SENSING SLEEPING SICKNESS: LOCAL SYMPTOM-MAKING IN SOUTH SUDAN

Jennifer J Palmer

Programs for neglected tropical diseases (NTDs) such as sleeping sickness increasingly involve patients and community workers in syndromic case detection with little exploration of patient understandings of symptoms. Drawing on concepts from sensorial anthropology, I investigate peoples' experiences of sleeping sickness in South Sudan. People here sense the disease through discourses about four symptoms (pain, sleepiness, confusion and hunger) using biomedical and ethnophysiological concepts and sensations of risk in the post-conflict environment. When identified together, the symptoms interlock as a complete disease, prompting people to seek hospital-based care. Such local forms of sense-making enable diagnosis and help control programs function.

Key words: South Sudan; diagnosis; neglected tropical diseases; sensations; sleeping sickness; symptoms

Running title: Sensing sleeping sickness

Media teaser: Pain, sleepiness, confusion and... *hunger*? I investigate some unexpected local discourses about symptoms of sleeping sickness in South Sudan.

French translation:

RESSENTIR LA MALADIE DU SOMMEIL: LA FABRIQUE LOCALE DES SYMPTÔMES AU SOUDAN DU SUD

Les programmes pour les maladies tropicales négligées telles que la maladie du sommeil impliquent de plus en plus les patients et les agents communautaires dans la détection des cas syndromiques, laissant peu de place à l’exploration des syndromes par les patients. A partir de concepts issus de l’anthropologie sensorielle, je propose d’étudier les expériences de la maladie du sommeil au Soudan du Sud. Les individus perçoivent la maladie par le biais de discours articulés autour de quatre symptômes (douleur, somnolence, confusion et faim) en recourant à des concepts biomédicaux et ethnophysiques, et à des sensations de risques dans un environnement post-conflit. Lorsque ces symptômes sont identifiés ensemble, ils prennent alors la forme d’une maladie cohérente, incitant les personnes à solliciter des soins en milieu hospitalier. Ces formes locales de création de sens permettent le diagnostic et aident les programmes de contrôle à fonctionner.

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Rose[1] had been watching her neighbor, 18 year old Okot, for some time. Eventually she decided to introduce herself to Okot's uncle, and asked him: "How does that boy feel?" He asked her why, so she told him,"boy looks for me somehow abnormal."

Rose suspected Okot had sleeping sickness. She knew the disease well from having cared for her brother when they were both young, and from a rotation working as a nurse in the sleeping sickness ward in the hospital. Okot's uncle was also aware of the disease and told her: "Well, if boy has nothing to be done [no tasks to perform], he can just sleep. And if he is in the room, his colleagues complain of mosquito bites but he can sleep up 'til morning." Rose continued her enquiry, saying, "fine, how does boy behave?" Okot's uncle replied, "Boy is just somebody who stays, like, he thinks, doesn't reason well." They chatted a bit about this and concluded that this might be because he was the first born. First-borns are favored by their parents and this can make them lose all sense of responsibility.

Rose continued: "How does he eat? Because the way of seeing him, he looks healthy, but the healthy part, I'm seeing it on the face which looks somehow puffy. The body is not fat like the face. … Does he eat frequently, or when food is brought to him, he eats faster?" The uncle agreed he ate a lot: "Boy can eat now, then after a short time he again feels hungry … then again, the same like that."

Okot himself was unaware he was sick. Nevertheless, Rose convinced everyone that she should take him to the hospital for a sleeping sickness test. Okot was diagnosed in late stage and admitted for treatment.

The above account, narrated to me by Rose the following day, reveals how sleeping sickness (a fatal but curable infectious disease also known as human African trypanosomiasis) is diagnosed in Nimule, South Sudan. As a disease which slowly affects nearly every part of the body including the mind, it has an odd presentation, requiring a keen sense of sociality to distinguish ‘odd’ from diseased. This means that observant people around patients who know what the disease is like –whether biomedically trained or not – are key to connecting patients with detection and the treatment services that might save their lives and reduce the human reservoir of disease.

A Syndromic Turn for NTDs

How to capitalize on such interactions is a key challenge facing programs seeking to control or eliminate a class of so-called “neglected tropical diseases” (NTDs) such as sleeping sickness. Mass campaigns which preventatively treat or screen populations at risk is the gold standard for controlling many NTDs but, as the burden of most NTDs falls globally, such campaigns cannot affordably be continued indefinitely. Facility-based testing and treatment, based on health workers’ assessments of patient symptoms, is now the mainstay of control for sleeping sickness, visceral and cutaneous leishmaniasis, Chagas disease, leprosy and Buruli ulcer. For other NTDs (including guinea worm, lymphatic filariasis, schistosomiasis, onchocerciasis, trachoma and yaws) syndromic surveillance is required during or after mass campaigns to help verify elimination and identify patients needing surgery and rehabilitation.

Alongside simpler diagnostics (Street 2018) and pictorial screening tools (WHO 2018) which help programs detect disease in the remotest areas of a health system, NTD actors are gradually realizing the importance of culturally sensitive community engagement strategies to make universal technologies work. Proposals to train former patients, volunteers and traditional healers to refer patients will, however, require capacity-building to help staff interpret patient accounts of disease symptoms and supply messages about available services in intelligible, relatable ways (Awah et al. 2018; Palmer et al. 2014a). To do so, programs will require a much more detailed understanding of local NTD symptom knowledge than is currently available. Understanding diagnostic stories like Okot's, and why these particular symptoms so concerned Rose, is essential.

