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Knowing hypertension and diabetes: Conditions of treatability in Uganda

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ABSTRACT

In Uganda, hypertension and diabetes have only recently been included in the health policy agenda. As they become treatable disorders, they take on more distinct contours in people's minds. This article relates knowledge about these two conditions to health institutions and technology for diagnosing and treating them. The response to the AIDS epidemic in Uganda provides an important context for, and contrast with, the emergence of hypertension and diabetes as social phenomena. Ethnographic fieldwork shows the interplay between experience of these conditions and the political economy of treatability.

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Both medical professionals and lay people assert that hypertension and diabetes are recent, widespread and growing health problems in Uganda. In different ways, they link the increase of these conditions to transformations in political economy. Health policymakers say they are caused by changing patterns of eating and exercise following on economic development and more prosperity. Many lay people associate them with the difficult conditions of contemporary life: poverty, worry, violent conflict, hard work, and heavy burdens of care for dependent relatives. Yet political economy is relevant in other ways beyond the perceived social determinants of health. This article examines the connections between policies, funding, existing treatment possibilities and people's knowledge of these two conditions. It argues that the landscape of therapeutic opportunities shapes understanding and practice, giving form to these 'new diseases' as social phenomena and personal experience. That is, questions of policy, implementation, treatment availability and access in a place like Uganda are crucial for the knowledge practices that make them realities for people.

In some ways the situation resembles that described by Livingston for cancer in Botswana. She writes of how scientific objects take on ontological status as distinct entities. 'It takes an array of technological, intellectual, social, political and economic circumstances to perceive these entities and make them widely acceptable as facts' (Livingston, 2012: 52). Without the diagnostic

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and therapeutic possibilities that are common experience in the global North, cancer does not have a clear collective image or set of expectations. People in Botswana must learn about tumors, scans, chemotherapy, and radiation through their own bodily encounters and those of their families. Livingston shows how the first oncology ward in the country creates and embeds cancer as a reality in the lives of patients.

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

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convinced me that the patterns I saw are widespread in Uganda. The broader background for this study is ethnographic research in Butaleja District beginning in 1971 and continuing collaborative research with Ugandan scholars on communities and changing health care systems, including a long-term project on the response to the AIDS epidemic (Whyte, 2014).

Ethnographic research deepens work on health politics and health systems. Recent discussions on public health in Africa revolve around the changing nature of the state in relation to medical research and provision of health care (Prince and Marsland, 2013; Nguyen, 2005; Masquelier, 2001). Geissler (2015) proposes the notion of 'para-states' to denote the organizations that take on some of the roles of the nation state in relation to health, be they philanthropic foundations, pharmaceutical companies, bilateral and multilateral donors, NGOs, or well-funded research enterprises. Instantiated as a network of enclaves reaching across national boundaries, these organizations nevertheless articulate with the state and with particular segments of the population, albeit for limited periods of time. Ethnography can qualify this big picture by examining the extent to which these parastates affect given health conditions and actually shape people's knowledge and practice. It can reveal agency in the face of historical changes and difficult conditions, so that we better understand how people, both health workers and patients, manage when state and para-state interventions are weak or lacking.

1. The real neglected tropical diseases

Health workers in Butaleja District unanimously affirmed that hypertension and diabetes are on the rise and were concerned at the lack of attention to them. The former District Health Officer called them the real Neglected Tropical Diseases (as opposed to parasitic diseases like bilharzia and onchocerciasis, which are objects of a donor funded program by the same name). At a global level, the United Nations and the World Health Organization have now declared the relative neglect of these conditions in low and middle-income countries a matter needing urgent attention. But the situation differs in each member state, and it is important to situate the Butaleja observations within the history of Ugandan health care.

As in other African countries, infectious diseases have long dominated the health policy agenda. It was not until 2005 that non-communicable diseases were given an explicit place in the national health sector strategy (Ministry of Health, 2005: 46-47). A small unit was established within the Department of Community Health to manage all NCD activities. However, resources are extremely thin. The unit is allocated 0.01 percent of the Ministry of Health budget (itself largely based on external funding), which amounts to about 27,000 USD annually. The World Diabetes Foundation (established by the pharmaceutical company Novo-Nordisk) has provided a five-year grant bringing the total to 270,000 USD. Thus 90% of the NCD budget comes from short-term project funding (Schwartz et al., 2014). The tiny proportion of the health budget assigned to NCDs reflects the priorities of the government and its donors. The dependence on donors and the key role of the World Diabetes Foundation exemplifies the idea of the para-state.

The first point of the NCD strategy established in 2005 was a national survey to determine risk factors and prevalence, measuring body-mass index, blood pressure, cholesterol, and blood glucose.² After years of delay, it was finally carried out in 2014;

² The priority given to epidemiological surveillance over primary and secondary prevention has been noted for other African countries as well (Aikins et al.,

results should be available by mid 2015 (personal communication, S. Behendeka, 9 May 2015). Meanwhile, prevalence information is limited to a few population-based studies from different locations. For hypertension, a crude prevalence rate of 30.4% was found among people age 20 and older in Rukungiri District in 2006 (Wamala et al., 2009). Mayega et al. (2013) found prevalence of diabetes among people age 35–60 at 7.4% in eastern Uganda. Another study found that 96% of men and 86% of women with hypertension were not aware of having it, while nearly 3/4 of those with probable diabetes did not realize it (Maher et al., 2011a, 2011b). It is evident that these conditions are not being diagnosed. Even those who were aware of their hypertension diagnosis were apparently not receiving adequate care since only half of them had controlled blood pressure (see also Kalyango et al., 2008; Kibirige et al., 2014)

The lack of diagnosis is reflected in the near invisibility of high blood pressure and diabetes in the records of public health care facilities. A small exploratory study in northern Uganda examined the out-patient registers for one month of the year 2011 at six health units. Less than one per cent of patients age five and above was diagnosed with hypertension, except at the one private-not-for-profit hospital, where prevalence was 2.5% (Whyte et al., 2015).

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

The response to the AIDS epidemic in Uganda provides an important context for, and contrast with, the emergence of hypertension and diabetes as social phenomena. AIDS has been a government priority since 1986 and has received massive donor support. In its first years, the US President's Emergency Program for AIDS Relief made Uganda one of its top recipients, allocating 148 million USD in 2005, the highest amount given to any country. The flood of resources for AIDS meant disproportionate attention to one disease, yet that is not the only reason for the neglect of hypertension and diabetes. African countries not receiving mammoth donor support for AIDS have also failed to develop comprehensive interventions for NCDs (see Aikins et al. (2010) for the case of Ghana). In Uganda, the success of antiretroviral therapy programs demonstrated that chronic conditions could be treated systematically and effectively by local health workers, given adequate support. The regular ART (antiretroviral therapy) clinics in hospitals and health centers, as well as screening, prevention, and information campaigns, could be a model for the management of other chronic diseases. So could the multi-pronged, multi-sector approach that mobilized civil society, patient organizations, media, workplaces, and schools.

For hypertension and type 2 diabetes, existing interventions are few and modestly funded, constituting a scattered network of enclaves with links to the national health care system. In addition to the support mentioned above from the World Diabetes

(footnote continued) 2010).

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