RESEARCH ARTICLES

Diagnosing Diabetes, Diagnosing Colonialism

An Ethnography of the Classification and Counting of a Senegalese Metabolic Disease

Emma Bunkley

Abstract

This article explores the top-down production of the statistics frequently circulated in global health. These data must first originate in a place like the public hospital in Saint-Louis, Senegal, in doctor's offices and laboratories and medical archives. At their root, these data are an accumulation of individual bodies, experiences, and intimate diagnostic moments. This aggregation turns the afflicted into categories and statistical regimes that shape a global health understanding of diabetes specifically, and noncommunicable diseases broadly. This article explores the individual diabetes diagnostic moment itself and the politics of the current nosology of Type 1 and Type 2, a seemingly neutral dichotomy that belies colonial relationships between Senegal, slavery, sugar production and consumption, and the effects these relationships have on contemporary conceptions of diabetes diagnosis in Senegal and global health.

Keywords

Senegal, Diabetes, Diagnosis, Women's Health.

Fasting glucose test with glucometer, Saint-Louis, Senegal. Photo by the author, 2019.

Introduction

African nations have the highest levels of undiagnosed diabetes and the highest levels of mortality for diabetic individuals under age 60 in the world (International Diabetes Federation 2019, 64). The World Health Organization (WHO) reports that diabetes is rising most rapidly in low- and middle-income countries (World Health Organization 2020). In Senegal, West Africa, these global figures are reflected in national statistics: In a 2016 country profile, for example, the WHO stated that 5.1%

of the Senegalese population was diabetic (WHO 2016a), with numbers of afflicted expected to double in the coming decades (Nye 2019).

Where do these data come from? According to the WHO, they are based on the results of fasting glucose tests and *self-reporting* (idem, 64, emphasis mine). Diagnoses through lab analysis and clinical testing are difficult to come by in Senegal, which raises important questions about the factors that influence clinical diagnosis, including the available nosology, and how clinical diagnosis shapes treatment. In this research article, I draw on 15 months of ethnographic research into the rise in incidence of diabetes in Senegal to understand women's experiences of diabetes diagnosis in the country; the 'colonial nosologies' that underpin processes of clinical diagnosis in lieu of medical testing; and the ways in which colonial legacies impact the care that women receive and inform the production of statistics such as those listed by the WHO and International Diabetes Federation (IDF).

The rise of diabetes in a food-insecure region of the world, I argue, forces us to seek better understandings of the biological, social, and political complexities of diabetes diagnosis globally and to challenge dominant narratives about the causes of diabetes. These dominant narratives, as I will show, are frequently neither recognisable nor relevant from the perspective of patients and biomedical providers in the low-and middle-income countries that are the targets of many global health diabetes programmes.

In this research article, I explore the politics of the current nosology of Type 1 and Type 2 and how this nosology unfolds within the individual diagnostic moment. The seemingly neutral dichotomy between Type 1 and Type 2 belies colonial relationships between Senegal, slavery, sugar production and consumption, and the effects these relationships have on contemporary conceptions of a diabetes diagnosis in global health and in Senegal. This article challenges the hegemony of the Type 1 and Type 2 categorisation of diabetes, positing and discussing instead a possible third type of diabetes—a malnutrition-related diabetes—as a way of problematising the current framing.

The article then moves to investigate hospital memory, medical records, the creation of data, and the ways statistics are generated from those data to be used by national and international actors. Medical data must originate in places like the public hospital in Saint-Louis, doctor's offices and laboratories, and medical archives. At their root, these data are an accumulation of individual bodies, experiences, and intimate diagnostic moments. I argue that diagnostic moments— the moment an illness is named (Smith-Morris 2015)—and nosological categories shape individual lives and epidemiological imaginations of disease. The aggregation of the afflicted into categories and statistical regimes shapes a global

health understanding of diabetes specifically, and noncommunicable diseases broadly. I argue that surveillance through patient records and national data sets are all tightly bound in colonial ways of asking, or not asking, certain questions. Simultaneously considering the well-documented legacy of colonialism in shaping global health (Rieder 2017; Storeng and Behague 2014; Greene 2013; Livingston 2012; Chorev 2012; Brada 2011) and Frantz Fanon's (1967; 2004) belief that anti-Black colonialism is a totalising project, I see colonial ways of asking or not asking certain questions within global health as aligned with colonial projects of keeping colonisers' bodies safe, viewing the African continent as 'dirty' and 'infectious', and controlling nosological categories in ways that only represent certain kinds of bodies (namely white, male, Western bodies). Global health is driven by organisations based in the West and Western thinking: the WHO is headquartered in Geneva, Switzerland, for example, while the Gates Foundation is headquartered in Seattle, United States. Throughout this article, I use the terms colonial, Western, neoliberal, and global health. These are distinct phrases with particular practices, knowledges, and frameworks, but they are also interconnected. For example, I see global health as being mostly driven by Western (Euro-North American) thinking, which itself includes neoliberal thinking, which places emphasis on individual responsibility and does not account for the external, structural forces that shape people's lives. Neoliberal practices and colonialism—the practices and after-effects of violently dominating and occupying another country—are inextricably economically entwined (for example, see Menon 2019 or Venn 2009). Though these words describe different ideas and projects, they rely upon and feed into each other in many ways.

