4 Controlling sleeping sickness amidst conflict and calm: remembering, forgetting and the politics of humanitarian knowledge in Southern Sudan, 1956–2005

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Introduction

Sleeping sickness (human African trypanosomiasis) is a parasitic disease spread by the tsetse fly across a large belt of Sub-Saharan Africa. It is one of the great stories of success – and failure – of public health in the twentieth century. Nearly all conventional histories, such as those found in project proposals written by international organisations or in World Health Organisation (WHO) documents, begin by recounting the story of the disease’s ‘U-shaped’ curve on graphs depicting reported cases on the continent over time (see, for example, Simarro et al., 2008; WHO, 2013; Ruiz et al., 2008; Figure 1, page 28). Although the curve takes different forms in individual endemic countries, this emblematic continental graph conveys a particular message about the history of this disease, which has had far-reaching consequences on how disease control is understood today.

Sleeping sickness is often seen as a quintessential colonial disease (Lyons, 1992): with a continental peak of 60,000 cases in 1930, controlling the disease and its tsetse fly vector were core imperial priorities. Control of the most prevalent form of sleeping sickness, gambiense, was achieved through a succession of strategies involving coercive measures that reflected broader patterns of political domination: forced resettlement, denuding of land supporting tsetse, years-long interment of patients in isolation centres, treatment with extremely toxic medicines, punishments for chiefs that did not present their populations for medical inspection and mass prophylactic injections.¹ Today, the most well-known method from this period is medical inspection (now referred to as mass or active screening) by mobile teams operating in Central Africa. Designed by military physicians to achieve near 100% population coverage, this strategy worked so well, so the story goes, that Africa came close to eliminating the disease by the 1960s and found itself at the bottom of the ‘U’. The near-success of elimination coincided with independence for many African states, however, and these new governments had other priorities, but also wanted to distance themselves from the coercive practices associated with colonial methods (De Raadt, 2005). Control programmes thus collapsed. When sleeping sickness resurfaced to its second peak of over 30,000 annual cases during the civil wars in Central Africa in the late 1990s, contemporary histories recount how medical humanitarian organisations, particularly Médecins Sans Frontières (MSF), were the only actors with sufficient interest and means to re-engage with the disease (Corty, 2011). This second continental epidemic was successfully controlled, again via mass programmes (Maurice, 1930; Bloss, 1960) and by historians since then (Bayoumi, 1979; Bell, 1999; Leonardi, 2005).

¹ Sleeping sickness control by colonial authorities in Southern Sudan has been reviewed by scientists involved in these colonial
screening. Revitalising this strategy involved creating a global logistical supply chain to bring diagnostic tools and medicines which had been improved in the meantime from Europe to rebel strongholds in Angola, Sudan, Uganda, Zaire (now the Democratic Republic of Congo) and the Central African Republic. Whereas colonial public health programmes had struggled to secure compliance from recalcitrant African populations, for humanitarians the main struggle was with the pharmaceutical companies that produced the medicines needed to control this deadly but commercially unviable disease. But the lessons for history became clear: active screening is the best – indeed, the sole – strategy to control HAT in Africa.

Whilst this general narrative makes a strong case to focus minds and resources for control, it also conceals various important heterogeneities and inconsistent logics in the sleeping sickness story from place to place and over time. This is a problem germane to disease control in Africa. Lessons from past disease control initiatives on the continent, despite their long history and large scale, have remained largely unarticulated or misconstrued and therefore unable to inform contemporary efforts (Webb and Giles-Vernick, 2013). Programme planners generally ‘have not sensed a first imperative to understand the worlds in which their projects would operate’, tending rather to assume that there was no need to do so because the disease was well understood biomedically (ibid.: 1). This failure to take socio-cultural and geographic contexts into account still plays a critical role in global health today. Given the essential role of humanitarians in controlling sleeping sickness in the most recent continental epidemic it is important that we clarify, with the benefit of hindsight and the space to do so outside of an outbreak and conflict situation, exactly how they selected disease control priorities from the range of different options available, and the assumptions on which that choice was based. Further, we ask how the era of humanitarian intervention marked a break from the colonial past, and what the continuities were. And, most importantly for the purposes of this collection of papers, what does the history of sleeping sickness reveal about the nature of humanitarian actors and their ability to carry out complex, long-term projects such as continental disease control?

Figure 1: ‘U’-shaped epidemiological curve of sleeping sickness cases in Africa, 1927–97

To explore these issues, we track the development of this story in a single place, Southern Sudan, over the period 1956–2005. This case is chosen in part because it represents a ‘ground zero’ in terms of the dominance of humanitarian actors – Southern Sudan’s two civil wars (1955–72 and 1983–2005) meant that state capacity for health care and disease control was extremely limited throughout this period, leaving international agencies free to act with an unusually broad mandate. In theory, with the civil war beginning a year before independence in 1956, continuities between the colonial and humanitarian systems should be easier to identify in Southern Sudan. As well as being of historical interest, we believe that this case is significant for modern priorities. Since the end of the civil war in 2005, most humanitarian organisations have ceased their involvement in sleeping sickness control, leaving the task to a network of other types of global health actors.

