting on anti-hypertensives and anti-diabetes drugs are told little about their medicines. There is no emphasis on continuity; except for clients of dedicated clinics, many took them intermittently. Even health workers were unsure about whether these medicines had to be continued if patients improved and their values fell to normal. If institutions are rules, then ARVs are heavily institutionalized, while medicines for hypertension and diabetes are not.

There are ART clinics in every hospital and in all level III and IV government health centers. Some of the routine work of operating these weekly clinics is delegated to ‘expert patients’, who have been on treatment for some time and have some secondary school education. They administer HIV tests, weigh their fellow patients, give health education, organize files, and do some of the paperwork. The few diabetes and hypertension clinics that now exist at district hospitals have adopted this model, in that experienced patients assist health workers. At the district hospital, Tefiro, who attended the NovoNordisk sponsored clinic in Kampala, was set to do glucose tests and give health education, including instructions on how to angle a syringe for insulin injection. Another patient, who is a teacher by profession, helped to pack medicines. In these ways, knowing medicines was being standardized.

Knowing medicines for chronic conditions like HIV, hypertension, and diabetes is different from knowing drugs for acute conditions and for pleasure or enhancement. The necessity of numbers for initiating treatment, the sheer duration of medication, and the ideal of monitoring set these medicines apart. A proper regime of treatment is fundamental for creating an aura of facticity around these diseases as biomedical entities. Examples of such regimes are only now appearing here and there in Uganda, and are weak shadows of the well-resourced regimes for managing HIV.

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