Turning next toward the initial moment where these numbers originate, individual bodies and somatic diagnostic moments are discussed. Diagnosis is an intimate interaction constructed between patient and provider. This is the moment when classification criteria make contact with the body. Moving from the nosology of how clinicians construct diabetes, I look to how individual bodies are diagnosed in relation to that nosology. Diagnostic moments and nosological categories shape individual lives and epidemiological imaginations of disease. The diagnostic moment creates a shared sense of meaning between afflicted and healer; it is a 'sentinel act' that, when successful, 'leads to efficacious care' (Smith-Morris 2015, 2). Diagnosis has a 'transubstantiating impact' on the afflicted (idem, 1) that allows for treatment plans to be designed and followed. Nosology provides the framework, the reference, and the way for clinicians and epidemiologists to classify disease, think about population health, and conceptualise individual health. Ethnographic narratives taken from a doctor's office and from conversations with two diabetic Senegalese women ground these abstract concepts in everyday lived experiences. Finally, this research article concludes with a call to decolonise

conceptions of diabetes at the levels of the diagnostic moment and global health nosology.

This research is based on 15 months of ethnographic fieldwork (February 2018 to May 2019). Nine of those months were spent as an observer at the public hospital in Saint-Louis, Senegal and between two Diabetes Association locations. The public hospital is part of the national health infrastructure in Senegal. It is a former colonial French hospital, previously only serving the French military. Now, however, it is a national public hospital serving the general population—anyone who needs treatment. The Diabetes Association is affiliated with the public hospital but receives funding from non-governmental organisations, such as Sister Cities International. These were good places to study diabetes, as they were the primary avenues people used to receive a diagnosis.

This research includes over 60 interviews with women, men, clinical providers, traditional healers, and statisticians. Over 100 women were surveyed using four different validated public health surveys. The research shared here primarily centred on 36 women who were a 'focal-follow'—that is, a group of individuals chosen from survey participants who then participated in interviews and participant observation. Most women who participated in this research identified as being part of the Wolof ethnic group, though I do not assume that all Wolof women share the same experiences. The mean age for research participants was 46 years old. These women were wives, mothers, restaurant owners, public servants, and maids. They ranged from well-off to poor. A few of these women's particular experiences are highlighted later in the article in the form of ethnographic vignettes.

Beyond Types 1 and 2: Decolonising nosology

In Senegal, the history of sugar consumption, the slave trade, and modern-day experiences of diabetes are intricately entwined. The phrase 'blood sugar' was first used by 18th-century British abolitionists protesting the production of sugar and its linkage to slavery (Muhammed 2019; Hatch 2016; Rice 1970; Fox 1792). Now, blood sugar is a colloquial phrase that refers to the amount of sugar present in one's bloodstream, monitored with a glucometer. In Senegalese contexts, colonialism and sugar haunt the 'fleshy situatedness' of bodies and 'modes of living' (Mol and Law 2004, 43). Similarly, current global public health conceptions of metabolic disorders haunt Senegalese bodies and clinical spaces of care (Kehr 2018; Hatch 2016). African bodies have been colonised twice by the global sugar trade:[1] first, through the slavery needed for the mass agricultural production of

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1   Thank you to Reviewer One for helping me to clarify this point.

sugar in the New World, and second, through the contemporary consumption of sugar. African bodies are overburdened by a disease linked with slavery that results in countless African and African American deaths. Today, African Americans are second only to indigenous Native American populations for rates of incidence of diabetes in the United States (Centers for Disease Control 2020, 4).

Senegal remains haunted by its colonial past. Current metabolic states are disturbed, registering a history tied to sugar agriculture and slavery—a frightening experience, but one with potential for 'something-to-be-done' (Gordon 2008, xvi). Diagnostic moments and nosological categories are grounded in ways of thinking that incorporate or wilfully ignore historical, political, and economic spectres. The conception that noncommunicable diseases, like diabetes and other metabolic disorders, arise from overconsumption, increasingly 'Westernised' foodways, and sedentary behaviour is indicative of a colonial way of thinking about the rise of metabolic illness across the African continent. Diabetes is called a 'lifestyle' disease because global health continues to insist it is a disease that manifests due to an individual's choices. This is a neoliberal way of conceiving of illness; it places all blame on the individual, with no recognition of larger structural issues (Carruth and Mendenhall 2019; Weaver et al. 2014). Foodways are changing in Senegal, but this change follows along lines of power and status: how food is shared and with whom, the types of foods consumed, and collective nutritional practices are entwined with status, gender, and race. The ways in which diabetes is or is not surveilled through patient records and national data sets are all are tightly bound in colonial ways of asking certain questions while neglecting many others.

The creation of the subcategories Type 1 and Type 2 within the disease category 'diabetes' seemingly reveals more about those creating the categories than it does the afflicted. Additionally, these subcategories increasingly diverge from diabetic narratives in other parts of the world (Carruth et al. 2019; Mendenhall 2019; Moran-Thomas 2019; Weaver 2019; Solomon 2016; Yates-Doerr 2015). In global health, the distinction between Type 1 and Type 2 diabetes has implications that reach beyond a medical diagnosis and, in the West, the distinction is a moral one. The idea(s) behind Type 1 (insulin dependent) versus Type 2 (non-insulin dependent) was not discussed with women in Senegal. Type 1 is hereditary, meaning genetic and therefore outside of an individual's control. Type 2, on the other hand, is believed to be caused by one's own shortcomings: overindulgence in food and sweets and an underindulgence in exercise (Yates-Doerr 2011). The term 'diabesity', a portmanteau of 'diabetes' and 'obesity', associates diabetes with being overweight. Despite the aetiology of Type 2 diabetes remaining unclear, the correlation of obesity and overconsumption is one that has been commented upon frequently in biomedical and public health literature (Farag and Gaballa 2011; Astrup and Finer 2000). In Senegal, however, when women are diagnosed with

diabetes, patients do not categorise the disease in the same way. In Saint-Louis public hospital, I observed women receiving a diagnosis of diabetes. Sometimes Dr Ndiaye,[2] the head diabetologist at the hospital, would specify to me whether it was Type 1 or Type 2, but I never saw this written on anyone's paperwork during my research. Women differentiated their diabetes by whether or not they took pills (metformin) or had to have injections (insulin).