Although this paper does discuss the perspectives of those witnessing or receiving humanitarian assistance, it is not primarily an attempt to reconstruct a view of humanitarian actors ‘from below’. Such histories are valuable, particular as they offer a counterpoint to dominant humanitarian narratives. We believe however that the specificities of Southern Sudan require a different approach, not least as the fractured, multiactor nature of intervention in this country (formerly a region of Sudan) has meant that there may be less of a clear, dominant narrative to overturn. Instead, we identify which actors carried out what activities, and the reasons and assumptions that led them to pursue those strategies in an institutional and intellectual history of sleeping sickness in Southern Sudan. Understanding the decision-making of dominant actors is central to a critical history of this period, and allows reflection on those ideas and histories which may have fallen out of favour, or been silenced or overlooked.

We begin with an outline of the events of the colonial period, which prefigure in important ways the period under discussion. Whilst this period involved widespread use of coercive methods, there were also other more holistic strategies, in which medical and environmental approaches were combined, along with broader attempts to encourage agricultural development. The remainder of this paper traces trends in disease control through the three dominant organisations active in sleeping sickness here. The World Health Organisation (WHO) was the dominant actor in the 1950s – where it pursued a medical strategy that continued some colonial measures, but tended to ignore vector control. The suspension of conflict in the 1970s provided WHO with a second opportunity to intervene, but its ambitious plans were thwarted by logistical difficulties. The Belgian Development Cooperation (1978–90) and MSF (1995–2005) then became active, particularly in experimenting with new forms of diagnostic tests and treatments. Significant successes were achieved with new medical tools and strategies, but again vector control remained largely neglected.

To tell this story, we use substantial archival material alongside interviews with key individuals to reconstruct the history of sleeping sickness control in Southern Sudan. Specifically, we consulted the WHO archives on Sudan (for material covering the period 1926–95), the South Sudan national archives in Juba (1931–78), the Rift Valley Institute’s Sudan Open Archive (1860–2009), Durham University’s Sudan Archive (1950–70), Tvedt’s 2004 annotated bibliography of Southern Sudan (1850–2004), the Belgian Development Cooperation’s archive (1978–91) and one NGO archive (Merlin 1996–2010), as well as relevant academic literature. We supplemented this material with 18 interviews with experts familiar with the subject, mostly active or retired NGO workers and civil servants.

Colonial sleeping sickness administration and resistance (1910–54)

Sleeping sickness was most likely introduced to Southern Sudan in colonial times. Soldiers, labourers and traders are thought to have carried gambiense sleeping sickness from ancient endemic foci in West Africa into the Belgian Congo and then into the Lado Enclave and Uganda from the late 1880s (Lyons, 1992; Bell, 1999; Morris, 1960). Based on extensive epidemics in neighbouring Uganda and Congo, sleeping sickness was feared by Anglo-Egyptian administrators and preventive control measures were implemented before any cases were detected. Border tours by British scientists in 1904–1905 identified no human cases (Bayouni, 1979; Bell, 1999), but medical inspection posts were nevertheless established at road and river borders in 1909 to turn away or quarantine
tsetse vector capable of carrying this type of sleeping sickness in the area local transmission was never established (Bloss, 1960). It was only in 1910, after the AngloEgyptian government took control of part of the Lado Enclave containing the present-day sleeping sickness foci of Yei and Kajo-Keji, where cases were thought to have occurred since 1885 (Bell, 1999), that Southern Sudan inherited an epidemic of sleeping sickness (see Figure 2 and Figure 3). Another sleeping sickness focus at Nimule was brought into the country in 1914 when colonial authorities adjusted the border east of the Nile for the express purpose of simplifying international medical governance of this riverine disease (Leonardi, 2005; Merkx, 2000). Sleeping sickness eventually spread with *G.f. fuscipes* tsetse
to the margins of its existing habitat, incorporating Tambura, Yambio and Maridi to the north-west in 1918, 1923 and 1941, respectively, and to Mundri, Torit and the outskirts of Juba in the 1970s as fuscipes habitat expanded north-eastwards during the first civil war^3^,^4^ All of these foci continue to yield cases today.

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3 *Rhodesiense* sleeping sickness, which mainly infects cattle, has been clinically suspected in several areas of Southern Sudan at different points in history (Tambura during the colonial period, Akobo during the 1970s, Torit in the 1970s and 1980s and suburban Juba in 2010) (Abdel Gadir et al., 2003; Adamson, 1978; Archibald and Riding, 1926; Baker, 1974; Bell, 1999; Hutchinson, 4; Leak, 1999; Mohammed et al., 2010; Picozzi et al., 2005; Ruiz et al., 2008; Snow, 1983). Apart from Akobo at the
As Southern Sudan represented the northern limit of *gambiense*-transmitting tsetse habitat in the continent, this region was typically viewed by British administrators as a place where concerted environmental and medical intervention could beat back the disease entirely, out of Sudanese territory (Bell, 1999; Morris, 1961). Such intervention, however, would require much greater engagement with the south, beyond the existing reaches of the Anglo-Egyptian administration. Previously seen as economically insignificant and politically unstable, the threat of sleeping sickness is arguably what made the remote south of Sudan matter in Khartoum, drawing administrators ‘out of colonial enclaves and into the lives of local people’ (Bell, 1999: 29).

