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## What drives distress? Rethinking the roles of emotion and diagnosis among people with diabetes in Nairobi, Kenya

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### ABSTRACT

Type 2 diabetes mellitus is a condition that both results from and produces social and psychological suffering. As ‘diabetes’ increases among low income patients in poorer nations, new challenges arise that drive, co-occur, and result from the condition. In this article, we describe how social suffering produces diabetes by way of addressing the varied social, psychological, and biological factors that drive diabetes and are reflected in diabetes experiences among patients seeking care at a public hospital in Nairobi, Kenya. We recruited a non-probability sample to participate in a cross-sectional study of 100 patients (aged 35–65 years), where half of the participants sought care from a diabetes clinic and half sought care from the primary healthcare clinic. We obtained informed consent in writing, and collected life history narratives, surveys, anthropometrics, and biomarkers. This paper evaluates survey data using frequencies and regression tables. We found that social factors as opposed to disease factors were major drivers of psychological distress among those with and without diabetes. Psychological distress was associated with female gender and feelings of financial and personal insecurity. We also found insulin resistance was common among those undiagnosed with diabetes, suggesting that many seeking primary care for other health conditions did not receive a routine diabetes test (most likely because it is an out-of-pocket cost, or other competing social factors) and therefore delayed their diagnosis and care. Thus, social and economic factors may drive not only emotional distress among people with diabetes but also delayed care seeking, testing, and self-care as a result of cost and other social challenges.

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## Introduction

I was stressed when I initially learned I had diabetes but then I got used to living with it. [...] The problem I have is financial because without money you can't do anything. You can't even take the kids to school, and you can't do anything. That is the challenge I have because I have never had enough money. I always get a little and use it all. So that is the biggest problem that

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I have in my life and I think that is what contributed to my diabetes. – Matu, a 50 year old man from Kibera, a low-income neighborhood, or slum, in Nairobi, Kenya

Matu is one of 415 million adults who have Type 2 diabetes in the world. Some call Type 2 diabetes one of the greatest public health emergencies of our time: in 2015 more people died from diabetes complications than AIDS, tuberculosis, and malaria combined (International Diabetes Federation 2015). And nearly 318 million people are living with impaired glucose tolerance, indicating that they are on the brink of developing diabetes (International Diabetes Federation 2015). Type 2 diabetes remains the leading cause of adult blindness, kidney failure, and loss of limbs, and a significant contributor to heart disease and stroke (Nanayakkara et al. 2018). Type 2 diabetes is more common among older adults but increasingly afflicts much younger and thinner populations, especially in South Asia and Sub-Saharan Africa. In these contexts, diabetes often goes undiagnosed and most die from the condition in their most productive working years (International Diabetes Federation 2015). These numbers have risen exponentially in the past three decades (now in Sub-Saharan Africa to include more than 400 million people) and many project these numbers to continue to rise (International Diabetes Federation 2015). In contexts like Kenya, diabetes is shifting to afflict lower income populations, as opposed to wealthier populations – to which the disease has long been tied (Ayah et al. 2013; Cheng et al. 2013; Corburn and Hildebrand 2015; Kaduka et al. 2012). Yet, as Matu indicates, rarely is diabetes the most pressing stress in people's lives because they face chronic social and emotional burdens that precede it, and their social lives and economic livelihoods are impacted by living with the chronic condition.

Matu and others we interviewed in Nairobi, Kenya, describe how social suffering produces diabetes, chronicled by the stress associated with financial obligations to meet their family's basic need for food, housing, and school fees. Although many had physical health conditions, such as diabetes, rarely did diabetes take priority in how they thought about their social well-being. In addition to financial concerns, loss of a loved one, feeling unsafe in their neighborhood, memories of past or ongoing interpersonal abuse, caring for children or grandchildren, and other dimensions of life caused them worry and symptoms of anxiety and depression (Mendenhall et al. 2015; also see Liani 2014). Around the world, ethnographers have found that prioritizing family over diabetes care is intuitive for so many because competing challenges (from school fees to putting food on the table) often present more immediate basic needs (Carney 2015; Hardin 2016; Mendenhall 2012, 2019; Weaver 2016, 2018; Yates-Doerr 2015). Even so, receiving a diabetes diagnosis was stressful; for many, the initial diagnosis was surprising and draining, although this was one of many equally difficult challenges they faced.