The morality inherent in the differentiation between a Type 1 and Type 2 diagnosis makes it easy to continue a series of judgements against diabetic individuals, including the determination of what kinds of people they are. Type 2 diabetes, associated with 'lifestyle' choices such as overconsumption, poor nutrition, and sedentary behaviour, generates moral judgements that paint individuals with this diagnosis as lazy and incapable of control or willpower, and suggests that they make or have made bad decisions (Carruth et al. 2019; Yates-Doerr 2011). In the West, diagnosis of diabetes is not just about diagnosing a metabolic illness; it is also rooted in the diagnosis of lifestyle and behaviour. Inversely, this pattern of diagnosis provides a means of diagnosing the medical system that created such distinctions: 'Since it is the privilege of the powerful to be able to name or attribute meaning to a text, it is also a privilege of power to diagnose, to call something a disease, or to withhold a diagnosis' (Smith-Morris 2020, 4). Western conceptions in global health have thus far driven the nosology of diabetes, which in turn has driven the global health approach to diabetes treatment and prevention. The classification of diabetes into Type 1 and Type 2 subtypes is a legacy of colonial medicine that continues to inform global health policies and programmes for the disease, limits the questions that clinicians ask, and shapes the ways in which the disease is monitored and researched. The nosology of diabetes might thus be seen as a basis for diagnosing global health programmes as colonial (Smith-Morris 2005).

Malnutrition-related diabetes

The current global health narrative of Type 2 diabetes—i.e., as a lifestyle disease of overconsumption and sedentary behaviour—does not translate to Senegal. In 2019, the World Food Programme ranked Senegal at number 67 out of 117 countries in the Global Hunger Index (WFP 2020), which tracks hunger levels globally. With 7.2% of the population categorised as 'food insecure' and an additional 8.2% of the population considered 'malnourished' (ibid.), higher rates of diabetes cannot be clearly linked to higher rates of overconsumption in Senegal. Another type of diabetes—malnutrition or 'tropical' diabetes (Abu Bakare, Gill, and

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2   All names are pseudonyms for privacy.

Alberti 1986)—is perhaps a better way to understand the aetiology of diabetes in Senegal, but it requires further clinical research.

A World Health Organization (WHO) Study Group in the 1980s listed malnutrition-related diabetes mellitus as a primary subtype, saying:

> In tropical developing countries, young diabetics often present with a history of nutritional deficiency and a constellation of symptoms, signs, and metabolic characteristics which fail to meet the criteria used to classify the two main clinical subclasses of diabetes—IDDM and NIDDM.[3] The distinctive clinical features and course, the uncertain etiology and pathophysiology, and the great number of such cases in some regions justify the creation of a new, major clinical class of diabetes, namely malnutrition-related diabetes mellitus (MRDM). This new category of diabetes includes the variety of types known in the past as tropical diabetes, pancreatic diabetes, pancreatogenic diabetes, endocrine pancreatic syndrome and ketosis-resistant diabetes of the young (WHO 1985, 20).

As we can see above, the WHO felt confident that areas of the world referred to as 'tropical' and 'developing' exhibit a type of diabetes different from the standard Type 1 and Type 2 categories and that this difference was enough to merit the creation of a third category: malnutrition-related diabetes mellitus (MRDM). In 2016, the WHO released its first 'Global Report on Diabetes'[4] on World Health Day as a global 'call for action on diabetes'. The document does not once mention MRDM (it does, however, mention obesity 50 times). The current 2020 WHO 'diabetes' informational website does not mention MRDM. Articles and chapters discussing malnutrition-related diabetes usually end with a question mark: consider, for example, 'Tropical or Malnutrition-Related Diabetes: A Real Syndrome?' by Abu-Bakare, Gill, Alberti (1986), 'Malnutrition-related Diabetes Mellitus: Myth or Reality?' by Jean-Marie Ekoé and J. Shipp (2001), and 'Insulin-Requiring Diabetes in Rural Ethiopia: Should We Reopen the Case for Malnutrition-Related Diabetes?' by Alemu et al. (2009). While all three articles' authors conclude that this third type is a promising concept and merits further acknowledgement and clinical testing, little research has followed these publications, and the Western typology prevails. What happened to the discussion of malnutrition-related diabetes? Perhaps it was deliberately displaced in favour of Type 1 and Type 2 categories and a narrative that better fit Western bodies.

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3 IDDM: Insulin-dependent diabetes mellitus (Type 1); NIDDM: Non-insulin-dependent diabetes mellitus (Type 2).

4 See https://www.who.int/publications/i/item/9789241565257.

A 1986 article in *The Lancet*, 'Tropical or Malnutrition-Related Diabetes: A Real Syndrome?', highlights the possibility that there are many types of diabetes with differing aetiologies that thus require different treatment paths:

> The syndrome known as tropical diabetes seems to be distinct from the two main types common in developed countries. Major pancreatic exocrine disease may or may not be present, and within these two groups there are clinical and biochemical variants. For these conditions the term malnutrition-related diabetes has been proposed. Although malnutrition is a plausible unifying factor, there is a good case for retaining the term tropical diabetes until there is more information on clinical and biochemical features on aetiology (Abu-Bakare, Gill, and Alberti 1986, 1135).