During the first two decades of colonial control, measures were typically implemented as if they were military campaigns, reflecting the choices commonly implemented in countries where the epidemic was more advanced. Borders were closed, tsetse areas were mapped and whole populations were moved away from the most infested areas, typically onto roads cut for the purpose of sleeping sickness inspections. Historians have highlighted the coercive nature of these interventions, which involved forced inspections and the lengthy confinement of suspected patients (Bell, 1999; Leonardi, 2005). Later, however, more consensual methods emerged. As the epidemic moved into the remoter, forested areas of Tambura and Yambio, where state resources were particularly stretched, treatment camps were transformed into self-sustaining communities. Here, sleeping sickness patients were encouraged to move with their families, who could provide labour that was otherwise unavailable to the state to grow food for the increasing numbers of patients and to cut back tsetse habitat along the 10km stretch of river in the isolation area (Bell, 1999). Perhaps most importantly for colonial administrators, these isolation centres provided an unprecedented opportunity for development of the South. Dubbed ‘model villages’, sleeping sickness control here allowed administrators to live alongside affected people, both to ‘know’ them, as anthropologist E. E. Evans-Pritchard sought to do (Evans-Pritchard, 1937; Gilles, 1976), and to introduce modern systems of social organisation. Here, wage labour was introduced alongside large-scale agriculture, market trading, medicine and education – the kind of development previously only attempted.
in places like the Gezira cotton scheme in the north. With their strong harvests and access to salt via colonial supply lines, these settlements were tolerated, and even attracted Zande people from across the Congolese border (Bell, 1999).

By 1937, a decade after the country’s first major epidemic, a relaxation in population control for sleeping sickness was justified in epidemiological, economic and environmental terms. The 1940 Sleeping Sickness Regulations introduced a system of medical passports so that border traffic was no longer prohibited altogether.4 Inspections were less frequent. Preparations began for a Southern cotton scheme around Yambio, which would necessitate opening up tsetse habitat for farming, overriding the sleeping sickness concerns of the previous three decades. For medical personnel who had any lingering fears, a new more efficient method of vector control had emerged in Kenya which promised to avoid the ‘irksome restrictions’ on people’s lives that resettlement and inspections entailed (Bloss, 1960; Hunt and Bloss, 1945: 57). This new ‘block clearance’ method involved clearing only small (800 x 200-yard) sections of tsetse habitat along rivers to confine flies’ flight to blocks which could be surveilled by boys paid to catch flies.5 Trials of the new method showed rapid and largescale fly suppression. They were even combined with a system of prophylactic suramin injections in an attempt at sleeping sickness elimination in Tambura and Kajo-Keji in 1937–41, but the drug was expensive and medical personnel argued that tsetse suppression would have a more sustainable effect on transmission.6

This preference for environmental over medical methods of control was at odds with medical opinion in other gambiense-affected areas of Africa. By the 1950s, globally, sleeping sickness control was increasingly being discussed in terms of elimination because of the success of mass screening and treatment activities in neighbouring French Equatoria and West Africa (Buxton, 1949; Morris, 1961). Pentamidine was also being used prophylactically to protect people from transmission between screening rounds in French Equatoria and the Belgian Congo (Muraz, 1954).7

WHO elimination ‘success’ and reconstruction failure (1955–78)

As independence neared, mutinies erupted across Equatoria in 1955, igniting the first civil war (Gilles, 1976). For sleeping sickness control, the external partnership brokered with WHO the year before to support pentamidisation was fortuitous. For one thing, it allowed the external financing of pentamidine administration on top of the medical inspections and treatment activities which the Anglo-Egyptian government had always financed, and guaranteed continued Sudanese government commitments via this international agreement. Second, through consultancies and formal positions in the WHO regional office, it allowed some of the departing British colonial administrators an avenue to return to Southern Sudan to see through the sleeping sickness control plans they had helped put in place. There were further examples, for better or worse, of the continuity of colonial arrangements from an earlier period. At WHO’s insistence, sleeping sickness programmes regained remarkable administrative authority in the name of disease control: Equatoria Province decreed that prophylactic injections were compulsory; chiefs

As early as 1948, Southern Sudan was considered a

6 Ibid.
8 This was also partly on the grounds that vector control would be more difficult to apply in Yambio than in Tambura or Kajo-Keji, because of the diffuse habitat.
were instructed to prosecute in court those who did not attend inspections and conscript them into hospital labour; all government soldiers in the southern region, even those in non-endemic areas, received two rounds of pentamidine; and international borders were policed for anyone not yet been given pentamidine. Meanwhile, the vector control measures that had previously gone hand in hand with drug administration ceased. While those within Sudan had maintained to the end of the colonial period the idea that elimination would necessitate tsetse control, under international WHO leadership pentamidisation was selected as the sole strategy needed for both control of acute outbreaks and ‘permanent’ control in areas with residual transmission (Haddad, 1955).

By 1962, scientists at WHO’s first meeting of the Expert Committee on Trypanosomiasis declared pentamidisation a success, writing: ‘It can now be said with certainty that T. gambiense in the Sudan will be eradicated within a year’. But while reported cases had indeed declined substantially, sleeping sickness was almost certainly not gone in 1963. WHO’s withdrawal of support that year was more likely related to the intensification of the Southern conflict and the dysfunctional postindependence politics in Khartoum (Cockett, 2010). With the consolidation of rebel movements in 1963, conflict in Equatoria became entrenched and expanded to the other Southern provinces. Simultaneously, large numbers of expatriates were expelled from the country, including many missionaries who had been providing the majority of non-governmental support to healthcare in the South (Cockett, 2010). After WHO’s withdrawal, Sudanese hospital staff continued sleeping sickness control as best they could with remaining stocks of medicine, but the ability to screen patients systematically largely collapsed.

