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Changing landscapes, changing practice: Negotiating access to sleeping sickness services in a post-conflict society

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ABSTRACT

For several decades, control programmes for human African trypanosomiasis (HAT, or sleeping sickness) in South Sudan have been delivered almost entirely as humanitarian interventions: large, well-organised, externally-funded but short-term programmes with a strategic focus on active screening. When attempts to hand over these programmes to local partners fail, resident populations must actively seek and negotiate access to tests at hospitals via passive screening. However, little is known about the social impact of such humanitarian interventions or the consequences of withdrawal on access to and utilisation of remaining services by local populations. Based on qualitative and quantitative fieldwork in Nimule, South Sudan (2008–2010), where passive screening necessarily became the predominant strategy, this paper investigates the reasons why, among two ethnic groups (Madi returnees and Dinka displaced populations), service uptake was so much higher among the latter. HAT tests were the only form of clinical care for which displaced Dinka populations could self-refer; access to all other services was negotiated through indigenous area workers. Because of the long history of conflict, these encounters were often morally and politically fraught. An open-door policy to screening supported Dinka people to 'try' HAT tests in the normal course of treatment-seeking, thereby empowering them to use HAT services more actively. This paper argues that in a context like South Sudan, where HAT control increasingly depends upon patient-led approaches to case-detection, it is imperative to understand the cultural values and political histories associated with the practice of testing and how medical humanitarian programmes shape this landscape of care, even after they have been scaled down.

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1. Introduction

For over five decades, conflict in South Sudan has caused massive and continuous population displacement across ethnic boundaries. The repercussions for health system development have been dire: by 1990, 4 out of 5 health facilities in the country were shut (Salih, 1996) and the main providers of care became (and remain) international humanitarian agencies. Having only experienced formal healthcare through the punctuated cycles of

emergency aid programmes, South Sudanese populations have been exposed to vastly different medical practices and cultures: from the traditional health and religious systems of neighbouring tribes, to the emergency triage systems of rebel groups on the front lines, to the many faith-based and secular humanitarian organisations intervening with their own myriad vertical programmes. This varied and highly fragmented landscape has shaped the ways populations understand and seek care.

To grapple with that legacy, this paper examines a particular example of medical care in context: screening for human African trypanosomiasis (HAT or sleeping sickness) among the displaced populations inhabiting post-conflict Nimule, South Sudan, between 2005 and 2010. The strategic location of Nimule Town and surrounding areas, where the Nile intersects the Ugandan border, has

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often served as a fertile mixing ground between human, tsetse and parasite populations. HAT was first identified here in 1914, but the majority of cases reported since have been associated with war-related migration, beginning with the northwards repatriation of Sudanese Madi populations from endemic areas of Uganda in the 1970s after the first civil war (Hutchinson, 1975), followed by displaced Ugandan Madi refugees ten years later (Harrell-Bond, 1986; Snow, 1983). As the Dinka-led rebellion of the second civil war spread south in 1989, Madi people again sought refuge beyond the border and civilians and soldiers from all areas of the country funnelled behind the Nimule frontline, rapidly enlarging the local HAT reservoir (Ruiz, 2005). A second Madi repatriation after the 2005 peace agreement amplified both ethnic tensions and epidemic risk. With each population wave to the area, modest humanitarian-led primary healthcare and nutrition programmes attempted to meet health needs, but HAT control services could never be mounted until the establishment of full-scale hospital services with the entry of Merlin, an international medical organisation, in 2005.

At the eastern edge of South Sudan's HAT transmission belt, Nimule was a late recipient of the humanitarian HAT response. Whereas by the end of the war, most humanitarian organisations in the rest of the country's hospitals were withdrawing from HAT control (Ruiz-Postigo et al., 2012), Nimule hospital was able to benefit from the substantial domestic technical and programmatic capacity created over the last decade by expert organisations such as Médecins Sans Frontières (MSF). At the encouragement of the World Health Organisation (WHO), specialist South Sudanese clinical officer, nursing and laboratory staff were recruited to Nimule from an MSF programme winding down in Kajo-keji in 2004. As the area's 1% prevalence and humanitarian best-practice dictated, these staff conducted active screening of populations in the area. With limited resources for implementation, the programme could only achieve modest population coverage of active screening but was able to institute a robust passive screening and in-patient treatment service, available to patients on-demand through the hospital lab.