Social science research on NTDs to date has focused on giving voice to social suffering (Gyapong et al. 1996; Hagenbucher-Sacripanti 1981; Manderson 2012), explanations for socio-political engagement in control programs (Bardosh 2016; Keys et al. 2018; Moran-Thomas 2013; Palmer, Robert, and Kansiime 2017; Palmer et al. 2014b; Parker and Allen 2014; Parker, Allen, and Hastings 2008) and perceptions of illness and outbreak causation (Giles-Vernick et al. 2015; Gyapong et al. 1996; Koka et al. 2016; Leygues and Gouteux 1989; Mpanya et al. 2012; Parker and Allen 2013). Compared to the legacy of robust anthropological work on local symptom sense-making for malaria, respiratory and diarrheal illnesses (Nichter 1994; Williams and Jones 2004; Yoder 1995), in the NTD field explorations of how hallmark symptoms inform program engagement tend to be rare, fragmented or superficial (with some notable exceptions: Boock et al. 2017; Gyapong et al. 1996; Pearson 2018; Woolley et al. 2016).

In sleeping sickness, in-depth observation of peoples' experiences of disease has not been undertaken for decades, when accounts were mainly from a physician's perspective (Lambo 1966; Tooth 1950). Most recent studies of symptom presentation treat patient reports of bodily and behavioral changes as real, measurable, universal experiences, "leaving to others the task of a more careful study of the semiology" (Bertrand et al. 1973).

The relatively new field of sensorial anthropology, which focuses on the complex interfaces between mind/body, groups/individuals and knowledge/practice, offers the potential for timely insight in this area (Hsu 2008).

Sensing and Sense-Making in Syndromic Diagnosis

Sensing something abnormal in one's own or another's body is both a physical and a cultural act. Different cultures extend the senses in different directions (Andersen, Nichter, and Risør2017; Good 1994). Touch, smell and sensations such as tingling or dizziness are embodied feelings, which can be novel or similar to ones previously internalized with contextual associations. Spaces or social settings associated with vulnerability or protection may predispose people to feel particular sensations or to look for them in others (Nichter 2008). How or why some sensations are acknowledged, while others are not, depends on the material, social and spiritual context that mediates the experience.

To make sense of and index embodied sensations as symptoms, cognitive interpretation is necessary (Hay 2008). Healing systems tend to do so by using iconic associations such as metaphor or homology, drawing on knowledge of how something else works to organise experiences across domains (Nichter 2008). The appearance of Guinea worms in bodies, for example, might be associated with a healthy process of decay like earthworms tilling soil (Moran-Thomas 2013); hydrocele as a result of filariasis might be explained as unresolved fever settling in men's scrotums or women's breasts (Gyapong et al. 1996). Cultural scripts transform uncomfortable sensations or states of negative psychological affect through ritual or narrative into publicly accepted sets of meanings that can be dismissed, recognized as part of a particular disease, or dealt with in some other culturally salient way (Nichter 2008).

As a form of cultural expression, the act of recognizing symptoms can have political implications in that symptoms speak of suffering and contribute to formations of self, social organization and cultural ideologies (Andersen et al. 2017). Syndromic sensing and sense-making thus exist in a field of relations where the dichotomy between the individual and the group is dissolved through a "communion of experience" (Ingold 2011: 314).

Drawing on such insights, in this article I present an in-depth social account of the syndromic experiences of patients and other people affected by sleeping sickness in Nimule.

RESEARCH SETTING AND APPROACH

Gambiense sleeping sickness, the most common variety in Africa, has been endemic in Nimule and surrounding areas of South Sudan and Uganda since at least 1914 when it spread from the Belgian Congo (Palmer and Kingsley 2016). This was a public health event of such political significance that it caused the re-drawing of international borders and even helped establish the Madi ethnic identity now claimed by the indigenous people of Nimule (Allen 1996b). This is when the word now most commonly used by Madi people to refer to sleeping sickness, *mongoto,* emerged, borrowed from tribes to the west and southwest. The literal translation in Madi is also used -- *laza odu drii* (*laza* meaning "illness/misfortune" and *odu* meaning "sleep"). Madi people have lived with both low levels and epidemics of the disease since then, including during periodic migrations across the border during Sudan's two civil wars (1955-72, 1983-2005). The second civil war also displaced ethnic Dinka people southwards from Bor into Nimule. Coming from an area that does not support transmission, this was most Dinka peoples' first exposure to both the disease and the terms invented to label it: *marothnuum* (an adaption from the regional lingua franca, Arabic, merging *marda* meaning "illness" and *num* meaning "sleep") and *bɛc de niim* in Bor Dinka (*bɛc* meaning "illness," *niim* meaning "sleep"). Such local terms both allude to a key symptom of the illness and place it in historical linguistic context.

Despite the disease's rarity, typically affecting less than five percent of a village even in the worst outbreaks, sleeping sickness tends to be widely known among people at risk of it as a dangerous disease which physically and mentally disables before it kills (Allen 1992;

Kovacic et al. 2016; Mpanya et al. 2012). Since colonial times, laboratory diagnosis of sleeping sickness has frequently been a public affair, with blood, lymph from enlarged nodes around the neck and shoulders, and cerebrospinal fluid examined during campaigns attended by the entire population. Depending on the patient's disease stage and co-morbidities, treatment involves one to two weeks' hospitalization with medicines complex to administer. Treatment has > 95% success, but mental sequelae can persist in people detected late and children's development can be affected (Aroke, Asonganyi, and Mbonda 1998).

With support from a non-governmental organization with which I was embedded, sleeping sickness services have been available at Nimule hospital and during intermittent campaigns since 2005 (Palmer and Kingsley 2016). During fieldwork for this study (eight months over 2008-9), the prevalence of sleeping sickness was around one percent, with slightly higher levels in adult men and among Madi people who were spread throughout rural and urban parts of the Nimule area. This compared with Dinka, who were concentrated in Nimule town (Palmer et al. 2014b) and were the majority users of sleeping sickness screening services at the hospital.[2]

Both Madi and Dinka people associated sleeping sickness with their displacement but had different conceptualizations of Nimule as a site of risk or protection (Palmer et al. 2014b). Madi people highlighted the process of repatriation as "risky" because of their proximity to tsetse flies while establishing farms and because they were separated from more familiar health services in Uganda. Dinka people thought of sleeping sickness as something they only learned about during displacement because of better access to health services than had been available at Bor. Many people believed sleeping sickness had existed in Bor, but had gone unrecognized because of "ignorance" and the northern government's denial of health care.