In this article, we rethink what drives emotional distress among people living with diabetes in urban Kenya. In part, we challenge the broadly accepted notion in biomedicine that living with diabetes largely drives emotional distress and related depression among those with diagnosed diabetes (also see Pouwer, Kupper, and Adriaanse 2010), a notion that has been increasingly challenged by pointing out psychological, biological, and biobehavioral pathways through which depression and diabetes become bidirectional (see Golden et al. 2007; 2008; Holt, Groot, and Golden 2014; Renn, Feliciano, and Segal 2011; Talbot and Nouwen 2000). In doing so, we build upon the common theoretical notion in medical anthropology that social suffering produces diabetes (Carney 2015; Ferzacca 2012;

Kleinman, Das, and Lock 1997; Mendenhall 2012, 2019; Rock 2003; Scheder 1988; Yates-Doerr 2015). We evaluate the black box of social suffering through the targeted analysis of the social and emotional factors that produce distress in the mind and body (as measured through anxiety, depression, and hemoglobin A1c [HbA1c]). HbA1c is both a biological marker of insulin resistance, or diabetes control, and a stress hormone, which reflects buildup of stress over time, and has been used frequently as a measure and point of contention among anthropologists interested in diabetes and diagnosis (see Degeling and Rock 2012; Rock 2005). Physicians and public health practitioners, especially in academic circles, are increasingly taking seriously the social and emotional complexities of diabetes; however, still the condition is often perceived as primarily a physical disorder. By weaving together biomarkers with discrete markers of social suffering, we intend to break down the complexities of what drives distress among those with diabetes. Thus, this paper demonstrates how diabetes is both produced through social and psychological suffering and can similarly affect physical, mental, and social well-being.

### What drives diabetes?

Anthropological scholarship on diabetes and social suffering has focused on the complicated interactions of political marginalization, racism, classism, and sexism at work, home, and the clinic in North America (Ferreira and Lang 2006; Ferzacca 2000; 2012; Hunt, Valenzuela, and Pugh 1998; Mendenhall et al. 2010; Montoya 2011; Rock 2003; Scheder 1988; Schoenberg et al. 2005; Smith-Morris 2008). Diabetes in the Global South, in contrast, has received little attention until recently (Hardin 2016, 2017; Mendenhall 2019; Moran-Thomas 2012, 2019; Solomon 2016; Weaver 2018; Yates-Doerr 2015). These studies challenge the widely accepted linear argument of nutrition transition, where diabetes moves from wealthy to poor countries, and wealthy to poor populations as a reflection of modernization and culture change (Basu et al. 2012; Monteiro et al. 2013; Popkin 2006, 2015; Popkin and Hawkes 2016; Vellakkal et al. 2013). In contrast, these anthropological studies indicate that diabetes produces a localized interaction or, as Solomon (2016) refers, 'absorption' of foods, fats, toxins, stress, and other external factors that become transduced in metabolic realities. Yates-Doerr (2012, 2015) has argued that the construction of the body, self, and weight, which are so closely linked to diabetes, cannot be dissociated from how nutrition is 'enacted in human relationships' (2012, 139) and that these interactions may be as or more impactful than power dynamics or structural inequalities. In other words, she argues that the more intimate aspects of care or care-giving, such as 'tenderness, empathy, compassion, and respect', cannot be overlooked when thinking about what drives diabetes (Yates-Doerr 2012, 139). Similarly, Weaver (2016, 2017) reminds us that important gendered subjectivities are enacted in how women experience diabetes, engage in care-giving, and are cared for, often putting their families first and leaving their own health up to God (also see Hardin 2016, 2017). Many ethnographic details reveal how people navigate cultural complexities of food, gender, and caring for loved ones while managing chronic illness. Recent work goes a step further to contextualize what diabetes looks like within a context of nutrient deficiency, or 'wasting away' among Somalis in eastern Ethiopia who primarily link diabetes onset with recurrent exposures to stress, trauma, crisis, and displacement (Carruth and Mendenhall 2018, 2019); in fact, this study suggests that such experiences may be at the center of what drives diabetes in the first place.

In contexts of nutrient deficiency, diabetes diagnosis is often low in part because of low rates of detection. In Kenya, large surveys of diabetes suggest that diagnosis is so very low; the STEPS study found that 88% of Kenyan adults never had been tested for diabetes and that only 40% of those who met the WHO criteria for diabetes had begun taking medication (Ayah et al. 2013). This is in part due to the high cost of diagnostic tests, which are prohibitive of people seeking medical care for what is known as a ‘specialty’ disease at public clinics in Kenya. This is contrasted to other specialty diseases, namely HIV, tuberculosis, and malaria, for which international donors provide funding for all or part of testing and medication (Bernstein, Oomman, and Rosenzweig 2007; Kenworthy and Parker 2014; Kenworthy, Thomann, and Parker 2018; Menzies et al. 2011). Thus, we focus on who is diagnosed with diabetes from a primary clinic where people are primarily seeking care for other symptoms or conditions, and contrast their HbA1c to those people who have already been diagnosed with diabetes and are seeking care from the specialty diabetes clinic at a public hospital in Nairobi.