Like the 1985 WHO Study Group before them, Abu-Bakare and colleagues discuss a subtype of diabetes rooted in hunger (and possibly, hidden hunger) experienced in early life. In their 1967 article, 'Diabetes in the Tropics', Silas Dodu observes multiple regional variations on the Type 1 and Type 2 categorisation in Ceylon (Sri Lanka), Jamaica, Indonesia, Kampala, and East Pakistan, as well as among natal Indians (Dodu 1967, 748). Contemporary research, however, on different subgroups and aetiologies of diabetes has not only not been a focus or priority for the field of medicine but has been entirely absent in the broader research of major global diabetes institutions such as the WHO, American Diabetes Association, and International Diabetes Federation (IDF). Recently, medical anthropologists and clinical researchers have taken up questions related to the aetiology of diabetes and more nuanced diabetes subgroups (Carruth et al. 2019; Carruth and Mendenhall 2018; 2019). Current global health approaches to metabolic illness are modelled after strict Western narratives of Type 1 and Type 2. These hegemonic narratives ignore the possibility for much more nuanced aetiologies and prevention and treatment plans for diabetics.

Diet and the household

The World Health Organization (WHO) and the International Diabetes Federation (IDF) list 'nutrition' as a primary way to prevent and manage diabetes (Type 2 in particular). Healthy eating advice, including 'reduce rice intake' and 'eat more vegetables', is given by Saint-Louis's Diabetes Association as well as doctors and nurses. This advice is broadcast over the radio and appears in popular television programmes. According to interviews and raw survey data, in Senegal, the ability to follow a prescriptive diabetic diet was complicated by the fact that many women's households experienced chronic or acute food insecurity. In addition to thirst and frequent urination, wasting (or rapid weight loss) is also a symptom of diabetes. The symptom of wasting often forced women to reluctantly seek

biomedical treatment from the doctor, at which point they became entangled in the process of receiving a diagnosis of diabetes (which often takes weeks). Interviews and surveys revealed that wasting as a symptom of diabetes was further compounded by the fact that women faced a choice to either eat what they prepared for their family or not eat at all. In households facing hunger, women reported that they consumed less and ate only what was affordable and available. Sometimes they took their children to the homes of family members at mealtimes to ensure their children would have at least one meal. But this practice was also viewed as an example of giving up control over diet. Sharing food (or sharing in the absence of food) illuminates the household nature of diabetes. While public health and biomedical prevention and treatment approaches to diabetes focus on the individual, shifting the unit of analysis to the household is necessary to fully grasp the complexity of the disease (Nichter 1995; Berman et al. 1994).

The existing nosology and its explicit moral judgments will be hard to uproot. In an interview with a Senegalese midwife researching gestational diabetes, women's behaviours around food were described to me as 'laziness' and as an 'unwillingness to change' (Interview 26 March 2019). I had come to understand food and mealtimes as structurally and culturally very difficult to change, especially within the social context of the household, while she had come to understand these moments as bound entirely to individual willpower. When faced with clinicians like this midwife, who are trained in Western biomedical ways of thinking about diabetes and who often continue to reproduce these ways of thinking, women simply opt not to discuss their diets during office visits. Over and over again, I witnessed women sitting silently as they were each given the same message: that their diet absolutely had to change (reduction in rice, increase in vegetables) or they would continue to suffer and be sick. No one ever asked them if they thought that was possible or worked with patients towards a solution to changing the diet of the entire household. This midwife's repetition of Western-driven global health narratives around diabetes is a powerful example of how internalised the moral judgments and neoliberal values of Type 2 diabetes are among Senegalese clinicians and how current Senegalese medical training reproduces colonial concepts and approaches.

These women's children were always present during interviews. These children's exposure to early life malnutrition is potentially setting them up for future diabetes. While the Demographic and Health Survey (a standardised international survey that collects data on health and illness statistics) does not collect information on chronic illnesses in Sub-Saharan Africa, it does collect extensive data on malnutrition. As medical anthropologist Lauren Carruth argues, 'Untreated diabetes eventually causes wasting, but the reverse is also true' (Carruth 2019).

Chronic hunger and malnutrition trouble global health narratives of diabetes being about genetics (Type 1) or lifestyle (Type 2). Globally, many diabetic people are left out of this Western conceptualisation of diabetes diagnosis and typing, rendering them invisible to global health, which is dominated by research and evidence generated at well-resourced institutions in Europe and North America. In turn, identifying this invisibility or absence is one way to diagnose global health as colonial—that is, as overly focused on Western narratives and clinical practices only possible in well-resourced places. Ethnographic studies of metabolic diseases in places that have high rates of diabetes concurrent with malnutrition and food insecurity allow for more nuanced understandings of diabetes to emerge (Carruth et al. 2019).

Patient experiences and the somatic diagnostic moment in the Saint-Louis public hospital

Waiting to see Dr Ndiaye, one of the two doctors at the Saint-Louis public hospital who treated diabetes, sometimes took all day. As part of the former and original capital city of colonial French West Africa, the hospital in Saint-Louis was designed with aesthetics in mind rather than practicality. Built in the 19th century, the hospital's retro-fittings seemed jarring against what otherwise might have been a pristine relic. Originally designed and built for use by the French military with Senegalese people excluded, the hospital, like much of Saint-Louis, has inverted these colonial hauntings. Now, only Senegalese and Mauritanian people use the hospital, and the only French people present are visiting doctors working rotations.

Dr Ndiaye's office had an air-conditioning unit jutting into the open-air waiting room. Whether the fan was running or not was a sure way to know if he was in his office for the day. I waited with everyone in the 38 degrees Celsius heat, watching the air-conditioning unit drip water into a bucket. After about three hours, Dr Ndiaye came to the door and called me in, saying he was going to start seeing the women who had diabetes. He called in three women at once. At first, I thought they were kin—mother and daughters, or sisters perhaps. Quickly I realised they did not know each other. What they did share was a diagnosis of diabetes, and Dr Ndiaye was seeing them together for efficiency. At 4 p.m., the waiting room was still full of people. In order to see all the patients by the end of the day, Dr Ndiaye had to see people with seemingly similar problems at the same time. With these women, he did not talk generally about metabolic illness or about diet. He listened to each woman talk about her symptoms and slightly adjusted the strength of her pills (metformin) or the amount of insulin. I asked one woman if she had a refrigerator; she replied that she did not. Dr Ndiaye seemed concerned by this answer and asked if she was keeping her insulin on ice. The temperature was regularly over 38 degrees Celsius. She said she tried to keep it on ice.