When Sudanese President Jafaar Nimeiri switched allegiances to Western, and particularly US, actors in 1971, a peace agreement with the South swiftly followed, ushering in the country’s first full-scale, Western-led humanitarian response. Most scholars consider this moment as marking the emergence of welfare privatisation in Southern Sudan as Khartoum sought to contract-out social services to international agencies (Large, 2012; Johnson, 2011). UN plans for rehabilitating the South after 17 years of war entailed funneling $20 million in the first year alone to 180,000 refugees and 500,000 people displaced internally by the war. Faith-based organisations were influential in drawing global attention to a suspected resurgence of sleeping sickness at the end of the war. This resurgence was in the same south-western area that WHO pentamidisation campaigns had focused on at the beginning of the war, but advocacy at this time did not frame the problem in terms of a failure of strategy. Rather, humanitarians focused on the urgent need to address the epidemic of ‘madness’ reported from ‘areas hard hit by the disturbances’. They pointed to the apathy of neighbouring governments in tackling the problem in refugees and criticised British pharmaceutical companies for stopping production of sleeping sickness drugs for use in the UK’s former colonies (L’Etang, 1975). At the request of the Sudanese government, the UN High Commissioner for Refugees (UNHCR) therefore granted sleeping sickness control its own $81,000 budget line, with WHO expected to fund the difference and work out the details.

The WHO regional office supporting Sudan (the Eastern Mediterranean Regional Office (EMRO)) responded quickly, drafting a comprehensive proposal incorporating state of the art serological and parasitological diagnostic technologies forecast to cost $193,000 over three years (see Table 1 outlining other elements of WHO plans).

Although ambitious, the plan stopped short of proposing elimination, which was no longer considered feasible.

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12 Pentamidisation was later discredited as having little protective effect against new infections and even inhibiting case-detection efforts by masking parasitemia (Pepin and Labbe, 2008; Stanghellini, 1999).
Table 1: Key elements of WHO’s post-war sleeping sickness reconstruction plans (1970s)

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<tr>
<td>1.</td>
<td>Lab personnel training in:</td>
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<td></td>
<td>• Serological diagnostic methods (capillary haemagglutination, latex agglutination, immunofluorescence)</td>
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<td></td>
<td>• Parasitological diagnostic methods (identification of parasites in body fluids using simple microscopy and in buffy coat isolated through centrifugation)</td>
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<td></td>
<td>• Animal inoculation and blood culture diagnostic methods</td>
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<td>2.</td>
<td>Treatment at hospitals and field stations</td>
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<td>3.</td>
<td>Establishment of mobile screening teams</td>
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<td>4.</td>
<td>Pentamidine chemoprophylaxis campaigns</td>
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<td>5.</td>
<td>Census of population at risk</td>
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<td>6.</td>
<td>Entomological, socio-economic, epidemiological and cost–benefit studies</td>
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<td>7.</td>
<td>Coordination with neighbouring country sleeping sickness programmes, liaison with WHO reference labs</td>
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<td>8.</td>
<td>Design of long-term control programme</td>
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Table legend: Information comes from plans and correspondence in the WHO Southern Sudan sleeping sickness file 1973–83. Not all control programme elements appeared in all WHO plans and individuals debated the appropriateness of particular elements (such as chemoprophylaxis) throughout the decade.

The plan, however, never really materialised, despite visits by WHO personnel in 1973, 1974 and 1978, and the director of sleeping sickness at WHO headquarters personally redrafting it in 1976. Individuals within WHO were some of the most vocal critics of this failure; two European staff assigned to work on the programme in Maridi and Yambio eventually resigned in exasperation at ‘administrative delays’. One of the main problems appeared to be the year-long wait at Port Sudan customs for lab equipment and supplies, which crippled screening and capacity-building activities. By 1978, sleeping sickness in Yambio had become so acute that one WHO staffer argued they could no longer wait for external assistance, highly trained personnel or a ‘magic screening formula’. In this case, the staffer recommended relying on only the simplest and swiftest techniques (mainly cervical lymph node puncture) which had already been proven during colonial and WHO pentamidisation campaigns. This recommendation furthermore fitted in with a new framing for sleeping sickness which WHO promoted through the 1980s around integration of control activities into primary healthcare structures, part of a wider institutional focus on rural primary healthcare (WHO, 1987).

Others in Yambio were also critical of WHO’s seeming inability to mount a response. An international NGO working in Yambio, Caritas, for example, had been reporting cases to WHO since 1973. In the absence of the promised UN intervention, Caritas had resorted to borrowing sleeping sickness equipment and drugs from the Belgian Development Cooperation (BDC)’s bilateral programme in neighbouring Zaire (Akol, 1981). Belgian scientists brought in from Zaire were scathing of the WHO response, estimating that the delay had cost 3,000 new infections at a price of $1.2 million, which the Belgian government now had to fund (Akol, 1981).

The Southern Regional Government, at least in the most affected areas, also found ways of making do without the technologies of the UN programme by returning to interventions known from the colonial period. Between 1975 and 1977, at the request of Yambio area chiefs, the Commissioner of Western Equatoria initiated a series of radical environmental and population control measures, framed as a national duty in the ‘War against Sleeping Sickness’.24

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19 Regional Director EMRO to P. de Raadt (19 February 1976) ‘Revised plan of operation for a trypanosomiasis control project, Southern Sudan’, WHO archives, SUD-MPD-005.
20 See Hutchinson’s 1974 and 1975 reports and various
correspondence in 1975–76 in WHO archives, SUD-MPD-005; see also Binz’s 1975 and Lapeysonnie’s 1978 reports in WHO archives, Trypano1-EMRO-Sudan.