In biomedicine, HbA1c is known as glycosylated hemoglobin, which is a measure of glucose concentrations in the blood over a three month period and commonly used for diabetes diagnosis and monitoring progression of the disease. Yet, HbA1c also reflects stress over the life course, as it is interconnected to processes of inflammation, the hypothalamic pituitary adrenal axis through its relation of cortisol (a glucocorticoid), and other macrovascular and microvascular complications (Stratton et al. 2000; The Diabetes Control and Complications Trial (DCCT) Research Group 1995). For instance, scholars have argued that HbA1c serves as an important reflection of chronic stress, such as culture change (Daniel et al. 1999) and the breakdown of social cohesion (Long et al. 2010), which illuminate how HbA1c is connected to chronic stresses associated with upstream social determinants and transformations. Thus, HbA1c is useful not only as a clinical marker of diabetes prognosis but also as a reflection on how external factors may become embodied and reflected in diabetes individually and at the population level (see Degeling and Rock 2012).

This article investigates the social, psychological, and biological factors that produce insulin resistance among low-income patients with diabetes in urban Kenya. We ask a number of questions to achieve this, such as: how commonly is diabetes undiagnosed in a public hospital in urban Kenya? Among those who have been diagnosed with diabetes, how many control their diabetes? What factors may be associated with distress, diagnosis, and diabetes control? Finally, how does one’s gender affect anxiety, depression, and HbA1c? And, does HbA1c, as a biological measure of stress, reflect these psychiatric distress measures? How do these biological and psychological processes inform the ethnographic work that is emerging?

## Methodology

### *Setting and data collection*

We conducted this study at a public hospital in Nairobi, Kenya, situated next to Kibera slum. Nairobi is Kenya’s green capital city and largest urban conglomerate, filled with public parks and forests, and home to more than 6.5 million people from all reaches of East Africa. Founded in 1899 when the Uganda Railway line was built for the British Empire, the city has a history of hyper-segregation, such as the 1922 Vagrancy Act that segregated people by income, ethnicity, and economic identity (Ekdale 2004). This hyper segregation was epitomized in Kibera: land settled during the colonial era as an informal

residence of returning Nubian soldiers who were relegated to the periphery of the city as a result of a racially exclusionary informal settlement after their service. These ‘native reserves’ were physical spaces but did not permit land tenancy, something that has persisted for many families to present day (Ekdale 2004). Kibera itself remains an informal settlement owned by the government, although the government has formally acknowledged Kibera and it has political representation. Kibera has grown exponentially with many African migrants moving to Nairobi seeking economic opportunities. Estimates of the population of Kibera differ – from 250,000 residents to more than one million – with generous ethnic diversity, including Luo, Luyia, Nubian, Kikuyu, Kamba, Kissii, and others (Davis 2006). The population of Kibera represents the socioeconomic diversity in Kenya itself, with many families experiencing social mobility amidst the majority of residents who survive extreme poverty, earning less than one USD per day. This is physically evident in the houses that are packed together in Kibera, mostly small shacks made of wood with concrete floors that serve as home to around eight people. Most families are tenants with limited rights and voice concern for access to safe water, electricity, sanitation, jobs, health facilities, and secure homes (APHRC 2014).

The research study was conducted at a public district hospital that serves as one of the largest feeder hospital clinics for Kenyatta National Hospital (a public, tertiary referral hospital for the Ministry of Health). We consulted with their Chemistry Lab to analyze some biological data for the project. Many people from Kibera seek medical care at the district hospital simply because of its location and accessibility. Yet, the diabetes clinic is one of few such clinics across the city so those seeking care at the diabetes specialty clinic, from which many of my interlocutors were drawn, resided in various low-income neighborhoods.

We recruited a non-probability sample to participate in a cross-sectional study of 100 patients from the district hospital. We invited 50 men and 50 women from primary care ( $n = 50$ ) and the biweekly diabetes ( $n = 50$ ) clinical waiting rooms from June to August 2014 to participate in this study. Inclusion criteria were between 35 and 65 years of age, ability to consent in Kiswahili or English (both of which are official languages widely spoken in Kenya), and willingness to participate. We excluded patients who had cognitive impairment, active substance abuse, or psychosis severe enough to interfere with the interview. Institutional Review Boards at Georgetown University (USA) and Maseno University (Kenya) provided ethical approval of the study. Those from the primary care clinic waiting room had not previously diagnosed with diabetes. Two potential participants declined to be interviewed, citing time limitations. In-depth interviews were conducted that day, on the spot, or the day after recruitment. The quote from Matu at the outset of this article comes from one of these interviews, which have been analyzed and reported in other publications (see Bosire et al. 2018; Mendenhall et al. 2015).

A bilingual Kiswahili and English speaking male nurse invited patients in clinical waiting rooms to participate in a study about stress and chronic illness. He administered written informed consent in a private clinical room and collected anthropometrics, including weight, height, waist circumference, and blood pressure, and an intravenous blood sample for analysis at the University of Nairobi Chemistry Lab. We analyzed HbA1c from these samples and informed each participant of their results free of charge. In this paper, we present HbA1c as in terms of percentages, means, and thresholds used in clinical practice (6.5% for diagnostic purposes, and 8% to denote poorly-controlled diabetes).