METHODS

To study peoples' sensations of sleeping sickness in Nimule, I analyzed individual accounts of their experiences of symptoms during illness episodes, and group discussions of perceptions of the disease. I carried out fieldwork primarily with Madi and Dinka populations, using five assistants fluent in Madi or Dinka, Arabic and English who provided both linguistic and cultural interpretation. Migrants from neighboring ethnic groups were included when they could speak one of these languages. All study participants provided written or witnessed verbal consent.

Case studies were constructed around 33 patients (15 females and 18 males aged 11-65 years old, including 16 Dinka, 12 Madi and one each of Acholi, Kakwa, Lotuko, Lolubo and mixed Lango-Acholi ethnicities). These participants were chosen to achieve a balance of gender, age and ethnicity, and representing 61% of cases identified syndromically during the study period. Nearly all were in the final (second) stage, defined biomedically when parasites can be found in the brain or spinal fluid (28 in stage 2, two in stage 1; three others died between the time when infection was confirmed and disease staging could be carried out). Five patients had been treated for sleeping sickness three to seven years earlier, enabling me to study post-treatment syndromic experiences; I also followed two patients prospectively for six months.

Interviews were conducted with patients or guardians (if the patient was under 18 years old or had a cognitive impairment that made it difficult to participate fully) soon after hospital admission and field notes were made of the team's interactions with patients, their family members, friends and health staff involved in diagnosis. Staff were nearly always South Sudanese and fluent in Madi, Arabic and English. Informants were asked how they realised they or the patient was sick, their memory of particular sensations, and how their experiences compared with what they knew about sleeping sickness. Patient files provided additional insight into symptoms observed by health workers before diagnosis. Key symptoms discussed in the case series (with numbers of people discussing them in parentheses) mainly covered: body pains (19); weakness (6); weight loss (7); visible swellings/oedema (5); abnormal sleep patterns (excessive daytime sleep or insomnia) (20); appetite changes (19); behavioral problems (21) including audio-visual hallucinations (5); neurological issues (5) such as walking difficulties, tremor, numbness or increased sensitivity to pain; convulsions (4); reproductive changes (5); itching (4); and lymph node enlargement (2).

Twenty-nine group discussions were conducted (seven with Dinka-speaking adults living in Nimule Town, 22 with Madi-speakers inside (8) and outside (14) the town, separately for each gender). The first 13 were held with people attending mobile screening campaigns to elicit descriptions of common discourses about sleeping sickness and its symptoms. The remaining 16 were held with natural social groups to explore care-seeking responses to categories of symptoms present in sleeping sickness and fictional illness scenarios.

Interviews and discussions were fully transcribed then translated into English for analysis and discussion with the mixed language team. Acknowledging that sense and language work together to make sense of suffering (Andersen et al. 2017), information collected in group discussions was treated as reflective of communal knowledge about the disease, which people drew on to interpret their specific experiences; likewise, individual processes of sense-making were seen as capable of reinforcing or refining communal discourses. While age, gender and other demographic characteristics influence sense-making for many illnesses (Andersen et al.), we focused on the particular influence of Madi and Dinka culture on sleeping sickness syndromic experiences given their vastly different historic and contemporary engagement with testing services.

SLEEPING SICKNESS SENSATIONS IN NIMULE

Among both Madi and Dinka people, sleeping sickness was widely acknowledged as a disease present in the area and understood to be transmitted by tsetse flies near rivers or bushy areas. During mobile screening campaigns, many people who came for testing said that the only way to know if someone had the disease was to be tested in a lab. Yet all groups and all patients emphasized they knew what the disease looked like.

The symptoms explored in Okot's story were not the only ones people associated with sleeping sickness, but the same symptoms Rose discussed with the uncle tended to be ones which first came to mind, particularly for Madi people and patients from other Equatorian groups.[3] In addition to abnormal sleep, mental confusion and appetite changes, certain types of pain were considered pathognomic of the disease, particularly for Dinka. While people sometimes thought of pain as an early manifestation and madness as a "third," extreme stage, patients in the case studies sensed or searched themselves for evidence of these symptoms throughout their course of illness to prompt or confirm biomedical diagnosis.

How sleeping sickness was sensed through each core symptom, and how "swelling" is seen as a core ethnophysiological concept which explained disease progression, is discussed below. Peoples' descriptions of how to recognize these symptoms illustrated their inter-relationship in communal images of the disease (Figure 1). Discrete concepts such as noticing someone "stealing food" or "having a quick temper" could relate to two (or more) of the core symptoms, which likely reinforced peoples' understanding that both were important to know. Differences in the ways Madi and Dinka people spoke about symptoms is noted where relevant.