Women who arrived in Dr Ndiaye's office may or may not have had a fasting plasma glucose test or an A1c glycated haemoglobin test before, two of the primary biomedical diagnostic tests for diabetes in most well-resourced locations. The A1c tests the amount of blood sugar attached to haemoglobin, providing a measurement of average blood sugar over the previous two to three months. It gives a more accurate reading than a fasting glucose test. Dr Ndiaye always told women to complete lab work that included one of these tests, but many factors complicated adherence to this request. Lab work could cost anything from 10,000 XOF to 60,000 XOF (20–120 USD), making it unaffordable to most. Lab work required another day of waiting for blood to be drawn. Some women even talked about waiting all day only to have the lab run out of needles, tubing, or vials before they could be seen and being told to come back another day. Additionally, at the time of fieldwork, the Saint-Louis hospital had been experiencing ongoing strikes among healthcare workers for several years, so it was difficult for women to know which day to show up. The labs were not considered to provide essential services and were shut down periodically to create disruption.

Most women had been given their diagnosis not after completing the fasting glucose or A1c test, but after giving an explanation of their symptoms to a doctor or because the results of a glucometer finger stick had indicated high glucose levels. Receiving the 'gold' standard of either the fasting plasma glucose test or an A1c diagnostic test could take many weeks. First, a woman must visit the doctor and receive a referral to go to the lab for further diagnostic testing. This in itself can take several weeks to accomplish. Once a woman has the referral to visit the hospital lab, she must make another appointment with the lab coordinator. The day of her appointment, however, can be interrupted by hospital strikes (explained in detail below) or lack of materials (tubing, needles, vials for storage, etc.), in which case, the woman will then return to the lab coordinator to try to book another appointment. How most women visiting the hospital had arrived at their diabetes diagnosis was often unclear, as was whether this diagnosis had been recorded anywhere other than in their memories (especially as patients did not have individual medical records kept at the hospital). With the diagnoses arriving through several channels (symptoms, lab analysis, occasional glucose tests) but ultimately becoming part of women's health status, these women's disease experiences were shown to follow Mol and Law's idea that 'knowing is a practice': a way of blending together medical approaches that objectify the body coupled with the 'intro-sensing' of symptoms and experiences an afflicted individual understands from within her own body (Mol and Law 2004, 146–48). For both the afflicted and the clinical provider, these overlapping lenses—that is, clinical gaze and embodied symptoms—are critical for arriving at a diabetes diagnosis in Senegal.

My ethnographic work revealed that most women received a diagnosis of 'diabetes' on the basis of their presentation of symptoms rather than through biomedical testing. Diagnosis of diabetes requires laboratory testing (WHO 2019), preferably over a period of time, to better understand fluctuations in glucose levels in the body. As I describe above, testing is complicated by myriad factors in Senegal. As my months in the field progressed, I determined that the way in which diabetes is biomedically diagnosed in well-resourced places is not feasible in public hospitals in Senegal. I also came to understand that, while a diagnosis based on symptoms rather than biomedical testing might lack clinical accuracy, it does allow for crucial treatment to progress.

What does it mean to be diagnosed by one's diabetic symptoms instead of one's diabetes test results? Do the means through which one is diagnosed with diabetes change the kind of treatment that can occur? More importantly, how do standards about ideal diagnostic strategies—themselves laid out by international organisations such as the World Health Organization (WHO) limit or constrain the treatment of diabetes in resource-poor settings like Senegal, where cases of diabetes and chronic disease are rising? Echoing Duana Fullwiley's (2006) findings on the sickle cell trait in Senegal, I have found that diabetic symptoms drive individual experiences whether or not they are properly or appropriately diagnosed. In many ways, the symptoms of diabetes become more important than medical testing guidelines for addressing patients' disease and illness experiences.

In thinking through individual women's diagnostic moments, I often think about two women in particular: Maïmouna Diaw and her daughter, Diarra Fall. These two women's experiences illustrate the difficulty in receiving a diagnosis and also the lack of epidemiological data collected surrounding patients' experiences. Maïmouna Diaw had felt sick for years. Her symptoms—frequent urination, excessive thirst, wasting, and persistent dizziness—made it difficult for her to sleep at night or continue working as a housekeeper in the home of an elderly French man. She visited the doctor on several occasions but was told nothing was wrong—that she was just tired or not eating well. It was not until she arrived at the hospital in a diabetic coma about two years after the onset of her symptoms that she was diagnosed with diabetes. At 65 years old, she had been living with her diagnosis for 20 years.

When Maïmouna's daughter, Diarra Fall, was diagnosed with gestational diabetes during a prenatal check-up, Maïmouna became exceedingly worried; she was uncertain whether her daughter was receiving the care she needed. Diarra's baby died about a week after being born, and both she and Maïmouna were convinced the baby had not survived because of diabetes. Diarra's gestational diabetes

persisted, and she was told that she still had diabetes despite the pregnancy itself being over and that perhaps she had been diabetic even before the pregnancy. Both Maïmouna and Diarra struggled to get a diagnosis and, even after getting diagnosed, both women were uncertain about the diagnosis they had received; they weren't sure whether they had Type 1, Type 2, or gestational diabetes. The diagnostic moment for both women was fraught, contentious, and unclear. Both were taking metformin pills to treat their disease, but their ability to pay for medicine and appointments with doctors depended on their ability to work, which depended on how they were feeling. Often, they could not afford to visit the doctor and could not afford their pharmaceutical prescriptions. They would share each other's pills depending on who was able to afford medication, meaning dosage was variable. Based on what women shared with me, along with my interviews with those in charge of the hospital archives, these women's diagnoses were likely not captured in an account of diabetics in the Saint-Louis hospital catchment area, and so their cases were not recorded or used to help generate data at a global level.