We conducted interviews in private rooms in the public hospital clinic and at the Africa Mental Health Foundation (AMHF), an independent research organization near the hospital. Two gender-matched interviewers then conducted extensive mixed-method interviews that involved surveys of socio-demographic information; life history narrative interviews; and Beck Depression Inventory (BDI-II; Beck and Steer 1996) and Beck Anxiety Inventory (BAI; Beck 1990).

The BDI-II and BAI are common tools used to index depression and anxiety symptomatology. These psychiatric inventories were validated in Kenya for people seeking primary care by the second and fourth authors and demonstrated corresponding cut-offs (Ndeti et al. 2010). For depression, 21 BDI-II items were evaluated with a 4-point scale (from 0 to 3, from reporting symptoms never or rarely to most of the time). These scores were summed to give a single score and symptomatology in terms of minimal (0–13), mild (14–19), moderate (20–28), and severe (29–63) depression. For anxiety, 21 BAI items were evaluated with a 4-point scale (from 0 to 3, with 0 being none at all and 3 being it bothered me a lot). These scores were summed to give a single score and symptomatology in terms of minimal (1–21), moderate (22–35), and severe (36–63) anxiety.

## Analysis

For [Table 1](#), we analyzed demographics, measures of social stress, and measures of psychological stress among all 100 study participants, among women and men, and including those with HbA1c over 6.5% in each group, which indicates insulin resistance (which may have included patients from either clinic). We report means for daily food expense in Kenyan Shillings and numbers of co-morbidities people self-reported. All other variables in [Table 1](#) convey the number and percentage of people who reported the variable and those with  $A1c \geq 6.5\%$  who reported it. For [Table 2](#) we analyzed psychiatric symptoms, physical activity, and co-morbidities according to which clinic our interlocutors attended, separating those who had received a diabetes diagnosis and were seeking care at the diabetes specialty clinic from those who had not received any diagnosis of diabetes and were seeking care at the primary clinic for other problems. In [Table 3](#), we used multivariate regression to investigate what increased one's odds for insulin resistance ( $HbA1c > 6.5$ ), moderate anxiety, or any depression while controlling for age, education, and income (using variables described in [Table 1](#)). We evaluated the associations of gender, number of reported comorbidities, whether they were seeking care at the diabetes specialty clinic, if they reported feeling safe during the day or night, and whether they reported experiencing verbal or physical abuse.

## Results

[Table 1](#) shows that two-thirds of participants were 50 years old or younger, and those who were older were more likely to have higher HbA1c compared to younger patients. Most were born in urban centers, and those born in rural areas all had higher levels of HbA1c. However, more women than men born in urban centers were insulin resistant. Women were more likely to complete less than secondary education while half of men completed post-secondary education, and more people with elevated HbA1c had completed secondary or post-secondary education. Twice as many women were self-employed or unemployed