Insert Figure 1 about here

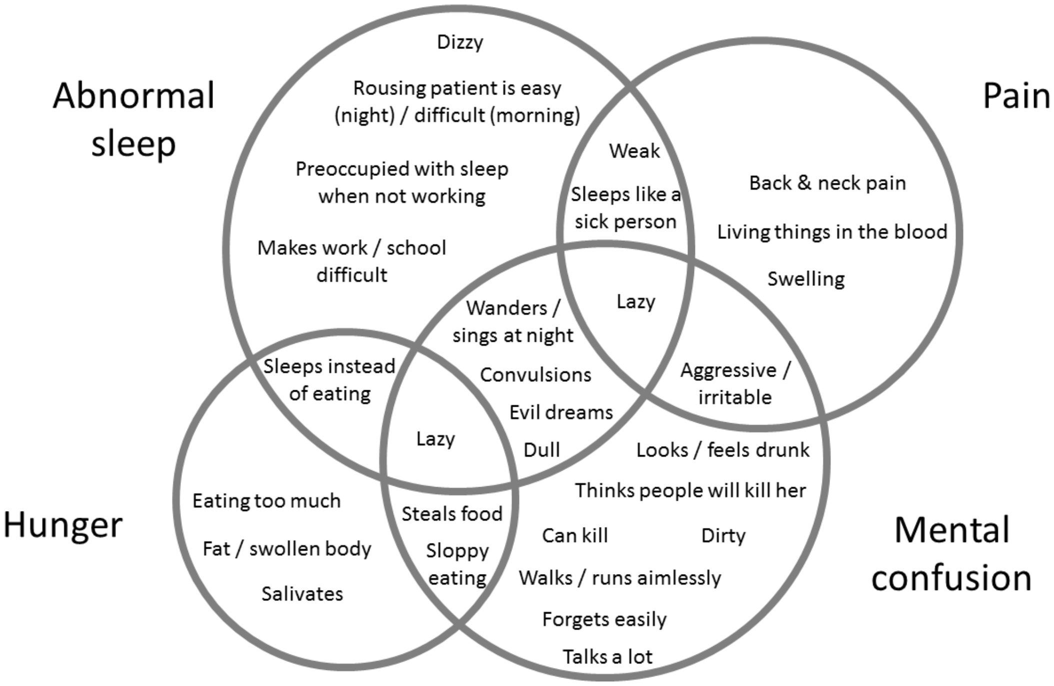

FIGURE 1. Four inter-related symptoms frequently associated with sleeping sickness in Nimule, indicated by inter-locking rings containing common illustrative descriptions of how each symptom can be recognised. Descriptions relating to more than one symptom are shown in areas of overlap.

Pain

Sensing and making sense of pain drew on embodied knowledge of sleeping sickness biomedical diagnosis and the ethnophysiological concept of swelling.

Prior to laboratory diagnosis, several patients claimed they knew sleeping sickness was in their body because they felt pain in their back, neck and lymph nodes. Tsetse flies, known to “chase” people moving through their habitat, were said to deliver painful bites on the back side of the body where they would inject small insects, worms or other living organisms. The back, neck and lymph nodes were also recognized as the places on the body necessary for diagnosis via lymph node and lumbar punctures so were conceptually linked. A Dinka patient described how she didn’t like turning her head because she felt like she had “been bitten or had swellings” on the neck, while a Kakwa patient described feeling “like there are some living things moving inside my backbone." Dinka patients, in particular, described how pain could differentiate sleeping sickness from other infections. Unlike malaria, in which pain was said to start in the head, sleeping sickness was known to start with back pain. This was the main symptom that prompted three patients to seek a sleeping sickness test, including one whose brothers insisted he test himself every three months until test results confirmed what they knew.

While hypersensitivity to pain (known to the biomedical community as Kérandal's sign) was systematically assessed and found by clinicians in nearly half of all patients on admission, patients rarely reported this as a remarkable sensation. Only one patient, a Madi woman, discussed it as a reason to seek care, after a relative recognised it as similar to the experience of someone else with the disease.

Sleeping sickness was known to cause pain and other pathologies through internal swelling [*pi* in Madi, *but* in Dinka], such as of the blood vessels in a Dinka patient who "felt like blood has stopped flowing … and I will shock [convulse]." When it happened in the cheeks, abdomen and legs, they would become visibly enlarged, akin to the narrower biomedical term, "edema." Thus, biomedical intervention was sometimes conceptualized as being effective through countering swelling. Men in a Dinka group discussion described how a lumbar puncture could be protective by slowing swelling and therefore the progression towards mental confusion in a female patient they knew:

> [before] the back pain of that woman was injected [treated through injection] … she could talk anyhow, she slept anyhow [in a haphazard way] but after … pulling that water [cerebrospinal fluid] out of her back, she was OK ... If that water moved to the brain then it could have mixed with some water in the brain.[4]

Swelling discussed in these ways mirrored language used to describe the effects of poisoning from witchcraft (Pearson 2018), as a Madi herbalist involved in treating one patient explained:

> The body will begin to swell because when you are poisoned it will cause a lot of interruption to the muscles [causing numbness/paralysis]. ... [Alternatively] wounds will fall on that person's body and make her fail to talk, like as if something is there in [closing/swelling up] the throat ... [In skin wounds] the person begins just swelling and ... as it destroys the body cells, it produces pus.

Through such processes, poisoning (*awola*, a Madi word and concept also recognized by Dinka communities) was widely known to lead to sudden and mysterious deaths (Allen 1992). Similarly, recognition of body swelling in sleeping sickness normally caused alarm. The husband of a Dinka patient who sensed swelling and numbness in her legs and her lymph nodes explained why he rushed her to the hospital for a sleeping sickness test, saying, "I thought she was going to die. I've seen body swelling like this on other people before and always those people die soon after."

Sleep

Abnormal sleepiness was said to be most identifiable in situations requiring strength such as physical work, going to school or travelling in the sun. One Lotuko patient with excessive sleeping and severe mental confusion, for example, said he had been staying at home for eight months because "when I come out into the sun it destroys me." His wife had left with their child since, according to him, being unable to work made him useless. People with sleeping sickness were therefore described by their families as "lazy to do work."

