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When HIV is ordinary and diabetes new: Remaking suffering in a South African Township

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Escalation of non-communicable diseases (NCDs) among urban South African populations disproportionately afflicted by HIV/AIDS presents not only medical challenges but also new ways in which people understand and experience sickness. In Soweto, the psychological imprints of political violence of the Apartheid era and structural violence of HIV/AIDS have shaped social and health discourses. Yet, as NCDs increasingly become part of social and biomedical discussions in South African townships, new frames for elucidating sickness are emerging. This article employs the concept of syndemic suffering to critically examine how 27 women living with Type 2 diabetes in Soweto, a township adjacent to Johannesburg known for socio-economic mobility as well as inequality, experience and understand syndemic social and health problems. For example, women described how reconstructing families and raising grandchildren after losing children to AIDS was not only socially challenging but also affected how they ate, and how they accepted and managed their diabetes. Although previously diagnosed with diabetes, women illustrated how a myriad of social and health concerns shaped sickness. Many related diabetes treatment to shared AIDS nosologies, referring to diabetes as ‘the same’ or ‘worse’. These narratives demonstrate how suffering weaves a social history where HIV becomes ordinary, and diabetes new.

Keywords: social suffering; HIV/AIDS; diabetes; mental health; South Africa

Introduction

Flory was a 59-year-old low-income woman residing in Soweto, a township in Johannesburg, South Africa. Throughout her life, community played a central role: from contributing to the resistance to apartheid, a cause that made her a widow, to managing a small business in Soweto and eventually serving as a community police force officer. She resigned as an officer in 2009 once her vision became blurry. Within months, her father died unexpectedly and her brother died of complications of both AIDS and Type 2 diabetes. Flory fell into a deep depression following this loss and ‘nearly died’. She lost weight and her diabetes was out of control. Together with the support of her doctors and sisters, who said, ‘if you continue like this, you’ll die’, Flory came out of her depression and busied herself caring for her grandchildren and ironing and washing for people to earn money on the side. Today, caring for her daughter’s bipolar disorder continues to cause her stress because her daughter ‘loses it and snaps at us’ and serves as breadwinner for eleven
dependents. Yet, Flory remains resilient – seeking medical care every three months for her now-controlled diabetes and improved mental health.

Woven into a complicated social history and complex epidemiological landscape, Flory’s narrative summary introduces how social and health problems come together in people’s lives. In Soweto, the psychological imprints of political violence of the Apartheid era and structural violence of HIV/AIDS have shaped social and health discourses. Yet, as non-communicable diseases (NCDs) increasingly become part of social and biomedical discussions in South African townships, new frames for describing what is sickness are emerging. Such frames incorporate the concept of syndemics, a portmanteau term that combines ‘synergy’ and ‘epidemic’ to conceptualise how social inequality fuels the mutual exacerbation of concurrent epidemics (Singer, 2009). Although syndemic clustering of communicable diseases, such as HIV/AIDS and tuberculosis (cf. Daftary, 2012), and NCDs, such as Type 2 diabetes (hereafter, ‘diabetes’) and depression (cf. Phaswana-Mafuya et al., 2013), has been documented in urban ghettos like Soweto, studies have yet to consider how the interaction of NCDs with infectious ones shape people’s lives.

The integration of epidemiological- and experiential-level analysis of multiple, overlapping social and health problems has been referred to elsewhere as ‘syndemic suffering’ (Mendenhall, 2012). The complexities of syndemic suffering in South Africa occur primarily among low-income groups who demonstrate marked increases in NCDs and experience the highest burden of infectious ones (Mayosi et al., 2009). For example, in Soweto, diabetes prevalence reaches 14% (Crowther & Norris, 2012) while HIV/AIDS continues to affect one in four (Karim, Churchyard, Karim, & Lawn, 2009). While the social epidemiology of these co-occurring diseases point to the complexities of how people may experience sickness within their social landscape, little is known about how people conceptualise such syndemic suffering in everyday life.

