

Sensing sleeping sickness: local symptom-making in South Sudan

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What is the research?

The field of sensorial anthropology emphasises that different cultures extend the senses in different directions and use different cognitive metaphors to translate abnormal sensations into symptoms of illness. Undertaken in collaboration with Merlin and the London School of Hygiene & Tropical Medicine's RECAP project, this study investigated the local sense-making processes involved in sensing and detecting cases of human African trypanosomiasis (HAT, or sleeping sickness) in Nimule, South Sudan.

This study employed a sensorial anthropological lens which focuses on the interfaces between objective/subjective and individual/collective knowledge. It investigated how people share syndromic information in communal disease discourses and drew on them to connect partial, disparate and even nonsensical experiences of individual symptoms to diagnosis of a complete disease.

Why is this research necessary?

Syndromic case detection of NTDs like HAT is increasingly important as we approach elimination. Mass campaigns which preventatively treat or screen populations at risk is the gold standard for controlling many NTDs. However, as the burden of most NTDs falls globally, such campaigns become less cost-effective. Facility-based identification of suspected cases using health workers' assessments of symptoms they observe in patients who visit them (a strategy referred to as 'passive case detection'), is now the main way cases of HAT, visceral and cutaneous leishmaniasis, Chagas disease, leprosy and Buruli ulcer are detected to target treatment. 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.

How to best involve lay people and frontline health workers in syndromic case detection of NTDs is thus a key challenge for NTD programmes. Staff need help interpreting patient accounts of disease symptoms and supplying relatable messages about the services available to people with particular symptom profiles. Compared to the legacy of robust anthropological work on local symptom sense-making for malaria, respiratory and diarrheal illnesses, however, field explorations of how hallmark symptoms inform programme engagement tend to be rare for NTDs.

What is the research impact?

This study demonstrated the ways people can combine biomedical and ethnophysiological concepts with sensations of risk from their environments to identify suspected cases of HAT.

In Nimule, the disease was sensed through four main symptoms: pain, sleepiness, confusion and, interestingly, *hunger*. The archetypal image of a HAT patient was of someone running mad, stealing neighbours' food to feed ravenous appetites, leaving chaos and violence in their wake. People who suspected HAT in themselves or others looked for subtle indications that they could be developing such a condition, such as forgetfulness or sloppy eating. Particularly when symptoms of pain and weakness were also present, this helped people decide to seek a HAT test.

While hunger and fatness have been common elements of local discourses from diverse areas of Africa for centuries, these symptoms are rarely discussed in biomedical accounts of HAT. Such difference demonstrates how "seeing" disease is a context-specific social activity which might not be visible to outsiders without the aid of culturally meaningful approaches.

Using the example of HAT, this study provides a novel lens through which to research local sense-making of NTD symptoms and value the life-saving contributions of local syndromic knowledge which help make disease control programmes work.



Illustration from nineteenth century West Africa depicting HAT patients as fat and greedy. Artist unknown, image held by the Wellcome Trust Library