Despite these negative consequences, excessive sleeping was often not associated with illness until sleepiness was accompanied by weakness. This sensation was said to be more typical of the sleep “like a sick person” which required medical treatment-seeking. The concept of “dizziness” which incorporated the image of both sleeping and weakness (and occasionally also fainting and convulsions) was used most often to describe sensations before sleeping sickness was suspected and labelled. An undiagnosed patient whose health book included references to dizziness by primary health care health workers was also described as dizzy by the Madi receiving clinician at Nimule hospital as a justification for testing for sleeping sickness. His impression was that she “could sit unsupported, but she was unstable, like somebody who is dizzy with her eyes open … she can fall over.” Soon after, she slipped into a coma.

Family members who sensed patients were sleepy or dizzy were most likely to associate these symptoms with sleeping sickness if they could detect signs of mental confusion, with descriptions of “sleeping too much” even converging with descriptions of mental changes, as in this account of “dullness” by the father of a Madi boy:

> He used to be very clever but when he started sleeping he became dull, he would not pick what the teacher taught because of sleeping in the class. From primary one up to three … he was well, but last year and this year he is very dull.

Accounts of disordered nighttime sleeping had even stronger associations with mental confusion. Descriptions of insomnia in sleeping sickness included patients talking, laughing or singing through the night, similar to descriptions of inappropriate behavior by sleeping sickness patients with confusion in the daytime. Dinka and Madi people usually described hallucinations or convulsions at night as “evil dreams” or nightmares, as described by a young Madi man who spent a night running from imagined attackers and taking refuge in a graveyard:

> Patient: There were some people who wanted to catch me … so I ran in the bush and found an old grave which I entered up to morning …
>
> Interviewer: You said that you have been dreaming. Now, what was your dream about?
>
> Patient: It was about those people … It seemed like they could touch me so I would wake up and put on the light but I would not find the people inside the room … It [nightmares] happened to me twice, then the third one led me to sleep in the bush.

Mental Confusion

The most common terms used to describe the mental effects of sleeping sickness referred to how a patient's mind (head/brain) could become confused (e.g., *driciri* in Madi, *miol* in Dinka) and make them "run mad" (*ki mali* in Madi, *e Ɣa jot nhom* in Dinka). This could make sleeping sickness patients become dangerous or disgusting, as described in a discussion with Madi women:

> Participant 3: This person can become confused and can't take care of himself so they always become dirty …
>
> Participant 5: If proper care is not taken, a sleeping sickness person can injure someone with harmful things like stones, knives and spears.
>
> Participant 1: … he can even plan to kill.

People from all ethnic groups recognized sleeping sickness as a class of fever-inducing infectious diseases, including malaria, which could cause non-prophetic madness when severe enough to affect the brain (Hutchinson 1996). Unlike other infections, however, even the mild effects of sleeping sickness on peoples' personalities were considered to have the potential to endure.

Fearful of these well-known images of the disease, several patients examined themselves for indications that their minds or personalities had been affected. The quotes below, for example, show how a Dinka woman before biomedical diagnosis and a Madi woman after, respectively, sensed sleeping sickness was causing them to be increasingly forgetful:

> If I went to bathe in the shelter I could forget to put on my dress! [Laughing] … when I was young I was not so forgetful like this, this is why I know it is really a sickness and then I tried to look for treatment for it here.

> Forgetfulness is happening. So when I think of getting something from one room … before I reach the next room I will not know what I am going for … but mine [mental confusion] is not that much because I haven't yet lost my senses.

Dinka patients, particularly, also monitored themselves for signs of irritability (*piou ya dac riak*, literally, "heart feeling angry") that could result in unreasonable aggression, and some former patients in group discussions claimed that "[sleeping sickness still] makes me more aggressive than before."

However, patients with sleeping sickness also experienced social pressure not to feel sensations of mental confusion after treatment. Communal discourses about sleeping sickness helped people make sense of "odd" behavior leading up to diagnosis classifying patients as "diseased," but there was also a communal process after treatment which could return patients from "diseased" to "odd" but otherwise healthy. The experience of Stephen, a driver for our organization running the sleeping sickness program, was illustrative.

Stephen believed people in the rearview mirror were chasing him and started driving up a mountain path so fast that his passengers jumped out of the vehicle. He spent several days lost in the bush, not eating, not sleeping, just wandering and suffering attacks from tsetses. On his return, Stephen's Lutoko family sacrificed a goat and tied a piece of its skin around his wrist to banish the spirit he must have encountered in the forest and "carry away the death." Like patients from other ethnic groups who experienced hallucinations and convulsions, they suspected he was under the influence of one of several types of spirits present in the bush.[5] Within our organization, most people thought it related to his traumatic history as a soldier or his related recreational use of drugs. When Stephen was eventually diagnosed with sleeping sickness, we were relieved. So was his brother, who then claimed that sleeping sickness was the sole cause of Stephen's visions in the bush.

Months after treatment, however, many of Stephen's mental symptoms continued. When told that he could not drive for us, he held our boss for ransom with a gun, yelling: "You know, I am mad! Merlin [our organization] is the one who gave me this disease! I am suffering from psychotic illness. I could kill someone!" Observers of this event had different interpretations of the violence. Some assumed Stephen had not and would never fully recover from his sleeping sickness, and that this was a continuing manifestation of the illness. Others pointed to non-disease explanations. A Madi clinician wondered if the shock of having his salary stopped had triggered the episode. Sceptics believed Stephen's appeal to having sleeping sickness was a pretext for demanding more sick pay. Another dismissed him as a "cattle raider," a derogatory term for men from pastoralist tribes seen as violent.

Our labelling his symptom as sleeping sickness psychosis had prompted Stephen to behave –and explain his behavior– according to his understanding of this even after treatment. Despite recognition in both local and biomedical discourses that the mental effects of sleeping sickness can persist, however, there were limits to peoples' sympathy. This meant that some people stripped him of the sleeping sickness disease label and the right to manifest this symptom, relabelling him as "mentally confused" without a specific etiology, or as simply greedy but effectively well.