Personal monitoring

Diabetes requires constant self-surveillance. An individual suffering from this disease must dedicate fastidious attention to numbers by measuring blood sugar levels generated throughout each day. Lack of access to testing had an impact on the management of the disease in addition to its diagnosis. In well-resourced Western countries, diabetics typically check their blood sugar throughout the day, often before and after eating.[5] The amount of insulin injected should correlate to the types of food about to be consumed. It is a delicate balance of trying to equal out insulin hormone and sugar levels. A normally functioning pancreas is able to produce the 'correct' amount of insulin when food is eaten. If a pancreas can no longer produce insulin or no longer responds to sugar in the blood, external insulin injections are required. Too much insulin will leave a person hypoglycaemic, with low blood sugar. Too little insulin will leave a person hyperglycaemic, with high blood sugar.

In contrast to typical Western practices, the women I interviewed in Senegal took an insulin dose—prescribed to her by her doctor—not based on her individual level of blood sugar at a given moment in time. Doctors knew women were not testing their sugar every day, much less multiple times a day. Using insulin thus required the doctor to give a set dose of insulin without any correlation to diet. Doctors were doing the best they could, making calculations informed by who the woman was, her current and past symptoms, and the meeting they'd had that day. On occasion,

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5   Recent attention has been drawn to the difficulty and rising cost of monitoring blood sugar throughout the day in the United States; for example, see Epstein and Strodel (2018) and Ofri (2019). See also Amy Moran-Thomas's (2017) history of the glucometer and pricing of glucometer foils.

the insulin dose given by the doctor seemed to be fine; often, however, estimates were too high or too low, leading women to continue experiencing their symptoms or hypoglycaemia (low blood sugar). Insulin often left women feeling sicker than they had felt before they took it. Many women discontinued insulin use when side effects became worse than the diabetes itself (or if they could not afford to fill the prescription). Not using insulin when required leads to unregulated diabetes. Unregulated diabetes generally results in a near-constant state of hyperglycaemia. Prolonged high blood sugar severely damages the body—cardiovascular disease, nerve damage, and kidney damage can occur, among other co-morbidities. This is why, as a diabetic, it is so important to regulate blood sugar through constant self-surveillance.

A glucometer (glucose meter) is typically used to check blood sugar levels. The finger is pricked, after which blood is placed on a test strip and then inserted in the machine, which provides a near-instant reading of blood sugar levels. Finding a glucometer in Senegal was difficult. Only two women involved in the focal-follow of 36 women had their own personal glucometers. Both these women had run out of the test strips long before our conversations took place, and had been unable to use the machines for months, in one woman's case, and, in the other's, years. No one involved in this research tested their blood sugar daily. No one consistently tested their blood sugar before or after meals. Some women would go weekly to the Diabetes Association to have their sugar tested, but at 500 XOF (1 USD) per test, this was too expensive to do daily (and, for some women, too expensive to do weekly).

Diagnosis of statistics

Epidemiology surveils populations to understand incidence, rates, and distributions of diseases. But what happens when epidemiology does not have enough data to understand diseases within a population? National level epidemiological data can come from two sources: either from population-level research, such as prevalence surveys, or the collation of clinical data recorded at health facilities and aggregated by the Department of Health at a national level. But I found an absence of both kinds of data collection for diabetes in Senegal. If diabetes diagnosis and management in Senegal is determined by a colonial nosology that ignores local factors in diabetes aetiology, our knowledge about diabetes in the country is also shaped by a legacy of colonial ignorance around the presence of noncommunicable diseases in the country, which continues to be evident today in the lack of attention paid to epidemiological data for the disease.

Epidemiological research and surveys

Epidemiological research focusing on Senegal, and indeed most of Africa, routinely fails to prioritise and capture data on noncommunicable diseases. The Demographic and Health Survey (DHS), which has for the past seven years been funded by the United States Agency for International Development (USAID), for example, does not capture and record rates of noncommunicable diseases, a situation lamented by experts in noncommunicable diseases in Senegal. Epidemiological research has primarily centred on communicable (infectious) diseases as well as maternal and child health. These chosen foci reveal a colonial view of health in Africa, one focused on keeping certain bodies (colonial) safe from diseased, othered bodies (i.e., those of the colonised) and controlling the population of African bodies (Greene 2013). This colonial thinking, based on communicable disease and maternal health, continues to limit how global public health perceives illness and disease across the continent. Communicable disease remains an important issue but the rise in noncommunicable diseases has only recently begun to be noticed or prioritised.

The Western perception that researching and treating noncommunicable diseases in sub-Saharan Africa are neither high priority or cost-effective in terms of overall disease management means that, in a place like Senegal, it is a waste of local energy and resources to collect these data. Understanding the intricacies of maternal health garners funding, so putting emphasis on maternal health ensures continued funding for certain programmes.

Collating clinical data

There are also multiple obstacles to the collation of clinical data into national statistics. Madame Khadidiatou Camara was both the head nurse and the head archivist at the Saint-Louis hospital. We were introduced by the director of Human Resources. The bright outdoor hallways of the hospital contrasted with the near-complete darkness in Madame Camara's office. Madame Camara was wearing reading glasses that she kept pushing back into place on her nose. She was a petite lady, and her tone of voice was sharp and business-like. She was dressed in a beautiful purple dress with a matching headwrap. Given her title and mindful of how busy the hospital always was, I was already worried I was wasting her time.

