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Health work and skills in the last mile of disease elimination. Experiences from sleeping sickness health workers in South Sudan and DR Congo

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ABSTRACT

Human African trypanosomiasis (HAT) is considered a highly promising candidate for elimination within the next decade. This paper argues that the experiential knowledge of frontline health workers will be critical to achieve this goal. Interviews are used to explore the ways in which HAT workers understand, maintain, and adjust their skills amidst global and national challenges. We contrast two cases: South Sudan where HAT expertise is scattered and has been repeatedly rebuilt, and the Democratic Republic of Congo (DRC) where specialised mobile detection teams have pro-actively tested people at risk for almost a century. We describe HAT careers where skills are built through participation in HAT technology trials and screening programmes; in the DRC expertise is also supported through formal rotations in screening teams and HAT referral centres for new health workers. As cases fade, de-skilling is a real threat as awareness of populations and authorities diminishes and previously vertical programmes evolve, re-configuring professional development and career paths and associated opportunities for HAT practice. To avoid repeating the mistakes of the 1960s, when elimination also seemed close at hand, we need to recognise that the 'last mile' of elimination hinges on protecting the fragile expertise of frontline health workers.

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1. Introduction and rationale

In many respects, the control of Human African Trypanosomiasis (HAT), commonly known as sleeping sickness, is a global health success story. It is a story of a battle fought against a deadly disease by generations of health workers operating within under-resourced health systems, often in difficult personal circumstances, but with the backing of a global network of committed health actors, funders and scientists (Burri, 2020). In the last two decades, the number of reported HAT cases has reduced dramatically, by over 97%. The WHO-set objective of eliminating HAT as a public health problem by 2020 has arguably been met, and the global coalition of actors is now working toward the more ambitious goal of stopping all HAT transmission by 2030 (Akazue et al., 2019; Franco et al., 2020; Miaka et al., 2019).

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Most experts working in the HAT field, however, warn that true elimination is far from a *fait accompli*, pointing to the middle of the twentieth Century when elimination also appeared close at hand. In the 1950s and 1960s in Southern (now South) Sudan and in Zaire (today's Democratic Republic of Congo or DRC), the World Health Organisation (WHO), African and European academic institutions and government development departments engaged in scientific knowledge exchange and international, cross-border strategic planning. Innovative technology helped the technical challenge of elimination seem more attractive and feasible (even though some of the new technology eventually proved ineffective, in particular the heavily-promoted use of pentamidine as a prophylactic (Lachenal, 2014)). Practically, however, HAT elimination was hampered in Southern Sudan by armed conflict when control activities were suspended, HAT experts fled or were evacuated, and large-scale displacements made monitoring cases and understanding transmission nearly impossible (Palmer & Kingsley, 2016). In Zaire, HAT control was severely weakened by the financial difficulties of the 1980s and nearly totally collapsed as the country descended into war in the 1990s.

Since then, the HAT field has benefitted from the introduction of new technologies, notably, serological card agglutination trypanosomiasis tests (CATT) and rapid diagnostic tests (RDTs) which increase the sensitivity of previous screening methods based on manual palpation of lymph nodes at the neck and shoulders, as well as nifurtimox-eflornithine combination therapy (NECT) and the orally-administered fexinidazole which makes HAT treatment much safer and easier to administer. The threat of armed conflict remains a particularly nefarious challenge for South Sudan. Today, however, HAT elimination everywhere is also dogged by a more existential challenge relating to the disappearance of health worker expertise alongside the disappearance of the disease (Palmer et al., 2020). This fear is born of the difficult experiences of HAT actors on the frontline. They have spent decades rebuilding human resources infrastructures after the previous failed attempts at elimination, and through major political changes in the ways endemic countries are governed and the ways global health actors engage in health systems building.

In this paper, we reflect on the ways health workers at the frontline of HAT control have navigated the constraints, contradictions, and dilemmas they have faced so far in what is arguably quite a successful global elimination programme. We offer insight for what is likely to be an arduous last mile in the road to HAT elimination. We do so by examining HAT control in two country case studies, the DRC and South Sudan, which are central to the global struggle for HAT elimination but present very different models of global health engagement. Theoretically, we also engage with three main strands of literature on HAT, knowledge generation, and frontline health work labour, which we briefly review next.

1.1. HAT, knowledge generation & frontline labour

Operating at one end of a vast global health ecosystem, health workers find themselves as the ultimate implementers of solutions developed globally. Yet, research on social experiences of HAT control is rare, particularly explorations of the lives and experiences of frontline health workers – the coordinators, doctors, clinical officers, nurses, laboratory technicians, and support staff involved in diagnosing, treating, educating and reporting on the disease (Jamonneau & Bucheton, 2014; Palmer, Surur, et al., 2014). A few recent papers depict highly professional HAT workers working in very challenging conditions as part of vertical programmes (Falisse et al., 2020) or in more ‘passive’ encounters with HAT (Lee et al., 2020; Palmer, 2020; Palmer et al., 2020), and concerned with the effectiveness of the global health-inspired approaches of elimination that are being implemented.

The more general literature on health work near the ‘end’ of a disease is equally rare (Klepac et al., 2013); it recognises that the ‘last mile’ of elimination hinges on the labour of frontline national health workers to keep control programmes running and prevent the resurgence of the disease. Looking at ‘post-Ebola’ West Africa, Kingori and McGowan (2016) show health workers facing difficult financial and emotional situations after the withdrawal of international aid while

Loevinsohn et al. (2002) explain that, in the last stages of polio elimination, health workers are faced with a higher workload that affects their ability to provide other health services.