Hunger

Communal accounts of the way sleeping sickness affected eating habits depicted people salivating, with rolls of fat and ravenous appetites. Such a lack of bodily and social control suggested mental confusion sometimes underlay this symptom, too. Greedy behavior could be stigmatizing for sleeping sickness patients as it is elsewhere in South Sudan and Uganda (Allen 1996a; Hutchinson 1996; Kwacakworo 1994). Patients considered greedy would not be invited to share meals with others; over-eaters might be denied a proper burial. If sleeping sickness caused a patient to eat too much, families faced giving up their portions to a patient or going through their budgets too early. This was a serious concern in a region where, in 2009, people ate only 1.3 meals/day and spent 65% of their income on food (Ministry of Agriculture 2010). As one Madi woman described, "If you get sleeping sickness, your way of life will change completely. It …needs a lot of money, especially if you need to eat a lot."

Even worse, it was said that once a patient went through the family's food, he would want the neighbor's, leading to theft or murder. The family would be expected to pay compensation, and patients could be killed. Food thefts were implicated in witch-hunts during Madi migrations in the 1980s and 1990s (Allen 1996a) and worried the United Nations Refugee Agency in Nimule in 2008. Fear of the disease related to "eating too much" thus converged with notions about aggression and the risk that sleeping sickness posed to communal peace that all ethnic groups struggled to maintain in post-war Nimule.

Given that fatness and a robust appetite are typically associated with health in Africa, in practice, sensing these dispositions as symptoms of sleeping sickness was complicated. Recall Rose's description of Okot, for example, which mixed terms denoting pathology such as swelling and approving comments linking fatness to health and strength: "the healthy part, I'm seeing it on the face which looks somehow puffy."

Since mental confusion was anticipated as an embarrassing and dangerous complication of hunger, families sensed increased hunger by looking for taboo behaviors. This included seeing patients eating partially cooked or old food at great speed or with other small breaches of etiquette. One Madi woman, for example, noticed that her adolescent daughter had started eating food by the handful, rather than the characteristic three fingers, prompting her to take the daughter for a sleeping sickness test: “Before, she didn’t take food in handfuls … then I began to realize … because there is no sickness which causes people to eat a lot other than sleeping sickness.”

The most extreme communal consequences of hunger captured in public discourses were not evident in this research. I met only two people with bodies reported as swollen all over from excessive eating, but neither seemed especially fat compared to others around them (Figure 2). Eating-induced swelling thus appeared to be a comparatively rare sensation but one which was pathognomic to people attuned to living in a nutritionally and physically insecure environment.

Insert Figure 2 about here

FIGURE 2. A former sleeping sickness patient (holding card) recovering from excessive hunger and fatness with some male relatives, in Nimule.

SENSING SLEEPING SICKNESS IN GLOBAL, LOCAL AND INDIVIDUAL CONTEXT

Syndromic knowledge about sleeping sickness in Nimule was instrumental in influencing peoples’ experience of the disease and their interactions with hospital services, so supporting the detection and treatment program. Peoples’ understanding of how certain types of pain, dizziness, confusion and hunger could be associated with sleeping sickness led patients to testing services where they were diagnosed as cases. After lab diagnosis, peoples’ syndromic knowledge helped them understand the sensations they felt in their bodies or observed in others’. After treatment, this knowledge helped people sense when the disease’s influence had resolved, returned (requiring more testing and treatment), or when it had a lasting effect on their personality. Local syndromic knowledge thus contributed to saving lives.

How did this come to be? Peoples’ long and close contact with trypanosomes has enabled their knowledge of sleeping sickness to accrue iteratively through multiple and communal experiences of illness which feed public understandings. Importantly, while sense-making was specific for each core symptom, the symptoms were also connected through the image of sleeping sickness as a complete disease. As a result, sensations which at first went unacknowledged materialized cognitively as symptoms when complementary sensations of other symptoms were also felt. Sensations of mental confusion, for example, supported labelling a feeling of dizziness as sleepiness. Pain reinforced some sensations of mental confusion through knowledge of the disease’s progression, and so on. This image of sleeping sickness and its component interlocking symptoms reinforced understanding and allowed people to monitor their bodies and confirm what tests could (and could not) tell them.

Such meaning-making from the parasite’s action on bodies was specific to the cultural scaffolds onto which syndromic experiences of sleeping sickness were affixed. While Madi and Dinka people emphasized certain symptoms over others, sensorial experiences of both groups were informed by biomedical and ethnophysiological knowledge and practice, as well as moral and social interpretations of ill health linked to poverty, violence and war.

As for other NTDs (Parker and Allen 2013), health workers followed pluralist and social approaches to sensing disease similar to those of lay people, illustrating how sleeping sickness knowledge here, and likely elsewhere, does not exist in distinct, binary categories of “local” versus “biomedical” understandings. Rather, sleeping sickness diagnosis happens in a space of pragmatic enactment, where affected populations and staff navigate and co-create a collective understanding of the disease and its identification.

More than a symptom, swelling was a key ethnophysiological process understood to cause pain, fatness, mental confusion and dangerous disease progression. This was opposed to the way parasites interact with immune cells triggering inflammatory, endocrinological and other biochemical reactions on either side of the blood-brain barrier, the pathology as understood in current biomedical thought and to which even health workers had little exposure. Peoples' syndromic knowledge of sleeping sickness has evolved in the presence of laboratory technology. Colonial doctors began using needles and microscopes to look for sleeping sickness in southern Sudanese bodies even before the disease had spread to the region (Palmer and Kingsley 2016) and the concept of sleeping sickness remains explicitly linked to biomedical health care and laboratory practices (Allen 1991; Palmer et al. 2014b). Public diagnostic rituals focussing on the spinal cord and lymph nodes have led to embodied knowledge which influences how people sense pain. Hypersensitivty to pain, popularized in biomedicine in 1908 by French physician and famed sleeping sickness patient, Jean-François Kérandal, was not typically acknowledged in patient accounts in Nimule, so demonstrating how different sense-making can be, depending on exposure to discourses in the diagnostic culture (Hacking 1999).