**Table 1.** Demographics and social and psychological distress among men and women.

	Total		Men		Women	
	(n = 100)	A1c ≥ 6.5	(n = 50)	A1c ≥ 6.5	(n = 50)	A1c ≥ 6.5
<i>Sociodemographics</i>						
Rural origin	12 (12%)	12 (100%)	8 (16%)	8 (100%)	4 (8%)	4 (100%)
Urban origin	88 (88%)	75 (63%)	36 (72%)	21 (58%)	46 (92%)	34 (74%)
<i>Age</i>						
<50 years	64 (64%)	44 (69%)	33 (66%)	20 (61%)	31 (62%)	24 (77%)
≥50 years	36 (36%)	27 (75%)	17 (34%)	13 (76%)	19 (38%)	14 (74%)
<i>Education</i>						
Primary or less	48 (48%)	35 (70%)	18 (36%)	11 (22%)	30 (60%)	23 (46%)
Secondary	20 (20%)	16 (80%)	7 (14%)	6 (85%)	13 (26%)	10 (77%)
Post-secondary	32 (32%)	21 (66%)	25 (50%)	16 (64%)	7 (14%)	5 (71%)
<i>Type of employment</i>						
Self-employed	38 (38%)	31 (82%)	15 (30%)	11 (73%)	23 (46%)	20 (87%)
Unemployed	23 (23%)	12 (52%)	9 (18%)	3 (33%)	14 (28%)	9 (64%)
Casual/contract labor	20 (20%)	15 (75%)	13 (26%)	9 (69%)	7 (14%)	6 (86%)
Employed + pension	19 (19%)	13 (68%)	13 (26%)	10 (77%)	6 (12%)	3 (50%)
<i>Residence</i>						
Tenant	69 (69%)	47 (68%)	41 (82%)	27 (66%)	20 (40%)	14 (71%)
Own home	28 (28%)	22 (79%)	7 (14%)	5 (71%)	21 (42%)	17 (81%)
Other	3 (3%)	2 (67%)	2 (4%)	1 (50%)	1 (2%)	1 (100%)
<i>Type of home</i>						
Steel	35 (35%)	26 (74%)	20 (40%)	14 (70%)	15 (30%)	12 (80%)
Iron sheet	5 (5%)	2 (40%)	4 (8%)	1 (25%)	1 (2%)	1 (100%)
Wooden	60 (60%)	43 (72%)	26 (52%)	18 (69%)	34 (68%)	25 (74%)
<i>Lighting</i>						
Electric bulbs	83 (83%)	61 (73%)	44 (88%)	30 (68%)	39 (78%)	31 (79%)
Solar bulbs	2 (2%)	2 (100%)	1 (2%)	1 (100%)	1 (2%)	1 (100%)
Kerosene lantern/lamp	15 (8%)	8 (53%)	5 (10%)	2 (40%)	10 (20%)	6 (60%)
<i>Toilet</i>						
Communal pit latrine	31 (31%)	21 (68%)	10 (20%)	6 (60%)	21 (42%)	15 (71%)
Private pit latrine	16 (16%)	12 (75%)	5 (10%)	4 (80%)	11 (22%)	8 (73%)
Communal flush toilet	30 (30%)	21 (70%)	25 (50%)	16 (64%)	5 (10%)	5 (100%)
Private flush toilet	23 (23%)	17 (74%)	10 (20%)	7 (70%)	13 (26%)	10 (77%)
<i>Water access</i>						
Tap water	65 (65%)	47 (72%)	36 (72%)	25 (69%)	29 (58%)	22 (76%)
Buy from vender	25 (25%)	17 (68%)	11 (22%)	6 (55%)	14 (28%)	11 (79%)
Borehole	7 (7%)	5 (71%)	2 (4%)	1 (50%)	5 (10%)	2 (40%)
River	3 (3%)	2 (67%)	1 (2%)	1 (100%)	2 (4%)	1 (50%)
<i>Social stress</i>						
Neighborhood safety (feel unsafe at night)	44 (44%)	31 (70%)	23 (46%)	14 (60%)	21 (42%)	17 (81%)
Neighborhood vandalism	71 (71%)	48 (68%)	47 (94%)	31 (66%)	24 (48%)	17 (71%)
Graffiti	71 (71%)	50 (70%)	47 (94%)	31 (66%)	24 (48%)	19 (79%)
<i>Interpersonal violence</i>						
Physical total	17 (17%)	13 (76%)	2 (4%)	2 (100%)	15 (30%)	11 (73%)
Sexual total	2 (2%)	2 (100%)	1 (2%)	1 (100%)	1 (2%)	1 (100%)
Verbal total	33 (33%)	25 (76%)	4 (8%)	2 (50%)	29 (58%)	23 (79%)
Emotional total	37 (37%)	28 (76%)	13 (26%)	11 (85%)	24 (48%)	17 (71%)
Public gathering place (positive)	72 (72%)	52 (72%)	49 (98%)	32 (65%)	23 (46%)	20 (87%)
Financial autonomy (positive)	94 (94%)	67 (71%)	49 (98%)	32 (65%)	45 (90%)	35 (78%)
Daily food expense (Kenyan Shilling – KSh)	436.5 ± 23.8	447.2 ± 28.0	390 ± 36.3	425 ± 0.17	483 ± 29.7	457 ± 25.3
<i>Psychological stress</i>						
Moderate anxiety	16 (16%)	14 (88%)	1 (2%)	1/1 (100%)	15 (30%)	13/15 (87%)
Any depression	33 (33%)	27 (82%)	5 (10%)	5 (100%)	28 (56%)	22 (79%)
Moderate + depression	11 (11%)	10 (91%)	0	0	11 (22%)	10 (91%)
Comorbidities (mean ± SD)	2.82 ± 0.16		2.48 ± 0.17		3.16 ± 0.26	



**Table 2.** Clinical outcomes by those diagnosed and undiagnosed with diabetes.

	Primary clinic (n=50)	Diabetes clinic (n=50)	Total (n=100)
HbA1c (mean, SD)	6.47 ± 0.19	10.25 ± 0.37	8.36 ± 0.28
HbA1c ≥ 6.5	24 (48%)	47 (94%)	71 (71%)
HbA1c ≥ 8	2 (4%)	36 (72%)	38 (38%)
Psychiatric symptomatology			
No anxiety (n=84)	40 (80%)	44 (88%)	8.33 ± 0.31
Moderate anxiety (n=16)	10 (20%)	6 (12%)	8.51 ± 0.67
No depression (n=56)	34 (68%)	24 (48%)	8.04 ± 0.33
Any depression (n=33)	14 (28%)	19 (38%)	9.02 ± 0.50
Moderate to severe depression (n=11)	4 (8%)	7 (14%)	9.76 ± 0.97
Physical activity			
Inactive lifestyle (n=9)	7 (14%)	2 (4%)	9 (9%)
Active lifestyle (n=91)	43 (86%)	48 (96%)	91 (91%)
Self-report previous diagnoses			
Obesity (n=2)	1 (2%)	1 (2%)	2
Type 2 diabetes (n=50)	0	25 (100%)	25
Hypertension (n=39)	11 (22%)	28 (56%)	39
Depression (n=7)	3 (6%)	4 (8%)	7
Anxiety (n=2)	2 (4%)	0	2
Typhoid (n=46)	25 (50%)	21 (42%)	46
Malaria (n=74)	37 (74%)	37 (74%)	74
Arthritis (n=7)	4 (8%)	3 (6%)	7
Chronic pain (n=11)	7 (14%)	4 (8%)	11
HIV/AIDS (n=5)	3 (6%)	2 (4%)	5
Tuberculosis (n=8)	5 (10%)	3 (6%)	8
Chest problem (n=18)	13 (26%)	4 (8%)	17
Other (n=13)	9 (18%)	5 (10%)	14
Comorbidities (mean ± SD)	2.4 ± 0.25	3.24 ± 0.18	2.82 ± 0.16