23 *Ibid*.; see also WHO correspondence from 1983 with German primary health care programme in Equatoria, WHO archives, CTD/TRY T/7/360/6.SUD.


Strategies included financial penalties for people who did not attend inspections or absconded from treatment (when it was available), making it illegal for Zairean traders who could be infected to sell in Sudanese markets and compelling chiefs to clear tsetse habitat from streams and citizens to clear bushes from around their compounds. A sleeping sickness tax was levied to fund these efforts.  

Reimagining and relegating fly control

From this point on in Southern Sudan, WHO appears to have given up pursuing the idea of direct provision or financing of sleeping sickness services, as planned in the immediate post-war reconstruction period. Instead, the main activities it engaged in over the next decade were epidemiological and entomological assessments of sleeping sickness risk associated with development and humanitarian interventions. Investigations at Ture forest station near Kajo-Keji, a plantation in Maridi, a proposed cattle ranch at Loa and camps for Ugandan refugees near Nimule, for example, all paid considerable attention to how changes in the natural environment could influence transmission. A WHO entomologist deployed to the Belgian programme in the 1980s furthermore sought to revisit and reimage colonial tsetse control methods that could be applied there. In Tambura, the ‘blocks’ along rivers where tsetse habitat had been cleared in the late 1930s near the town were identified and reclered. Rather than recruiting boys to catch flies by hand, the entomologist designed a trial of insecticide-impregnated cloth targets to attract and kill flies – the first for control of *G. fuscipes* in Africa. In Yambio, where resettlement or pentamidisation were previously the only control options considered, detailed entomological and human screening surveys suggested that most transmission occured at particular wells dug in the forest. Medical screening therefore incorporated a team of people on bicycles to erect and maintain fly targets around these specific hotspots.

This disease control contribution by WHO was important given the Belgian programme’s restricted geographic focus to areas bordering Zaire (mainly Yambio and Tambura) and, particularly, their prioritisation of medical responses. Unlike in some West African settings, however, where tsetse trapping gained popularity because the French Office of Scientific and Technical Research Overseas (ORSTOM) promoted vector control as an alternative to coercive screening methods in the 1970s, trapping was not taken up in a major way here (Laveissiere and Penchenier, 2005). By and large, these WHO assessments and plans gave rise to little substantive non-medical activity (see Table 2), with vector control typically consigned to a supporting role. Entomological surveys, for example, were characterised in WHO reports as only useful to delimit an area needed for medical intervention or to increase its efficiency by decreasing the number of repeated population screenings needed to control disease.

As the humanitarian crisis grew over the next decade, vector control fell even further out of favour. Although Merlin later led a trapping project in Tambura in 1997 (Joya and Okoli, 2001, Moore and Richer, 2001), subsequent proposals to expand the programme to Yambio and Maridi went unfunded (interview with NGO staff, 2006), reflecting uncertainty about the economics of vector control in humanitarian interventions across the continent (Trowbridge et al., 2001; Shaw, 2005). A

25 By the time of another WHO visit in 1978, SDG 300 had been raised for this fund by leaders WHO staff characterised as ‘enthusiastic but inexperienced’ in sleeping sickness control (Lapeysonnie, 1978 report to WHO). WHO staff evidently felt responsible for offering guidance so that these funds would be spent efficiently, but further information on either the guidance offered or how these funds were eventually spent is unavailable. A similar pattern seems to have prevailed in the 1980s, when UNHCR officials declined to fund a vector control programme requested by Ugandan refugees in Yei (Harrell-Bond, 1986: 58, 333). Moreover, environmental considerations and vector control recommendations are noticeably absent from any of the WHO sleeping sickness assessments that have taken place in the last three decades.
26 See reports by Hutchinson (1975), Lapeyssonie (1978) and Snow (1983 and 1984) in WHO archives, SUD-MPD-005 and Trypano1-EMRO-Sudan.

27 Snow, 1984 report to WHO.

28 Unfortunately, because records stop, it is unclear whether this planned trial took place. Merlin records, however, suggest that the fly-boys from the colonial period were rehired for a short period to teach hand-catching techniques.


Belgian medical tools in a humanitarian space (1978–90)

Throughout the 1980s, serodiagnosis and treatment was the mainstay of the BDC’s control strategy in Southern Sudan. Modern serodiagnostics, a category of simple agglutination assays which screen for antibodies associated with infection, rather than the parasite itself, and thus require no

Table 2: Inter-war medical survey and vector control work recommended by WHO and implemented, by focus