By the time of our field work in 2008, a strange epidemiological pattern had emerged. Despite higher HAT prevalence levels in the local Madi population, the passive screening service was used far more often by the displaced Dinka population. This post-conflict context therefore presented an ethnographic puzzle: why would an ethnic minority displaced population be better served than a returnee 'host' population by a vertical humanitarian programme led by mainly indigenous area workers? Using an ethnographic approach and a combination of qualitative and quantitative methods, we draw insight from the testing experiences and expectations of patients, as well as our observations of the evolving configuration of service delivery in this humanitarian programme, to understand: (i) why, contrary to expectations, Dinka people were more likely to test for and be detected as cases of HAT than Madi; and (ii) what influence the programme had on differential HAT treatment-seeking and case detection. By studying these behaviours in recent historical context, we consider the legacy that such humanitarian programmes create as they are passed on and scaled down.

The paper begins with a description of humanitarian HAT programmes and the wider empirical and theoretical context. After a note on method, we present data collected by Merlin and analysed by us to describe the differences in treatment-seeking behaviour in more detail. We subsequently compare the treatment-seeking contexts and logics of these Dinka and Madi populations, and provide possible interpretations of the unexpected testing behaviours. Our discussion points to ways in which these insights can inform future humanitarian practice.

2. Background

Over the last three decades, medical humanitarian organisations such as MSF, have largely been credited with 'waking up' the global public health community to the need to control human African trypanosomiasis (HAT or sleeping sickness) (Corty, 2011; d'Alessandro, 2009; Redfield, 2012c). As one of the least researched and most deadly of the neglected tropical diseases (NTDs) (Balasegaram et al., 2008; Jannin et al., 2003), HAT in many ways accommodates a humanitarian ideology of engagement based on short-term and intensive 'relief' (Redfield, 2010). First, HAT mainly affects poor communities in remote and conflict-affected areas of central Africa where health infrastructure and political will to respond to public health needs are weak. The lapse of chronic 'endemic' conditions into uncontrolled 'epidemics' or 'emergencies' (Hasker et al., 2012) can be considered an indicator of state failure, providing ideological justification for international agencies to intervene and take responsibility for the well-being of affected populations. Second, HAT is considered to be a 'tool-deficient' disease (MSF, 2012) or, more precisely, a disease for which the standards of treatment, surveillance and prevention are deemed too complex for use at community or primary healthcare level (Simarro et al., 2011; Tong et al., 2011).

In light of these gaps, MSF is instrumental in managing the disease globally. Known from its inception as an international organisation unique in its focus on patient care (as opposed to public health promotion only) (Bradol, 2011), MSF has treated over 50,000 cases (MSF, 2012), equivalent to 10–15% of the global reported *gambiense* burden since its first intervention in 1986 (estimated using data from (Simarro et al., 2008; WHO, 1998, 2000, 2013)) and perhaps 20–30% of cases during the epidemic peak (Corty, 2011). In the case of HAT, MSF has ostensibly succeeded in "offering tangible proof that it is possible to do better" (Bradol, 2011, p. 217).

To address the "almost amateur situation" in which they initially found themselves (Corty, 2011, p. 136) (d'Alessandro, 2009), MSF modernised a vertical method of active screening and treatment of populations via mobile teams (Corty, 2011), an approach credited with continent-wide reductions in HAT burden before the 1960s (Louis et al., 2002; Simarro et al., 2008; WHO, 2000, 2013). They further developed procedures for community sensitisation, team and patient transportation, lab diagnosis via algorithms with contingency methods to reach populations off the beaten track, new treatments, detailed clinical protocols, and patient information systems that could be used to trace patients across front-lines and international borders. These systems not only allowed them to operate with relative autonomy, but also to share these innovations and influence the strategic decision making and practice of other humanitarian organisations and donors responding to HAT emergencies, thereby shaping the modern culture of HAT treatment provision.

As active screening is now practiced, statistics are kept on the populations served to provide evidence of equity in programme reach and coverage (Bouchet et al., 1998), sometimes allowing analysis of relative attendance of ethnic populations in conflict, or among vulnerable groups common to insecure settings such as internally-displaced persons (IDPs) (Kaba et al., 2006). However, apart from a few notable studies from non-humanitarian groups (Mpanya et al., 2012; Robays et al., 2004a, b; Robays et al., 2007), little attempt has been made to understand the socio-cultural dynamics that underlie HAT treatment-seeking and attendance at services in the rapidly changing, ethnically heterogeneous social environments where humanitarian HAT interventions take place. For instance, of 37 research articles on HAT authored by MSF (available at <http://fieldresearch.msf.org/msf/>), one refers to

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