My first question seemed benign and easily answerable: how many people come to the Saint-Louis public hospital in one year? Before answering, Madame Camara clarified that the numbers she had were from 2017 (the previous year); the hospital didn't have the information for 2018 yet. The numbers from 2017 were raw and had not yet been verified, gone through, or 'cleaned up'. I asked if she would prefer to use numbers from 2016 but she said she would just give me what she had from 2017.

She broke down hospital visits into three categories: consultations, consults, and hospitalisations. She told me there had been 63,724 consultations (ongoing appointments), 39,815 consults (one person seen once), and 8,250 hospitalisations. Madame Camara then gave the number 22,093 for instances of cardiovascular disease. I asked if this was the number of people in the hospital catchment area seen for cardiovascular disease or the total number of appointments regarding cardiovascular disease. She answered with another number: 3,235, saying this was the number of people with diabetes and/or hypertension. I asked what the original number of 22,093 meant. She answered by saying that, as someone living in Saint-Louis, she knew there was an issue with diabetes and that these were her personal numbers, which she had tracked on her own despite the Demographic and Health Survey not tracking either diabetes or hypertension. I pressed how she had arrived at these numbers. She replied that she knew there was a problem with tracking and, because she was curious, she distilled the number 3,235 from 22,093. Then she told me that, in 2016, 31 people had died from diabetes. When I asked her where the number 31 came from, she said she had gone through the ledgers given to her by the different doctors in the hospital. I asked if the number 31 included people who had died at home and/or those who had died in the hospital from something other than diabetes but who had diabetes. She wasn't sure.

I never discovered where those numbers came from. Even Madame Camara wasn't sure. Were they from 2016 or 2017? How did she have numbers that the hospital didn't have?

By the end of October 2018, I had begun identifying the ways in which patient records were kept and how diagnostic practices at the primary care and hospital level fed into national-level statistics. From observations with diabetologist Dr Ndiaye at the Saint-Louis hospital, I knew that each individual's name and information were handwritten into a large ledger kept on the doctor's desk. People came into his office with slips of paper, papers carefully filed in a notebook, or bulging plastic bags full of slips of old pharmaceutical prescriptions and doctor's notes. During interviews with women in their homes, these items were often excavated—from under beds, down from roof rafters, and out of cabinets—and shown to me. Doctor's notes, prescriptions, receipts, old pharmaceutical boxes … all were kept to create a history of a disease and illness experience, an archaeological record of attempts at biomedical intervention. These materials were shared with the doctor and, basing decisions on these notes in combination with the patient in question's medical history and examination, the doctor attempted to either diagnose or continue treatment.

Guillaume, the head of Human Resources, told me that information is often weaponised during strikes: doctors and nurses refuse to record data, and if they do record data, they refuse to share it with the administration, knowing this will impede the administration's ability to generate reports. Guillaume assured me that, after a strike was resolved, any data gathered was usually passed on to the hospital administration, but he cautioned that clinical staff often stopped recording data during this period and, even if there was not a strike, clinical staff still sometimes chose not to record data or put data into a report for administrative use. The hospital was in the midst of a strike as I conducted fieldwork. This strike began on 2 May 2018 and was ongoing when I left Senegal in May 2019.

The keeping of data then was weaponised by striking workers. Continuing to provide care allowed healthcare workers to fulfil the Hippocratic Oath, while withholding data made apparent their frustrations (Tichenor 2016). National statistics collated from hospital records were eventually shared with international organisations (in addition to DHS), which in turn determined the external funding given to Senegal. Withholding local-level data about patient information disrupted the chains of information being compiled across the country and was therefore one way that health workers could leverage their power over the government. As Marlee Tichenor (2016) argues, this was done intentionally as a way of making explicit the relationship between local data production and global aid.

My hope when I set out to complete my fieldwork had been to understand the exact number of people with diabetes and hypertension in the catchment area for the Saint-Louis hospital. To me, inculcated in a world of data systems and part of an academic system and public health system reliant on exact numbers, this seemed like standard information that would be readily valuable to anyone hoping to understand the epidemiology of diabetes on a global scale. My frustration spilled over when I went to the Diabetes Association and asked if they recorded the number of people who visited their buildings. Many people went to one of the two Diabetes Association offices in Saint-Louis for testing or to talk with the volunteers. Thinking this might be another way to triangulate the data and numbers in the area, I asked if they knew how many people in Saint-Louis had diabetes. They didn't know. People came in for testing and their names were recorded in a ledger, but these data were never compiled or sorted according to person and number of visits. The Diabetes Association on the northern part of the island did not even record individuals' names.

Hospital-level data about diabetes cycles into larger epidemiologic systems for understanding disease. In this instance, the broader nosology of Type 1 and Type 2 diabetes constrains what data are collected, while the data collected reinforce the nosology—thus a feedback loop is created. For understanding both the

nosology of diabetes and the colonial legacy determining which statistics are counted in global health, we see that 'the most influential structures are those unquestioned forms of naming: the taxonomies from which and through which dominant relationships are built and institutionalized' (Smith-Morris 2015, 7). What Smith-Morris calls a 'diagnosis of statistics' (ibid)—an examination of influential structures and powers of naming—is a way of commenting on the intersectional experience of diabetic women's suffering in Senegal.