<table>
<thead>
<tr>
<th>Sleeping sickness focus</th>
<th>Type of medical screening recommended</th>
<th>Type of vector control recommended</th>
<th>Activities successfully implemented (by 1990)</th>
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<tbody>
<tr>
<td>Tambura</td>
<td>As precautionary measure (1975)</td>
<td>Exploratory survey (1975), depletion trapping (1983), habitat clearance around streams in towns and trial of screens (1984)</td>
<td>Partial medical screening with CATT, some depletion trapping by fly boys</td>
</tr>
<tr>
<td>Yambio</td>
<td>As emergency control measure (1975)</td>
<td>Exploratory survey (1975), aerial spraying by helicopter (1978), depletion trapping (1983)</td>
<td>Full medical screening with CATT, entomological surveys, study of water source-related infection risk, elaboration of new Yambio-specific vector control method focused on wells, sticky screens pilot</td>
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<tr>
<td>Yei</td>
<td>As precautionary measure (1975)</td>
<td>Exploratory survey (1975)</td>
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<tr>
<td>Kajo-Keji</td>
<td>Exploratory survey (1983)</td>
<td></td>
<td>Partial medical screening via lymph node palpation</td>
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<tr>
<td>Akobo</td>
<td>Spot surveys (1975)</td>
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Table legend: Information comes from correspondence found in the WHO archive, particularly reports written by Hutchinson (1975), Lapeyssonie (1975 and 1978) and Snow (1983 and 1984), as well as correspondence in the Belgian and Merlin project archives.
laborious microscopy, were introduced into routine practice in Southern Sudan in the early 1980s – before anywhere else in Africa. Ironically, although serodiagnosis was primarily developed by Belgian scientists in the 1970s (Magnus et al., 1978; Wery et al., 1970), it could not be used in formerly ‘Belgian’ areas of Africa, namely Zaire/Congo, where the BDC had a large programme, until the mid-1990s because of ideological opposition (interview with former BDC staff, 2015). Since Zaire was the most endemic country in Africa, it also possessed the largest number of experts (both Congolese and Belgian), who were convinced through long experience that sleeping sickness could be most efficiently controlled through traditional microscopy. Deployment in the cross-border satellite Belgian programme in Sudan, however, allowed less experienced Belgian doctors, some of whom had recent training at the tropical medicine institute in Antwerp, to take up new innovations such as the serodiagnostic card agglutination test for trypanosomiasis (CATT test). The Sudan programme became a kind of haven for Belgians who did not fit into their own country’s programmatic culture in Zaire. Similarly, doctors from this programme reported some of the first field observations of today’s late stage sleeping sickness drugs, nifurtimox and eflornithine (Van Nieuwenhove et al., 1985; Van Nieuwenhove and Declercq, 1981).

WHO global technical reports from this period suggest a reluctance to endorse these technologies for use in country programmes without wider validation (particularly of the medicines (WHO, 1979, WHO, 1986)). By 1983, however, the BDC’s demonstration of CATT test feasibility contributed to a change in global thinking To WHO, the CATT test promised an even better entry-point than simple microscopy to attract a wider network of actors into sleeping sickness control under a framework of integrated healthcare, and Southern Sudan was viewed as politically stable enough to host such a pilot project. The re-emergence of conflict shortly afterwards, however, appears to have moderated some of this enthusiasm (for example, a proposed large-scale bilateral German investment went unfunded). Rather, under BDC leadership and the support of a new national control programme office in Juba, staff in existing NGO-supported hospital-based programmes across the rest of Equatoria were trained and equipped to do passive detection and treatment, but only using simple microscopy. Even with BDC help, the logistics of using the CATT test in this new conflict setting were deemed too difficult.

For individuals in the Sudanese government, the BDC’s use of unconventional technologies appears to have justified rare moments of programmatic regulation or interference in a collaboration which otherwise functioned effectively to win international support. In 1985, for example, the Ministry of International Health in Khartoum threatened to close the BDC programme upon discovering they were using unapproved medicines (which the Southern government condoned for compassionate reasons). In contrast, a perceived unfairness in access to the BDC technologies was behind an investigation by the Southern government. In 1986, the Provincial Governor of Western Equatoria, reportedly tired of international organisations taking unilateral decisions, colluded with an ex-employee of the Belgian programme to embellish reports of a sleeping sickness outbreak in Maridi neighbouring the BDC programme to embarrass the Belgians and demand more attention from the government. A key finding of this investigation was popular demand for tsetse control.

An emphasis on vector control, as well as expanded screening coverage of foci across the Equatoria region, was therefore among the objectives in the Southern-supported BDC’s proposal for a five-year extension of its programme in 1988. Development officials in Brussels, however, declined to renew the programme in a bid to consolidate the BDC’s sleeping sickness work in Zaire and Rwanda. For reasons never known to project leaders on the ground, the programme continued to receive unofficial support, and the centres in Yambio and Juba were able to keep basic medical screening activities going for another two and a half years until fighting reached project areas in December 1990 and the team evacuated to Zaire (interview with former BDC staff, 2015).


From 1986, MSF began to lead its own sleeping sickness interventions for displaced Southern Sudanese in Uganda. Individuals encountering sleeping sickness during this period felt themselves to be operating in a vacuum, without good tools or guidance on best practice (Corty, 2011; d’Alessandro, 2009). In one hospital, MSF staff systematically conducted lumbar punctures on patients to prove to themselves that the Belgian CATT test could be trusted (a practice known from, but not followed since, the
colonial period and contrary to longstanding WHO advice) (Interview with researcher associated with MSF programme, 2015). Eventually MSF engaged in a large global research and advocacy programme around medical innovations for sleeping sickness. Many of these (the CATT, efornithine and nifurtimox) were being used in Southern Sudan, but on a small scale or informally.

MSF emphasised transforming systems to support their use: validating tools in formal clinical trials so that they could be endorsed by WHO and more easily accepted into national programmes, pressing manufacturers to commit to producing medicines and diagnostics at scale and establishing a strong, sustainable global logistics supply chain (Corty, 2011).