The complex suffering in Soweto has emerged by way of a historical legacy of structural and political violence as well as rapid globalisation, transforming how people eat, move and interact (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). Economic development, changing lifestyles, rural-to-urban migration, new possibilities for wealth and social mobility and persistent inequality have cultivated a Soweto that is both the home of a burgeoning middle class and persistent underclass. These exposures shape how many Black South Africans residing in Soweto eat and move, exemplified by the influx of inexpensive energy-dense processed foods and high-density living; these changes are reflective in increasing numbers of NCDs like diabetes (Mayosi et al., 2012). They also produce context for complex medical problems among vulnerable populations. For example, a long-standing urban South African cohort study indicates that those most affected by an escalation of non-communicable hypertension and heart disease are older Black women originating from Soweto (Stewart, Carrington, Pretorius, Methusi, & Silwa, 2011). What is concerning is that the disproportionate social and biological impact of HIV/AIDS within the Soweto context further complicates women’s health as HIV is a risk factor for heart disease (Schwartz, Magdi, Steen, & Sjaastad, 2012). This interplay underscores syndemic suffering where social and economic circumstances exacerbate the interaction between NCDs and infectious ones.

This study concerns syndemic diabetes and depression, which is a dynamic comorbidity that epidemiologically clusters among the poor in low- and middle-income countries (LMICs; Leone, Coast, Narayanan, & de Graft Aikins, 2012). Indeed, in such contexts depression may be higher among people with diabetes when compared to those with diabetes in wealthy countries (Mendenhall, Norris, Shidhaye, & Prabhakaran, 2014). The substantial body of research on depression and diabetes in high-income countries demonstrates a bidirectional relationship, where depression contributes to diabetes, and
vice versa (cf. Holt, de Groot, & Golden, 2014). The convergence of diabetes and depression in LMICs is particularly concerning because poverty and depression are closely correlated and may worsen and complicate physical health problems (Lund et al., 2010). In addition to the social problems women face in Soweto, nearly one-third present with psychological distress and this increases exponentially among those with two or more physical disorders, including diabetes (Mendenhall, Richter, Stein, & Norris, 2013).

The ubiquity of suffering infused through the Soweto landscape illuminates dynamic social, economic and epidemiological transitions. Novel semantics of suffering emerge to make sense of contemporary lifestyles that describe how people experience and understand suffering of everyday realities. In Idioms of Distress Revisited, Mark Nichter (2010) states that we:

live with idioms of distress from the past, which may take on new or hybrid forms and maintain or fade in importance; idioms of the present, associated with the concerns of contemporary life and responses to social change; and emerging idioms. (p. 405)

Theoretically grounded in scholarship around cross-cultural constructions of illness and suffering (Garro, 2000; Good, 1977; Kleinman, 1980; Mattingly & Garro, 2000; Nichter, 1981, 2010), this notion of hybridity reveals that as culture changes so do the semantics of suffering change. For example, Mexican immigrants living in the USA use diabetes as an idiom of distress to communicate disorder from their social worlds, thereby connecting somatic symptoms with social and psychological suffering that emerges apart from and interconnected to biomedical realities (Mendenhall, Seligman, Fernandez, & Jacobs, 2010). Indeed, as women discover and renegotiate syndemic suffering in Soweto, the ways in which people interact with and interpret illness and suffering reveal important local sources of suffering, coping and surviving. This article critically examines how women in Soweto blur the boundaries between biomedical diseases to portray a nuanced construct of syndemic suffering that embodies a social and epidemiologic context in flux.

Methods
Participants

The 27 women in this study were recruited from the Birth to Twenty (Bt20) cohort study, which is situated at Chris Hani-Baragwanath Hospital (‘Bara’) located in Soweto – a township of Johannesburg, South Africa. This history and composition of Bt20 is explained in-depth elsewhere (Richter, Norris, Pettifor, Yach, & Cameron, 2007). Notably, in this paper we use the term ‘Black’ to describe the women interviewed for this study; we do so knowing that ‘Black’ is a political category instated during apartheid and that important cultural nuances linked with ethnicity exist in South Africa (Ellison, de Wet, Ijselmuiden, & Richter, 1997). The Black women who participated in this study represent various regions of South Africa and are unified by their resettlement in Soweto, long-term residence there, and enrolment in the Bt20 cohort study.