**Table 3.** Multivariate predictors insulin resistance, anxiety, and depression<sup>a</sup>.

	Hemoglobin A1c (≥6.5)			Moderate anxiety			Any depression		
	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
Gender	1.65	0.65–4.19	0.29	19.3	2.32–159	0.01*	10.9	3.55–33.5	0.00*
Comorbidities	1.51	1.08–2.11	0.02*	2.81	1.65–4.77	0.00*	2.56	1.65–3.97	0.00*
Diabetes clinic	23.1	5.38–99	0.00*	0.63	0.20–1.98	0.42	1.82	0.76–4.40	0.18
Feel unsafe during the day	2.18	0.24–20.1	0.49	1.88	0.26–13.4	0.53	12.7	1.33–121	0.03*
Feel unsafe at night	1.05	0.42–2.62	0.91	2.82	0.83–9.64	0.09**	1.30	0.56–3.20	0.56
Verbal abuse	1.45	0.53–3.99	0.47	12.1	3.01–48.9	0.00*	15.5	5.04–47.7	0.00*
Physical abuse	1.41	0.39–5.09	0.69	1.56	0.38–6.36	0.54	3.32	1.05–10.5	0.04*
HbA1c ≥ 6.5				3.40	0.70–16.7	0.13	2.34	0.83–6.61	0.1**
Moderate anxiety	3.4	0.70–16.6	0.13				1	1	0.00
Moderate + depression	4.62	0.55–38.5	0.16	7.99	1.93–22	0.00*			

<sup>a</sup>Control for age, education, income.

\*p &lt; 0.05.

\*\*p &lt; 0.10.

compared to half of men who reported casual or contract labor, or being employed with a pension. Irrespective of gender, the fewest with elevated HbA1c were unemployed, and those who were self-employed or worked in casual or contract labor reported the most elevated HbA1c. Most people rented their homes and these homes were mostly wooden and steel and relied upon electricity and tap water. There was also variation among those who used a communal versus private pit latrine or flush toilet: women were generally lower income (relying primarily upon communal pit latrines) compared to men who relied more frequently on communal flush toilets; fewer had private accommodations.

Table 1 shows that around half felt their neighborhoods were unsafe to walk in at night, and many reported vandalism and graffiti as sources of stress. More women than men reported all forms of interpersonal abuse, with verbal and emotional abuse being the most pervasive. More men than women reported feeling safe and supported in a public gathering space, and most felt that they maintained some forms of financial autonomy. More women than men reported higher daily food expenses; however, people with elevated HbA1c spent less on daily food expenses compared to others. In addition, those with elevated HbA1c were likely to have moderate anxiety, and some or moderate depression. Men reported very few symptoms of depression and anxiety – although, in their narratives they reported frequent substance use – mostly alcohol. Women reported more comorbidities than men.

Table 2 shows important differences between those diagnosed and undiagnosed with diabetes. While the mean of HbA1c was much higher among those diagnosed, the mean of those undiagnosed with the condition was at the common cut-off for diagnosis (HbA1c=6.5%). The overall measure of HbA1c indicated that diabetes was largely uncontrolled, especially among those who were undiagnosed. Symptoms of moderate anxiety were higher among those who were undiagnosed with diabetes, and while the number of people with depressive symptoms was higher among those diagnosed with diabetes. Most people were very physically active. Those diagnosed with diabetes were more likely to report having been previously diagnosed by a clinician for one additional health condition than those undiagnosed with diabetes. Those with the diabetes diagnosis were similarly more likely to have been diagnosed with hypertension, a condition that often accompanies diabetes.