Unlike during the war of the 1960s and 1970s, humanitarian organisations including MSF were eventually able to mount a robust response which far exceeded WHO’s 1995 proposal for a renewed network of basic integrated care providers. As we discuss elsewhere (Palmer et al., 2014), the need for complex tools and expertise to control sleeping sickness was one of the factors that attracted MSF to the disease. Through a programme of clinical and operational research, much of it carried out in Sudan itself (Chappuis, 2002, 2004; Balasagaram, 2006, 2009; Maina, 2006, 2007; Priotto, 2008, 2012; Checchi, 2012), MSF developed a system of good practice adapted to the Sudanese context and others like it. Over time, MSF became the global thought-leader on what was considered most ethical in a humanitarian sleeping sickness response. By demonstrating this practice and sharing its tools, MSF drew in other actors to multiply and sustain the response, including international organisations such as Malteser (in Yei since 2002) and Merlin (in Tambura in 1997 and Nimule since 2005), which are still present in endemic areas today. From the early 2000s, the Sudan Relief and Rehabilitation Association (SRRA), the humanitarian arm of the Southern rebels, became involved in coordination. After the end of the war in 2005, the Neglected Tropical Diseases Directorate within the Ministry of Health was formed partially because of the need to coordinate such large-scale responses to sleeping sickness (interview with Ministry of Health, 2014). In contrast, the substantial expertise in tsetse control developed by Khartoum-based academics (e.g. Mohammed et al., 2010), was taken up by neither humanitarian actors during the civil war period nor the Southern government afterwards.

As a medical organisation, it should not be surprising that MSF preferred a primarily medical approach to control, based on population screening and treatment. MSF has never strongly advocated a vector control approach to sleeping sickness (Corty, 2011), and many of the colonial-era approaches, such as forcible resettlement or the taxing of endemic areas to fund control, as advocated by Yambio chiefs in the 1970s, would be antithetical to its humanitarian principles. That said, when MSF first engaged in sleeping sickness control among refugees from Sudan in 1986, its response was strongly influenced by the work of a colonial French military doctor and Nobel Prize nominee, Eugene Jamot (ASNOM, 2001; Louis et al., 2002; Milleliri, 2004). Jamot’s systematic population screening strategy was a good fit with the organisational culture guiding MSF’s emergency medical interventions at this time, which sought to adapt innovations from emergency and military services (Vidal and Pinel, 2011). MSF’s understanding or assessment of local and continental sleeping sickness history was thus specific to its preferred way of working: Jamot had shown that sleeping sickness control was best done via mass screening and the epidemic MSF was seeing could be explained by war interrupting Belgian activities. More mass screening was thus the answer. This is important given that many of MSF’s norms related to sleeping sickness control have been adopted by others and persist beyond the acute conflict phase today (Palmer et al., 2014).

Conclusion

The tumultuous political history of Southern Sudan has meant that efforts to control sleeping sickness there have been both unique and uneven. Be it prophylactic injections, insecticide-treated targets, serodiagnosics or...
new medicines, we have discussed many examples of how, in periods of both conflict and calm, Southern Sudan was seen as an ideal place to test new strategies because of the right combination of endemicity, infrastructure and willing actors. It is also a history that complicates in important ways the general story of sleeping sickness in Africa. For instance, a common narrative is that the post-colonial period saw disengagement with sleeping sickness by the colonial authorities. But Allen (2007) has pointed out that colonial authorities b
colonial authorities b
have the authority to impose fines on people who do not keep paths to their homes clean (Allen, 2007). Punishment (of various kinds) for people who did not attend screenings (and their chiefs) continued until at least 1978. Even today, Zande chiefs in the Tambura area have the authority to impose fines on people who do not keep paths to their homes clean (Allen, 2007).

As well as contributing to a more nuanced narrative of sleeping sickness in the twentieth century, the Southern Sudan case has implications for the ways in which we think about the capacities, blind spots and limitations of international humanitarian actors. If the main story, as we have argued, is the progressive medicalisation of the response to the epidemic, and the neglect of vector control, what are the assumptions that have underpinned that perspective? And what does this reveal about the nature of humanitarian intervention in Southern Sudan and elsewhere? We propose that there are three more general issues that demand further reflection: the pattern of successive actors taking control, an increasing exclusion of indigenous perspectives and knowledge and a preference for portable technologies.

Firstly, the fact that the above narrative can be divided relatively straightforwardly into periods delineated by different dominant actors – the colonial era, the WHO era and so on – is itself revealing. The outbreak and cessation of war led to the involvement of different actors at different times, mostly notably with WHO most comfortable and capable of acting in times of calm, whilst MSF gained momentum – and spurred major control on the part of post-independence African governments, largely because they disliked the coercive practices of colonial administrations (ASNOM, 2001; De Raadt, 2005; Pepin and Labbe, 2008; Laveissiere and Penchenier, 2005). Yet in the Southern Sudanese case, many of the more intrusive practices had been relaxed by the
innovations – in periods of conflict and crisis. As different actors came and went, interest was lost not only in vector control, but also in schemes which integrated disease control and agricultural development. If it is a truism that development and humanitarian actors often fail to adequately learn from historical examples (Davey et al., 2013; Porter et al., 1991), this is especially so when institutional turnover is so marked. It is, after all, harder to learn from the mistakes of others.