Of more than 1000 women interviewed in a data collection wave in 2010 for Bt20, 73 women self-reported previous diagnosis of Type 2 diabetes and self-identified as ‘Black’. These 73 women were contacted to participate in this study by phone. The women who did not participate in the study were unavailable during the interview period, unreachable by phone, unable to travel or deceased. We excluded active substance abusers and individuals who had severely disabling diabetes complications, cognitive impairment or psychosis severe enough to interfere with participation in the interview.
Twenty-seven interviews were conducted at Bara between November and December of 2012. Nineteen interviews were conducted in English by the first author and eight were conducted in either Zulu or Sesotho by a multilingual research assistant (RA). The first author observed every non-English interview to ensure consistency across the interviews and discussed each of these interviews in-depth with the RA. The RA was the first contact for each study participant by inviting them to participate and scheduling an interview time. After providing informed consent, women participated in a 60–90 minute in-depth qualitative interview followed by the administration of the Center for Epidemiological Studies Depression Scale (CES-D), a self-report survey of previously diagnosed disorders and a brief sociodemographic questionnaire. All interviews were audio-recorded and women were compensated 50 ZAR (around 5.88 USD) for transportation costs. All data collection received clearance by the University of the Witwatersrand Human Ethics Committee (Clearance number M121059).

**Data collection**

The qualitative data presented in this article come from a larger interview around stress, social relationships, cultural beliefs and experiences with diabetes, perceptions about the relationship of diabetes and HIV and health care experiences. Each narrative interview began with: ‘Can you describe a typical day?’ The interview then shifted to address women’s understanding of and experiences with stress, including questions like ‘What does stress mean to you?’, ‘How do you define stress?’ and ‘What aspects of your life cause you the most stress?’. We also asked targeted questions about family and community relationships and support systems. We spent the last half of the interview discussing diabetes, including questions like ‘Has diabetes changed your life in any way?’ and ‘Does stress affect your diabetes in any way?’ Also, we inquired around their perceptions of relationships among multiple morbidities. We concluded the interview with questions around health care experiences.

Depression was measured by administering the CES-D, a widely used 20-item questionnaire designed to assess the major symptoms of depression in English (Radloff, 1977). A reliable and well-validated instrument, the CES-D’s targeted symptoms include depressed mood, changes in appetite and sleep, low energy, feelings of hopelessness, low self-esteem and loneliness. Respondents were asked to consider the presence and duration of each item/symptom over the past week and to rate each along a 4-point scale from 0 (rarely or never) to 3 (most or all of the time). Possible scores range from 0 to 60. We present data for ‘likely depression’ (CESD ≥ 16) to be an acceptable predictive validity as a screen for depression in a community population (Radloff, 1977).

We then asked the study participants if they had been previously diagnosed with the following disorders: obesity, hypertension, anxiety, depression, HIV, tuberculosis and arthritis. We concluded the interview with a brief demographic questionnaire to measure age, education, income, duration of diabetes, if she had ever visited a counsellor, health insurance and where she received health care.

**Data analysis**

The qualitative interviews were transcribed and those conducted in Sesotho and Zulu were translated into English. We examined emergent themes around stress and diabetes, which led us to three thematic sections. The first is how women conceived and communicated stress in their everyday lives, which resulted from questions such as ‘How do you define...
stress?’ and ‘What does stress feel like?’ The second theme was common social stressors women expressed from their daily lives, including both social and disease-related stresses. The final theme emerged around perceptions of a relationship between diabetes and other diseases, including HIV. The first author coded each of these themes and discussed the findings with the second author. Patterns in these data are reported in Table 2 and exemplar quotations of each category were excerpted.

We present measures of depression as descriptive data in conjunction with demographic information (Table 1) and co-occurring with social stressors (Table 2). These data are presented only to provide insight into the concordance between social stress and depression among those with diabetes, as opposed to correlation or causation.

Results

Table 1 describes the women in the sample as on average 59 (43–79) years of age, having lived with diabetes for (on average) 10 years, nearly two-thirds having less than 12 years of school, and around half relying on a monthly government pension or less. Few women had health insurance and most sought care from government health facilities. Although 45% reported depressive symptoms, less than one in five ever received counselling. In addition to diabetes, all but two reported ever being diagnosed with hypertension, almost half reported arthritis, one-third reported obesity, one-quarter reported depression and one-fifth reported anxiety. No women reported ever being diagnosed with HIV or tuberculosis, despite nearly 30% HIV prevalence among women, and half of tuberculosis cases afflicting those with HIV/AIDS, in poor Johannesburg neighbourhoods like Soweto (Karim et al., 2009). Although lack of reporting HIV positive status may be a reflection of stigma and fear around HIV disclosure, all women were HIV-affected, with one or more family members living with the virus.