Disease discourses were further embedded in the ways spaces and symbols featured in sleeping sickness recognition. Besides needles, this included the sun, flies and food, domestic areas where people felt safe and graveyards in the bush associated with danger (Allen 1992). In seeing someone tired after working in the sun or with a large appetite and plump cheeks, people sometimes struggled in transforming the sensations from an association with "health" to "illness." Conversely, sensations connoting social risk such as laziness, violent madness and voracious hunger could be explained as symptomatic of a curable disease. Dramatic symptoms of disease tend to be registered by large networks of people (Wilhelm-Solomon 2009).

Such social concerns are part of the communal image of sleeping sickness elsewhere. Global advocacy regularly recognises how an inability to work affects farming communities (Franco et al. 2014). Discourses in central Democratic Republic of Congo highlight how dangerous sleeping sickness patients can be (Mpanya et al. 2012). “Eating too much” and having a fat body appears to have been a hallmark of local discourses reported sporadically but consistently in diverse areas of Africa for centuries (Figure 3, 4) (Atkins 1734; Bertrand et al. 1973; Bukachi et al. 2018; Giordano et al. 1977; Hoeppli and Lucasse 1964; Kinung'hi et al. 2006; Soff 1971). In post-conflict Nimule migrants spent long days establishing homes, there was insufficient food, and theft and homicide were common (Deng 2013); in this context sensitivity towards risk was heightened. Syndromic discourses which emphasized how sleeping sickness can destabilise a society through chaos and crime functioned as idioms of distress (Nichter 2008; Parker et al. 2008).

Insert Figures 3 and 4 about here

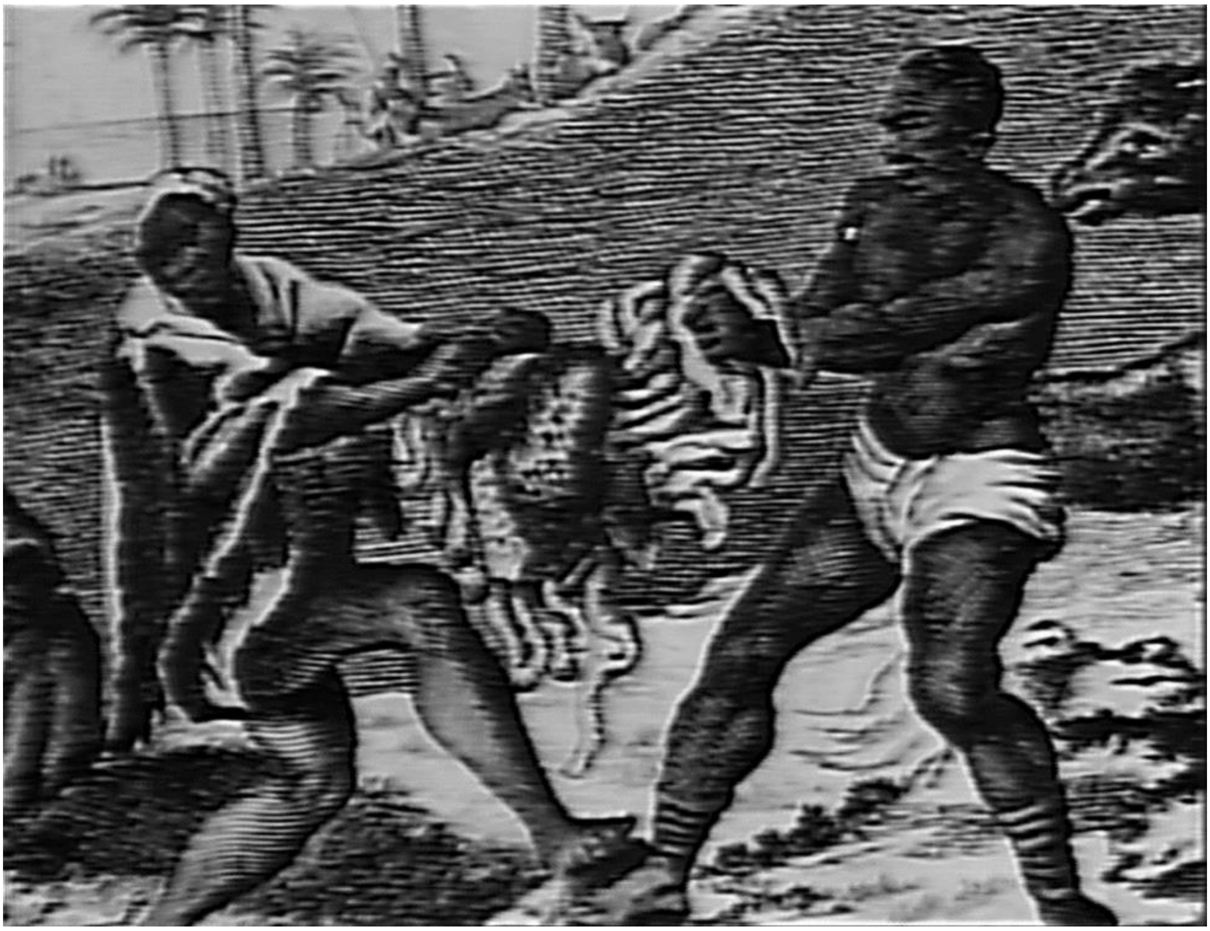

FIGURE 3. Illustration from nineteenth century West Africa of the ravenous appetite sleeping sickness patients were known for depicting patients fighting over raw intestines (Williams 1988).[6]

FIGURE 4. Illustration from nineteenth century West Africa depicting sleeping sickness patients as fat (Williams 1988).