Data production and the effects of global funding on data collection

So where had the data on diabetes in Senegal that I had researched prior to starting fieldwork come from? In preparing grant applications, I had quoted articles with specific numbers concerning noncommunicable diseases (diabetes specifically). The International Diabetes Federation (IDF) and the World Health Organization (WHO) use specific numbers. I knew that these data had to come from somewhere. I was confronting the reality that these numbers were not 'real' in the sense that people in the West have come to think of numbers as 'real' or 'reliable'. These numbers had become real in the global health imagination and were cited by scholars and practitioners, but their genesis remains a mystery.

The question of which diseases are or are not chosen to be surveilled by global health institutions is tightly bound to colonial ways of asking or, in this instance, not asking certain questions. Diabetes is a problem in Senegal. This was clear from the interviews I had conducted with women and doctors. But, where were the statistics and numbers coming from that were being circulated by the WHO and IDF? I spoke with both national- and city-level statisticians who were not able to give me the answers I was looking for; therefore, the numbers cited by the WHO and IDF are likely to be 'zombie statistics' (Kessler 2015)—that is, statistics that are generated, often by large development organisations such as the United Nations (UN), without any verifiable research or data behind them (Doss et al. 2013). Because of the trust placed in and authority associated with organisations like the UN, these statistics are taken as fact, reproduced, cited in academic journals, and used to solicit donations. 'They are referred to as "zombie statistics" because, though they have no basis in fact, they just won't die' (Mesce 2017).

Many of the people I spoke with offered their own statistics regarding diabetes in Senegal. A traditional healer told me that 60% of people in Senegal have diabetes. A pharmacist I talked with at the primary pharmacy servicing the hospital confidently said that 90% of people in Senegal have diabetes. People throughout the country told me that Saint-Louis specifically had the highest rates of hypertension and diabetes in Senegal. According to Mr Samba Ka, the Ministry of

Health statistician, the final year for the Demographic and Health Surveys (DHS) to be funded by the United States Agency for International Development (USAID) was 2017. The USAID DHS website continues to have Senegal listed for 2020, though it is still not collecting data for noncommunicable diseases.

The collection of data on noncommunicable diseases in Senegal should be prioritised. Certainly, data collecting is an important tool for improving the health of populations and individuals within those populations. However, rather than taking the colonial nosologies (e.g., Type 1 and Type 2 diabetes) for granted, Senegalese epidemiologists should instead generate nosologies from the ground up that reflect the lived experiences of disease among Senegalese people. A top-down focus from global health fails to do this. Clinical providers are reliant on these population-level epidemiologic data, which inform individual treatment plans and approaches to disease prevention. Given the findings from my fieldwork and other ethnographic accounts (e.g., Carruth and Mendenhall 2018; 2019; Vaughan 2018), diabetes and hypertension are growing issues across sub-Saharan Africa, but these metabolic disorders look slightly different than they do in Western countries.

The careful recording, archiving, and tracking of these data guides decision making in biomedicine and public health. It allows funding programmes to know where money should be directed. Additionally, the numbers that are collected, and how they are collected, are a function of power and the systems that enable that power. These numbers and their collection process also foreground the questions of who exactly is allowed to ask questions and who designs the research and recording. Uncertainty creeps into treatment plans without glucometers to measure blood sugar. Uncertainty surrounds understandings of the prevalence of diabetes in Senegal. This uncertainty leaves people without access to life-saving funding, medications, and clinical and international attention. At the heart of any of these numbers are the afflicted individuals. These are the people who have been diagnosed and are living every day with their disease. The diagnosis itself is bound by current understandings of what diabetes is as a nosological category.

Conclusion

Despite being a problem, diabetes is poorly understood in Senegal. Split into two main types, the second of which prompts heavy moral judgements about lifestyle and diet choices, current diabetes categories do little to reflect the lived realities of those suffering from the illness in Senegal. There is likely a third type of diabetes—malnutrition-related diabetes mellitus—but this type has not been a focus of research or funding. Global health needs to start looking towards food insecurity, hunger, and malnutrition as being causal drivers of diabetes. Focus must shift away from overconsumption, obesity, and 'diabesity' to include areas of the world

with rising diabetes levels but populations that are not always concurrently obese. The moral judgments behind a Type 2 diabetes diagnosis form a large part of clinical providers' treatment and perception of individual patients, as observed in the ways women are instructed to eat, but these judgements are not reflective of cultural context.

It is implausible to transpose Western expectations for diagnosis onto a context such as Senegal that has fewer resources. Diagnosis and access to healthcare are not easy or affordable. Tracing both individual and aggregate data would likely increase access to healthcare by garnering increased global funding. These sorts of approaches to collecting data need to be based on a Senegalese way of experiencing disease and not from a top-down global health perspective. Unfortunately, these metrics do not exist. The global health systems, as currently structured, do not record data on noncommunicable diseases in ways that account for Senegalese nosologies (e.g., malnutrition-related diabetes mellitus). When the only nosological categories that are available to medical providers are Type 1 and Type 2, diagnoses occur that don't necessarily help Senegalese women manage their illness experiences. This is a diagnostic sign of persistent colonial thinking within global health: the idea that approaches to disease management within sub-Saharan African should remain solely focused on infectious disease and maternal mortality.

Western narratives can no longer be the only way of understanding illnesses like diabetes. This article is a call for the 'something-to-be-done' (Gordon 2008)—for a reconceptualisation of diabetes nosology and data collection in the global health imagination that allows for and enables access to and quality of care. Senegalese women's experiences allow for an understanding of the ways in which reframing diabetes specifically and metabolic disease generally will benefit all of global health.

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About the author

Emma Bunkley is a medical anthropologist with interests in global health and women's health. Her ethnographic work focuses on Senegalese women's experiences with noncommunicable diseases. She is currently working as a postdoctoral research associate at Washington University in St Louis on the project *Caring for Caregivers* in a paediatric hospital in Zambia.

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