<table>
<thead>
<tr>
<th>Total (n = 27)</th>
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<tbody>
<tr>
<td>Age (mean, ± SD)</td>
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<tr>
<td>Duration of diabetes (mean ± SD)</td>
</tr>
<tr>
<td>Education (n, %)</td>
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<tr>
<td>Less than matric (12 years)</td>
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<td>Completed matric and/or more</td>
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<tr>
<td>Income (n, %)</td>
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<td>Pension or less (R1,260)</td>
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<tr>
<td>More than pension</td>
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<tr>
<td>Health insurance (n, %)</td>
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<tr>
<td>None</td>
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<tr>
<td>Health insurance</td>
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<tr>
<td>Health center (n, %)</td>
</tr>
<tr>
<td>Government</td>
</tr>
<tr>
<td>Private provider</td>
</tr>
<tr>
<td>Counselling for depression (n, %)</td>
</tr>
<tr>
<td>Never received counselling</td>
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<td>Ever received counselling</td>
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<td>Depression (n, %)</td>
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<td>None (CESD &lt; 16)</td>
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<td>Likely (CESD ≥ 16)</td>
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Most women believed stress will make you sick and defined stress in various ways, from ‘thinking too much’ to a physical pain manifest within the body, often in the shoulders or at the base of the neck:

I sometimes get stressed and I feel pain around my shoulders and the back of my neck. I hardly get any sleep when I am in that condition and I feel the same pain around the shoulder area. I also get very edgy and easily irritable when I am stressed. (50-year-old woman)

Others associated stressors with acute physical responses, such as making your blood pressure spike.

At times I think too much and become so stressed and my blood sugar level and pressure escalates. (55-year-old woman)

Many identified a lifetime of social problems as causal to sickness, such as stress from an abusive spouse contributing to diabetes, hypertension and other ailments.

I personally think that if I did not have all these problems I wouldn’t be having diabetes and [high blood] pressure. (78-year-old woman)

Specifically, one-third of the sample believed stress caused diabetes.

I suspect that diabetes was caused by the fact that I used to stress too much about the conduct of my eldest daughter. […] It could also be linked to the fact that thugs in Soweto hijacked and shot dead my 72-year-old father. (43-year-old woman)

I think it’s due to the worries that I have faced in my life. In my family I am the only one who is old that is left and that causes stress to me. (63-year-old woman)

These women connected deep emotional pain with physical manifestations of stress – from the neck to the shoulders to biomedical categories of disease, including diabetes.
Social origins of stress

The most common social origins of women’s stress were street violence, interpersonal abuses, concerns about children and grandchildren, family deaths, financial stress and diabetes stress. Women averaged nearly five stressors (4.8 SD ± 2.1) in their narrative interviews and 45% presented depressive symptoms.

Three-quarters reported an incidence of public violence to be stressful, with more than half of these women reporting depressive symptoms. This violence encompassed many forms, from burglary to gun violence. Some women reported that their husbands were shot during the apartheid struggle. Almost every woman reported being victim to violence associated with tsotsis (gangsters), and many of these experiences were extreme, such as one woman who reported she finally had to put iron bars on her home after tsotsis forced their way in once to steal a television and another time to rape her children.

I am scared of the young boys especially when they are under the influence of drugs. There is a new drug in town called Nyaupe, it is a combination of battery powder and crushed ARV tablets and they smoke them. These children become so wild and out of control when under the influence of these drugs. Those are the kind of people who make me uncomfortable walking on the road and feel unsafe. (53-year-old woman)

They [tsotsis] have burgled my house on two occasions and I have once been mugged while on the road and I lived in fear ever since. (60-year-old woman)

Domestic violence was reported by 16 women, and in many cases included repeated experiences throughout one’s life. One woman said, ‘I have basically been abused throughout all my life’. Four women reported sexual abuse, almost exclusively in childhood, and three of these women reported severe depressive symptoms:

My stepfather sexually abused me. […] He would force himself on me and when I told my mother the man would accuse me of things that I never did. My mother would get upset and punish me. (56-year-old woman)

Spousal abuse was common and two-thirds of these women reported depressive symptoms. In most cases, spousal battering was associated with an alcoholic husband, which was reported by one-third of the sample.