Syndromic knowledge in Nimule was of course incomplete. Most people, including health workers (Palmer et al. 2014a), seemed to have low awareness of the severe neurological symptoms of sleeping sickness such as seizures, paralysis and difficulty walking. Additionally, the reproductive changes this disease can induce seemed to rarely feature in communal discourses, although I did not take a gender or life-course approach which might have been more sensitive to this. Further research on how syndromic experiences differ between genders, age and other social groups is needed, as is the after-effects of sleeping sickness and treatment on patients' physiology, lives and identities.

Future research might also attend to how shades of meaning change through translation, and whether apparent similarities or gaps in vocabulary have practical implications. Whereas cultural differences surrounding similar linguistic uses of words for “swelling” matter, cross-cultural translations of other concepts might not. Most African languages do not have words for parasites or other microbes, for example, so terms for insects or worms are often used when referring to biomedical understandings. In Nimule, ways of talking about the signs and symptoms of sleeping sickness in Madi, Dinka and English translations were largely the same, suggesting health communication may be an arena of common interest for these ethnic groups despite other important social divisions.

Dinka fears about witchcraft controlled by Madi and other Equatorian groups is one social device that tends to preserve ethnic difference in South Sudan (Allen 2007), so it may be remarkable that sleeping sickness affliction, or complications of it, was not seen as resulting from interpersonal conflict with neighbors as in some parts of Democratic Republic of Congo (Mpanya et al 2012). This perhaps reflects Dinka peoples’ acceptance of Madi interpretations of the disease as having a biomedical etiology and Madi peoples’ own long history of involvement with sleeping sickness programs.

Comprehension of social experiences of disease should also not be limited to study of language. A phenomenological ethnographic approach to studying diagnostic practice might help center diagnostic consciousness and intuition in identifying disease symptoms. With phenomenological methods tending to be grounded in the direct experience of one’s own consciousness, however, the sociality of the sensorial approach taken in this study offers an additional tool to understand diagnosis as it happens through peoples’ awareness of others’ symptoms. This is important for a disease with mental health impacts, where the sufferer's ability to provide an account of the symptoms in language may be constrained.

A sensorial approach helps overcome the limitations of both subjective and objective research methods (Hsu 2008). Large-scale clinical studies of sleeping sickness, for example, indicate that headaches may be the most universal sign of disease when patients are systematically questioned (Blum, Schmid, and Burri 2006), but most families familiar with sleeping sickness in Nimule would not find this symptom remarkable. Conversely, increased appetite in signifying disease might appear underappreciated in biomedical thought (Blum et al.) until confronted with the difficulty of finding actual examples of hunger and fatness. Sensorial anthropology reminds us that “seeing,” like all sensations, is a participative, context-specific social activity which might not be visible to outsiders without the aid of culturally meaningful approaches (Hsu 2008). By focusing on the interface of mind and body, the subjective and objective, sensorial anthropology enables us to understand the social processes through which sleeping sickness is recognized in practice, and how people's sensory experiences are specific to their social context.

CONCLUSIONS

Mapping the local epistemic and moral spaces involved in NTD diagnosis is useful given the current trend in public health to rely on passive case detection to achieve disease elimination. Amidst initiatives to roll out new diagnostic technologies and treatment options and engage populations to use them, there is a need for communities to collectively recognise potential disease among their members and for NTD programs to understand the local communal language and semiology of disease sensations (Awah et al. 2018). We need to avoid universalizing subjective sensations (Good 1994), trivializing seemingly non-biomedical understandings of symptoms, and value the life-saving contributions of local syndromic knowledge, processes and actors which make universal diagnostic technologies work. In these domains, attention to the forms of sensing and sense-making that enable diagnosis can shed much light.

As I have illustrated, syndromic recognition is much more than a biomedical practice occurring in clinical spaces by appropriately trained medical personnel. It is inherently social. To identify potential cases, sense-check laboratory diagnoses and track the resolution of symptoms, patients and health workers interpret diverse sensations and draw on context-specific communal knowledge to connect partial, disparate and even nonsensical experiences of individual symptoms. People share long-established, emotional discourses about the core symptoms which, when identified together, overlap and interlock to suggest a distinct and complete disease. Sharing such syndromic discourses enables people to find those connections and reinforces information about the disease's devastating impacts on families and society. Through this process, sleeping sickness diagnosis comes alive for people working in and targeted by disease elimination programs.

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NOTES

[1] Only pseudonyms are used. Almost all quotations presented are translations from local languages.

[2] Screening rates were slightly higher in women and adults.

[3] Syndromic knowledge crossed not only ethnic but also international lines. For example, Rose was a South Sudanese Madi, Okot and his uncle were Lango from an area of northern Uganda where another form of sleeping sickness predominates, and Okot was also part Acholi. All three had lived and worked on both sides of the border. The discussion about Okot's symptoms took place in a mixture of English and Acholi.

[4] Screening programs use lumbar punctures to withdraw fluid for diagnostic examination, but here men refer to it as an injection (in English) and discuss fluid withdrawal as protective; both phenomena are examples of a general tendency in lay settings in Africa to conflate testing procedures with prevention and treatment. Talking or sleeping "anyhow" expresses that these are haphazard, not following a pattern or social norms.

[5] These could be spirits associated with trees and animals or the spirit of someone murdered during the war and seeking vengeance. See, for example, descriptions of *ceni* death spirits in Madi and Acholi culture (Allen 1992).

[6] The artist(s) responsible for illustrations in Figures 3 and 4 are unknown; the images are believed to have been created in the early 1800s, according to archivists at the Wellcome Trust.

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