Our interlocutors undiagnosed with diabetes and seeking primary care reported more symptoms of anxiety compared to patients diagnosed with diabetes. Patients diagnosed with diabetes reported more symptoms of depression and more co-morbidities overall than patients who had never been diagnosed with diabetes. The most reported comorbidities included hypertension (39%), typhoid (46%), malaria (74%), and chest problems (18%); the least reported comorbidities were HIV (5%), obesity (2%) anxiety (2%), and depression (7%). Although conditions like typhoid, malaria, and chest problems are unlikely to be currently comorbid with diabetes, these numbers reveal the lifetime of exposures that people have experienced in this context. Education levels, gender, and the number of co-morbidities were significantly associated with symptoms of anxiety and depression in linear regression analyses. On average, HbA1c exceeded 6.5% for patients seeking medical care in both the diabetes specialty clinic and the primary care clinic, indicating that insulin resistance and elevated risk for microvascular and macrovascular diseases are widespread in patients who have been diagnosed with diabetes as well as those never diagnosed with diabetes (and these means were significantly different according to independent samples *t* tests). Increased HbA1c levels were positively associated with seeking care in the diabetes clinic, and patients previously diagnosed with diabetes had HbA1c that exceeded 10%, demonstrating broad lack of diabetes control, indicating high-risk for microvascular and macrovascular diseases.

Table 3 reveals that reporting more comorbidities and seeking care at the diabetes clinic (and therefore having been previously diagnosed) were significantly associated with insulin resistance (HbA1c < 6.5). Gender, reporting more co-morbidities, feeling unsafe at night in one's neighborhood, and experiencing verbal abuse were significant predictors of moderate anxiety. Gender, reporting more comorbidities, feeling unsafe in one's neighborhood during the day, and reporting either verbal or physical abuse was significantly associated with increased odds of depressive symptoms.

## Discussion

To the best of our knowledge, this study is the first to unpack the social and psychological factors that interact with HbA1c, anxiety, and depression among low-income urban patients in Kenya. We found two major conclusions at the center of this study. First, our data suggest that social factors as opposed to disease factors were major drivers of psychological distress among those with and without diabetes, suggesting that the disease was not the primary cause of anxiety or depression. Instead, psychological distress was associated with female gender and feelings of insecurity, which were supported by various findings. Second, insulin resistance was common among those who had not been diagnosed with diabetes, suggesting that many seeking primary care for other health conditions did not receive a routine diabetes test (most likely because it is an out-of-pocket cost, or other competing social factors) and therefore delayed their diagnosis and care. Moreover, the fact that so many men and women who had received a diabetes diagnosis revealed poorly controlled diabetes – with mean of HbA1c that exceeded 8% – suggests that many delay care-seeking and may not routinely take medications. We discuss the relevance of the social drivers of emotional distress as well as the relevance of diagnosis in turn.

The first major social driver was related to gender. Women were more likely to describe more types of social stressors in their lives, symptoms of anxiety and depression, insulin resistance, comorbidities, and variation in food purchasing. Social stress stemming from threat within the home (interpersonal violence) and threat apart from the home (feeling unsafe in one's neighborhood) significantly increased odds of reporting symptoms associated with anxiety and depression. Women also had higher odds of reporting symptoms of anxiety and depression when compared to men – not an uncommon finding around the globe (Steel et al. 2014). Elevated HbA1c among women when compared to men (even without a significant association) also may reflect the unequal social burdens that many women carry. This may be explained in part by a number of findings. First, women reported less secure attachments to the paid labor force than did men (working more in the informal economy such as running small sidewalk stalls or businesses in the market), while men were more likely to have contract labor or secured pensions (also see Ayah et al. 2013). While this describes more precarious financial situations, it may be that women's informal networks provided essential support to navigate their economic and social needs in difficult times. Second, women were more likely to report all forms of abuse or violence when compared to men and less likely to describe social interactions (such as with others in public gathering places). Third, women reported more co-morbidities than men, and increasing number of co-morbidities was significantly associated with anxiety and depression, suggesting that the cascading of conditions cause stepwise increases in psychological distress (see Mendenhall et al. 2013). Paradoxically, women spent more on food overall, but women with diagnosed diabetes spent less on food for themselves than did women who had never been medically diagnosed with diabetes. This finding reflects other studies of gender and diabetes that reveal how women put their family needs before their own personal health care (Carney 2015; Weaver 2016; Weaver et al. 2015; Yates-Doerr 2015).

This brings us to our second finding about food as a major social driver of diabetes. Why did those with diagnosed diabetes spend less on food, and why were people with diabetes so unlikely to be obese? On the one hand, obesity was self-reported, and it's unlikely that anyone was 'diagnosed' with obesity when people were not routinely care-seeking. However, a growing

body of research indicates that people are developing diabetes at lower body mass index in sub-Saharan Africa (see International Diabetes Federation 2015), which may suggest that diabetes is presenting in different forms among people who are thin and potentially among those who experience nutrient deficiencies, thereby challenging long held notions of close links between obesity and diabetes in all cases and expressions of Type 2 diabetes (see Carruth and Mendenhall 2019). Nutritional deficiency among people with Type 2 diabetes presents a heterogeneity whereby stress, trauma, crisis, hunger, and displacement may contribute to the onset of diabetes through biological stress and inflammation as opposed to the widely accepted notion that obesity is the key driver (Carruth and Mendenhall 2019; Mendenhall 2019; Sapolsky 2004). Thus, this point questions what is driving diabetes: is it obesity or is it recurrent trauma and crisis? This study provides more evidence to suggest that diabetes is emerging among more food insecure populations. We also found that people with diabetes pay less per month on food than those without a diabetes diagnosis, which provides more questions than answers. Are people depriving themselves of food because of their diagnosis, or are those with a diabetes diagnosis more likely to have been nutritionally deprived? There may also be links between social stressors and nutritional deprivations at play.