My husband was a drunkard that was physically abusing me continuously. I had to get a court order against him. He threatened to shoot me and that was my cue to divorce him. (43-year-old woman)

In most cases, physical abuse was compounded by emotional or verbal abuse; one-third of the sample reported emotional abuse, and one-fifth reported verbal abuse:

I was never appreciated and at times he [my husband] would hit me for my cooking. He would also accuse me of promiscuity. He would at times refuse to look after his kids and claim that there weren’t his. That on its own was abusive. (48-year-old woman)

Nearly two-thirds described children and grandchildren as common sources of stress, and among these women nearly half reported depressive symptoms. Many women were primary caretakers for their grandchildren because their children died previously of AIDS, were in school, or working full time. Some women lived with their children and...
therefore took care of their grandchildren during the day; others worked to support their grandchildren in their children’s absence.

It [my stress] was mostly the fact that my daughter would abandon her kids with me and just come and go as she pleased and I wasn’t feeling too well myself as a diabetic. (58-year-old woman)

Other women were concerned with their children’s social mobility because they were unemployed or had not finished high school. Behavioural problems of children and grandchildren were common concerns, including youth substance abuse. One woman said, ‘My nephew bullies and abuses everyone in the household, especially when he is drunk’. In most cases, these complaints had to do with young people spending time outside the home, where ‘they fight and rape people in the streets at night’.

More than half grieved the loss of a family member, mostly due to AIDS. In many cases women described losing their children and therefore raising grandchildren.

P: [The oldest grandchild] is 22 years old, the second born is 20 years old and the last one is 10 years old.
I: And where are their parents?
P: Their parents have passed away.
I: How did they pass away?
P: They fell sick with AIDS. (60-year-old woman)

However, women described the loss of children and spouses to myriad illnesses:

[My son] was sick and died here at Bara. He had heart and kidney trouble; also his lungs were not fine because he drank a lot. […] My daughter died in 2009, and then my husband died in 2010. She [my daughter] had a bad liver. […] My husband then died in 2010 at the age of 76. He had kidney problems, high blood pressure, and diabetes just like me. (78-year-old woman)

Gun violence was also a common source of family death:

He [my son] was gunned down on his way from work. He was a police officer and he tried to stop a fight only to be shot at by the same people. (53-year-old woman)

Half described financial stress to cause chronic worry and half of these women reported depressive symptoms. Women linked financial stress both with their own jobs and worries and their children’s work and economic futures. More than half relied on pensions of R1200 per month (about $136) to, in many cases, support their families and in others pensions were supplemental income.

I only make a few cents from the beadwork and I supplement that with the social grant that I receive from the government. (63-year-old woman)

One-quarter of the women in the lower education group reported inability to buy foods that were necessary for their diabetes, including fruits and vegetables. One woman said, ‘I eat one fruit per day, and I should eat four, but I can only afford one’. Most women were aware of the foods they should eat, but their diabetes care was limited by, what we call, ‘diabetes food insecurity’.
I am not troubled much by being a diabetic; save for the fact that I do not have the money to buy the necessary food that I should be eating. The right food is very costly. (48-year-old woman)

Although many women described their diabetes diagnosis and adjusting to their diabetes self-care regimen as stressful, few found diabetes stressful in their daily life.

Diabetes isn’t a problem at all to me. I don’t feel sick and my condition doesn’t stress me. (48-year-old woman)

Some women described stress associated with diabetes complications:

To begin with, my overall health has deteriorated since I have become a diabetic. I now have problems with my feet, I also feel dizzy from time to time amongst other things. (48-year-old woman)

or dealing with diabetes management:

I think the food part is the most stressful one. I am the only one that’s diabetic at my home and the kids prepare food in a manner that is not always compatible with my condition. (60-year-old woman)

**Polysemous suffering in contexts of health transition**

Due to the plurality of suffering in Soweto, where HIV and opportunistic infections such as tuberculosis are common, we found it difficult to ignore how other illnesses affect women’s everyday lives. We explicitly inquired about perceived overlaps among diabetes, HIV, tuberculosis and obesity. Although most understood a link between obesity and diabetes, or HIV and tuberculosis, the starkest results were between the relationship of HIV and diabetes, such as ‘some people say that diabetes and HIV is just the same thing’. Others stated that HIV and diabetes revealed similar identifying symptoms:

Diabetes and HIV positive people both get a running tummy and loose stools and I get some kind of a rash on my chest area whenever my sugar level is high and HIV positive people have the rash on their chest. I even asked a nurse who assured me that some symptoms are common in both ailments but I shouldn’t worry myself much. (50-year-old woman)

Others described resemblances among the diseases because they both required treatment compliance for the rest of their lives.