This difficulty in securing long-term continuity of knowledge and planning is, ironically, at odds with discussions of the role of NGOs in Southern Sudan in other histories. Tvedt, for instance, argues that the long-term presence of international actors had a ‘crowding out’ effect as ‘NGOs unintentionally contributed to the erosion of the authority of a very weak state’ (Tvedt, 1998: 189). Others have expressed concern that the size and longstanding presence of aid would have a distorting effect, perhaps even contributing to a political economy of conflict (Duffield, 1993; Duffield, 2002; Macrae et al., 1997). Thus, whilst humanitarian actors tackling emergencies have sometimes been accused of causing problems by staying too long, the very different timescales involved in long-term disease control mean that even decadelong interventions end up being too short. Ultimately, this may be a limitation of any humanitarian aid: perhaps only nation states are fully capable of the multigenerational learning and planning necessary to comprehensively tackle complex diseases.

A second revealing feature of this era is the extent to which methods of sleeping sickness control were determined predominantly according to external priorities, rather than sustained consideration of what had worked (or not) in the past. What is so striking about the progressive medicalisation of sleeping sickness control in Southern Sudan is that, with all of the country’s attractiveness to test new innovations, the shift took place seemingly with very little circling back to examine strategy, or reconsideration of the benefits of alternative methods. The clearest example of
this is WHO’s decision to use pentamidisation as a solution to the second Sudanese outbreak defined by actors on the ground as a problem of increased contact with tsetse because of cotton scheme resettlements. Then, when WHO re-entered a decade later, their approach to the third epidemic focused on laboratory capacity-building with seemingly little reflection on whether and why pentamidisation had failed, or whether tsetse control might be appropriate (see Table 3). In rare cases where actors did attempt to rethink their approach (for instance, at various points with WHO in the 1970s and 1980s, the Belgian Development Corporation in 1988 and the unfunded Merlin proposal in 1997), such dissenting perspectives conspicuously failed to find purchase. This seems all the more striking in comparison with, say, the vigorous and wide-ranging debates regarding HIV and Ebola control strategies.

How can this seemingly single-minded pursuit of a narrow strategy be accounted for? We argue that it is related to the weakness of Southern Sudanese institutions. Whilst there have long been powerful actors in global health, social scientists have regularly highlighted the ability of African nations, professionals

Table 3: Sequence of theories about sleeping sickness outbreaks and the predominant control strategies

<table>
<thead>
<tr>
<th>Outbreak</th>
<th>Theories about cause</th>
<th>Control measures taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>1920s</td>
<td>British: Spill-over from neighbouring countries</td>
<td>British: Border control, isolation of communities and patients, tsetse habitat destruction, mass screening</td>
</tr>
<tr>
<td>1950s</td>
<td>British: Population resettlement to support agricultural scheme</td>
<td>British: Mass screening with pentamidisation</td>
</tr>
<tr>
<td>1970/80s</td>
<td>NGOs and WHO: Chaos of war and apathy of international actors</td>
<td>Local government: Tsetse habitat destruction WHO: Capacity-building for lab systems Belgians: Mass screening with new diagnostic</td>
</tr>
<tr>
<td>1990/2000s</td>
<td>NGOs and WHO: Interruption of Belgian mass screening programme</td>
<td>MSF: Mass screening with improved global support</td>
</tr>
</tbody>
</table>

5 This reluctance to engage with (or simply ignorance of) the prior histories of disease control goes hand in hand with a third key trend – a marked preference for portable technologies that avoid political entanglements. By portable, we mean ‘humanitarian goods’ in the sense of both tangible products that provide relief or care of some kind (of which a serodiagnostic tool is a key example) or programmatic strategies (such as mobile teams with prophylactic pentamidine) that avoid the need to build systems and infrastructures. Like other humanitarian goods, such as nutritional food additives (Scott-Smith, 2013), diagnostic tools and mobile teams offer the prospect of a technical humanitarism which need not engage with longer-term questions of planning, livelihoods and sustainability. As Peter Redfield has argued, MSF’s preference for standardised methods, kits and mobile teams ‘represents a mobile, transitional variety of limited intervention, modifying and partially reconstructing a local

5 In the context of neglected disease, see for example (Rumunu et al., 2009; Ruiz et al., 2008), and in the context of land tenure, see Badiey (2013).
environment around specific artefacts and a set script’ (Redfield, 2011: 281; emphasis added). Again, the shift from earlier broad approaches to screening and treatment represents both confidence in the power of improved diagnostics and drugs to tackle a problem, but also the reluctance of humanitarian actors to engage more broadly.

In conclusion, we have argued that Southern Sudan has seen an unusual pattern of humanitarian activity in response to sleeping sickness. The progressive medicalisation we have described was not simply an inevitable outcome as technologies evolved – other major African disease control projects such as malaria, and indeed sleeping sickness elsewhere on the continent, have continued to emphasise environmental methods. Rather, the European-driven, medical and technocratic methodology we identify became progressively more entrenched in response to a particular set of circumstances and assumptions. The perception, accurate or otherwise, that Southern Sudan lacks a tradition of disease control and the presence of (or even medium-term possibility for) health infrastructure has encouraged actors to focus on global tools over domestic systems.

Much has been achieved in controlling sleeping sickness in Southern Sudan, despite the very unpromising circumstances. We certainly hope this history does not read as a chastisement of successive generations of humanitarians who have acted with great courage and integrity. Instead, we argue that the unique circumstances of this case have rendered certain widespread trends in humanitarianism particularly legible, specifically the emergence of innovative tools and portable technologies which have the power to heal and care, but also a tendency to displace other approaches and perspectives. Future projects and research, we believe, must engage with history to explore more integrated approaches, in which transnational flows of expertise and resources can be more precisely calibrated towards the complex contingencies of local need.
References