The third finding sheds light on the stress of money that drives diabetes. Increasingly people with diabetes include many who struggle each day to make enough to pay rent, put food on the table, and care for their children in the way they expect. No longer is diabetes a disease of 'modernization' as it has so long been glossed; rather, it is a disease of poverty that is increasingly persistent. The strong link between poverty and common mental disorders, including depression and anxiety (Lund et al. 2010), is one reason diabetes is differently experienced among the poor; for instance, depression and anxiety were both significantly associated with feeling unsafe (and being a woman). Those with elevated hemoglobin (with or without a diagnosis) were more than two times as likely than others to report depression symptoms. Moreover, financial insecurities impede care-seeking and diagnosis. A recent study reported a fundamental lacking of knowledge about diabetes and diagnostic testing among adults seeking primary care at Kenyatta Hospital, the teaching hospital in Nairobi associated with the hospital where our research was conducted (Matheka et al. 2013). Our study participants, too, delayed testing and care-taking for diabetes – most likely due to cost or limited awareness of what symptoms were due to the recent emergence of diabetes. However, we also suggest that cost was a major inhibitor to seeking a diagnosis and taking diabetes medication (Bosire et al. 2018). This financial strain was also clear in Matu's comment: this financial strain was not only from diabetes but from everyday confrontations with basic needs.

Moreover, the 'cost' of diabetes shifts when people have multiple comorbidities. Study participants in Nairobi reported an average of nearly three comorbid conditions diagnosed, and being insulin resistant was significantly associated with having an increased number of comorbidities. These comorbidities were not uniform and included not only mental illness and non-communicable diseases, but also infections such as tuberculosis and HIV. Having multiple comorbidities was significantly associated with anxiety and depression, as well, suggesting that the increasing burden of physical illness takes a powerful psychological toll (see Patel et al. 2016). Given our finding that social factors were a powerful conduit of psychological suffering, then, we might suggest that the relationship between mental health and diabetes may be reflective of the cascading effects of multiple health conditions that frame arduous life circumstances (see Manderson and Warren 2016). In other words, the link between social factors and psychological symptoms may jointly fuel physical distress

(such as it is measured in HbA1c) and the collection of co-occurring social and health conditions that travel together.

This study is cross-sectional in design, which limits our ability to infer causality. Causal inferences are also limited because our sample was rather small and purposively recruited. Yet, these data invite further investigation of gender dynamics with respect to undiagnosed Type 2 diabetes and diabetes control in low-income settings, as well as how diabetes diagnosis may be related to spending on personal food consumption. As a mixed methods study, the study design further strengthens this paper, as our findings substantiate previous analyses published on life history narratives (Mendenhall 2012), and show the complexities of life experiences, stress, psychiatric distress, and HbA1c.

## Conclusion

In conclusion, we found that social pathways interweaving gender, food, and finances play an important role in diabetes diagnosis and experiences among the low-income patients we interviewed in Nairobi. These complexities are further complicated by the co-occurring conditions that many people experience that impede people's abilities to prioritize their diabetes care or pay for costly treatments. Thus, the more urgent interventions for diabetes in this context are policy ones. The most effective will be the equalizing of cost of diabetes testing, treatment, and medications so that cost is not a major impediment to care-seeking. Other interventions are social, including focus on reducing violence in low-income neighborhoods and providing more economic opportunities, especially for women. Further, there is a dire need for health practitioners, irrespective of background, to demonstrate an understanding of psychological and emotional issues embedded in diabetes (which often go unnoticed) by actively engaging a normal conversation with individuals struggling to cope with diabetes and to normalize this and integrate it into routine diabetes practice. This will improve self-care, which, in turn will benefit physical outcomes in the short-term and social discourse around the condition in the long-term.

## Ethical approval

Ethics approval and consent to participate was reviewed by Institutional Review Boards at Georgetown University (USA) and Maseno University (Kenya). Each study participant signed an informed consent form that was filed and secured under lock and key at the Africa Mental Health Foundation in Nairobi, Kenya.

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## Availability of data and material

The datasets generated and/or analyzed during the current study are not publicly available due to privacy issues but are available from the corresponding author on reasonable request.

## Authors' contributions

EM conceptualized the project, analyzed the data, and wrote the manuscript; AM provided oversight for project and commented on the manuscript; EB participated in data collection and commented on the manuscript; VM, and DN commented on the manuscript; MR contributed to the conceptualization of this manuscript and commented on multiple drafts.

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