I feel they are related because with diabetes if you don’t take medication you will die, and also with HIV if you don’t take your medication you will die. (60-year-old woman)

I think that HIV/AIDS is a better predicament compared to diabetes. To start with, HIV/AIDS is easily manageable relative to diabetes. Sugar diabetes requires more attention and there are certain foods that you have to forego as a diabetic unlike the HIV/AIDS patients who just need to stick to their treatment and can still eat anything; better yet they can still recover and be like any other normal person. But, regardless of how faithful you are to treatment and diet as a diabetic, it still attacks you when you least expect it. (58-year-old woman)
Many gave value judgements to the two diseases:

Diabetes is worse than AIDS because it requires a lot of adjustment and management; you have to eat healthy and look after yourself and you have to exercise. (59-year-old woman)

Others saw them as distinct, and these were often people who had close relationships with people who suffered and died from AIDS. In these cases, people used a prototype of someone with HIV or diabetes to make comparisons.

People think that HIV is better than diabetes. I personally think that diabetes is better because one of my kids died of HIV and I saw her condition and it was really horrible how thin she was because of the disease. […] HIV really eats you up. (63-year-old woman)

How people spoke about AIDS and other chronic diseases suggest that NCDs have become commonplace and are in some cases used to combat AIDS stigma. A 54-year-old woman stated: ‘A lot of people believe that HIV positive people prefer to say that that they are only suffering from diabetes’. Others suggested that people use other chronic illnesses, including diabetes, to convey their need for regular medical treatment to alleviate HIV/AIDS stigma. Some indicated that pastors would try to stamp out AIDS stigma in church by analogising HIV/AIDS to diabetes and cancer.

Discussion

This article describes how women in Soweto conceive syndemic social and health problems as mutually exacerbating, co-constructions of suffering in everyday life. When women communicated the factors in their lives that caused stress, they often prioritised social problems as opposed to medical ones. This was exemplified in the hypervigilance women faced while walking alone at night and the stress of putting one’s family needs before her own, despite new challenges associated with chronic illness. Indeed, many women showed how reconstructing families and raising grandchildren after losing children to AIDS was not only socially challenging but also affected how they ate, accepted and managed their diabetes. These data illuminate how social and medical complexities come together to shape syndemic suffering in Soweto and underscore how the semantics of suffering are transformed as notions of illness, disease and treatment adapt to emergent realities. We present four major conclusions that reveal how women experience and understand syndemic suffering in Soweto.

First, women conceived of physical suffering as deeply embedded into social and emotional trajectories across the life course, stating that stress was manifest in the body – from pain in the neck and shoulders – and communicated as ‘thinking too much’. This axiom of suffering and embodiment has emerged cross-culturally to demonstrate what anthropologist Kristin Yarris (2011) describes, with regard to Nicaraguan grandmothers, as ‘a near-constant worrying about the effects of social disruption – particularly the death, migration, and loss of family members – on their lives’ (p. 228). Grandmothers in Soweto similarly connected thinking too much with social disruption, such as interpersonal violence, loss of family members to HIV/AIDS and financial insecurities linked with the need to procure safe and healthy foods for diabetes. Many also perceived thinking too much to have a direct impact on biologies, such as glucose spikes, and stress as a diabetes aetiology, corresponding with a broader anthropological literature around the lived connections and aetiologies of stress and diabetes (cf. Schoenberg, Drew, Stroller, &
Kart, 2005). Others characterised physical suffering as a result of the ‘many problems’ they have faced throughout their lives – not identifying specific incidences but emphasising the ordinariness of multiple factors shaping their current health conditions.

Second, women’s perceptions of overlap among HIV/AIDS and other chronic diseases exemplify how syndemic suffering can shape biomedical categories of disease into a polysemous entity that makes their emergence, synergy and persistence converge. These are not ‘cultural syndromes’ (Good, 1977) or traditional ‘idioms of distress’ (Nichter, 1981). Instead, the nuanced ways in which women describe multilayered forms of syndemic suffering within communities of high disease burden illustrate how women use and reframe biomedical disease nomenclature (Nichter, 2010) to communicate suffering in everyday life. In this sense, the plurality of suffering comes together to incorporate social and biological maladies that take root via social, economic, psychological and physical pathways. Thus, the illness itself does not take centre stage because the ordinariness of suffering becomes part and parcel in everyday life. This has direct relevance for clinical practice and epidemiological research in public health because the ways in which people transmute biomedical categories into everyday forms of suffering may underlie how they identify or ‘name’ suffering in relation to or apart from biomedical frames. Moreover, it challenges the current biomedical model that separates treatment for infectious and non-communicable diseases (e.g., separate clinics for patients with diabetes and those with HIV/AIDS) and underscores the importance of primary care integration.

Third, how people perceived and understood diabetes provided some insight into the experience of diabetes-related suffering in Soweto. Our data demonstrate relatively low levels of knowledge about what is diabetes, its causes and how one treats the disease. This is surprising as one in seven women in Soweto are insulin resistant (Crowther & Norris, 2012), although those who reported a diabetes diagnosis in the cohort is half that number (Mendenhall et al., 2013), indicating that many with diabetes may remain undiagnosed. Socioeconomic status and access to health care may play a role in people’s knowledge of their diabetes status or about diabetes more generally. Indeed, one-third of the women interviewed were largely unfamiliar with diabetes causes or treatment modalities, despite having sought regular treatment. This may be a result of the fact that women perceived diabetes as any other physical malady for which they sought treatment, and specifically how they juxtaposed its severity to HIV/AIDS, such as ‘the same’ or ‘worse’.

Finally, the persistence of social and psychological suffering was common and overlapping with chronic illness(es). On the one hand, the chronicities of violence and poverty likely explain why women displayed elevated symptoms of depression, a finding that underscores the Global Burden of Disease data identifying interpersonal violence as a leading disability in southern Africa (Murray et al., 2012). However, our recent article on psychological morbidity in the larger Bt20 cohort pushes this interpretation further. We found congruent prevalence of psychological morbidity (45%) among women without and with one chronic illness, although somatic symptoms and anxiety were more common than depression† (Mendenhall et al., 2013). The data from the present study suggest that indeed structural violence and persistent social problems may underlie such high psychological morbidity. And, indeed, it is the syndemic convergence of social, psychological and physical suffering that compromises women’s health. Therefore, we argue that it is not enough to investigate ‘diabetes’, ‘depression’ or even ‘HIV/AIDS’ in such contexts without attending to how the synergies among these coexisting maladies come together to shape women’s social, psychological and physical realities.

This study is not without limitations. We interviewed a convenience sample of women with diabetes participating in a cohort study who self-reported diabetes, so these findings
may not reflect the experience of people seeking care at primary health care settings. As with all research of subjective experiences, there is also a possibility of recall bias. Moreover, this is a cross-sectional mixed qualitative and survey study, so we are unable to assign causality between stressors and depression (although, we do not claim to do so). We are also unable to say if the social experiences described by our sample resemble those of people with diabetes only, all Africans residing in Soweto or other social and economic groups in South Africa. Nevertheless, our study reveals important insight into how people perceive overlap among multiple, emergent diseases in geographies of health transition.

In conclusion, understanding how women like Flory conceptualise sickness and experience syndemic suffering provides insight into how communicable and non-communicable diseases converge and become realised in people’s lives. This is particularly important in contexts like Soweto where emergent diseases take hold not only materially through people’s bodies but also cognitively in how people perceive and interpret their condition. As multiple physical morbidities become commonplace, particularly among the poor, more recognition of the role of social and psychological factors that contribute to and exacerbate such maladies requires attention. Indeed, the syndemic clustering of depression, diabetes and other problems cannot be dissociated from a social context where HIV is ordinary, and diabetes new.

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Note
1. In this study we used the General Health Questionnaire-28 to evaluate psychological morbidity, which included somatic symptoms, anxiety, depression and social dysfunction. The 45% reporting across the sample \((n = 1,743)\) does not reflect depression prevalence in the sample; while depressive symptoms were common, they were less frequent when compared to somatic and anxiety symptoms.

References