Crucial to healthcare labour on any disease, but particularly for a rare condition like HAT, is healthcare workers' deployment of tacit, intuitive and experiential knowledge of the health systems in which their programmes work as well as the local social context in which disease spreads (Palmer et al., 2020). Unlike 'explicit' or theoretical knowledge which may be taught in a textbook or guidance document, tacit knowledge, being neither fully conscious nor written into policy, is something which is learnt through practice and over time, but should also be maintained through periodic exposure (Lam, 2000). As disease knowledge is contained at both a collective, as well as an individual level, system-wide interventions and challenges can have knock-on effects for individual health workers' learning, such that a lack of or threat to knowledge and awareness at one level also affects the other levels (Warne & Mukhier, 2021). Together, these literatures suggest the importance of looking closely at the careers and livelihoods of both those who have engaged episodically with HAT and those whose lives revolve around it (Lutumba et al., 2005), attending to ways HAT-related knowledge is both generated and maintained within wider country 'systems'.

1.2. HAT in the DRC & South Sudan

The DRC and South Sudan are currently the first and sixth-most HAT endemic countries in the world, respectively.¹ The *gambiense* variant of disease predominates, with most cases fatal unless patients access treatment. The disease lasts around three years, affecting several bodily systems and with neurological effects on the mind. With the control of the vector, the tsetse fly, difficult to control in the rivers and forests of the DRC and South Sudan, HAT control in both places thus tends to rely on medical interventions.

In the DRC, HAT attracted considerable attention from the Belgian colonists, who used it in a vast enterprise of social engineering (Lyons, 2002) and also set some guiding principles for HAT control that still have resonance today. They include a mostly vertical approach to the disease. The *Programme National de Lutte contre la Trypanosomiase Humaine Africaine* (PNLTHA) spearheads and organises HAT control activities across the territory and coordinates research with the support of external partners –the most significant in terms of resources at the time of our research were the Bill and Melinda Gates Foundation, which funded (among others) projects led by the public-private partnerships Drugs for Neglected Diseases initiative (DNDi), as well as the Foundation for Innovative New Diagnostics (FIND), the Institute of Tropical Medicine, Antwerp (ITM), and the Belgian government, which funded WHO and ITM programmes. The organisation of the PNLTHA is mapped onto the structure of the DRC's health system, with specific responsibilities assigned to national, provincial, and peripheral-level staff. The frontline consists of a limited number of generalist health facilities equipped to passively screen HAT and treat patients, and, importantly, specialised HAT treatment and detection centres. They are a key point of care for HAT patients and a hub for specialist diagnostic expertise. They also serve as an important training ground, coordination, and referral centre for the itinerant teams of active screening teams made up of laboratory staff, clinicians and logisticians who are expert in identifying HAT and reaching communities where it is endemic. In 2016, the PNLTHA was deploying 30 mobile teams of 7–9 people and 18 mini-teams on motorbikes in a system of 20-day shifts (followed by 10 days of rest and reporting), enabling each to examine around 66,000 people / year from the most endemic areas (PNLTHA, 2016, 2018).

South Sudan also has had a dedicated national HAT programme since 2005 and, in fact, the Neglected Tropical Diseases Directorate within the Ministry of Health was formed at the same time 'partially because of the need to coordinate large-scale responses to sleeping sickness' (Palmer & Kingsley, 2016). It, too, saw large-scale HAT work in the colonial period by the Anglo-Egyptian Sudan government. Control in the second half of the century was severely hampered by decades of war between the north and south until the engagement of emergency medical non-governmental

organisations (NGOs) in the 1990s (Palmer & Kingsley, 2016). At the time of research, only five sites in the country offered HAT detection and treatment, mainly government hospitals with a current or historical NGO partner. Mobile teams and ‘active screening’ have been sporadically organised with NGO, WHO and FIND support, but most of South Sudan’s HAT screening is ‘passive’, based on health workers’ or patients’ own suspicion of disease because of presenting symptoms.

In both countries, while significant efforts have sometimes been made to strengthen diagnostic expertise outside of HAT specialised centres, particularly with the recent introduction of rapid diagnostic tests for HAT, many leaders in the global HAT community maintain scepticism about the competence and vigilance of non-specialist Health Care Workers (HCWs) to recognise this usually rare disease in context and amidst competing priorities (Mitashi et al., 2015; Mulenga, Boelaert, et al., 2019; Palmer et al., 2020; Wamboga et al., 2017).

2. Methods

This paper brings together data collected as part of different streams of the Investigating Networks of Zoonosis Innovation project at the University of Edinburgh between 2012 and 2018. In HAT terms, it came in the time when RDTs were trialled and eventually implemented, and between NECT (introduced in 2009) and new oral medicines. The argument also unavoidably draws on observations conducted in the last two decades by the authors, as most have been involved in HAT research projects during that period. Two of the co-authors, Alain Mpanya and Elizeous Surur, have worked closely and in the field with the DRC and South Sudan HAT control programmes.

The main material related to South Sudan was collected in 2013–2014 and consists of five, sometimes repeated, long interviews with key personnel at the Ministry of Health and six long interviews with foreign and South Sudanese staff members of international organisations active in the fight against HAT. It also builds on some of the material presented in an earlier paper (Palmer et al., 2020), which was primarily concerned with HAT diagnostic knowledge and is based on data collected in Nimule in 2008–2009.

In the DRC, the main research was conducted in February 2018 in the (former) province most affected by HAT: Bandundu (present-day Kwilu, Kwango, and Mai-Ndombe). Interviews were carried out with twenty-one respondents purposefully selected to reflect staff occupying a range of key positions in mobile teams (6 team leaders, 1 secretary, 2 technicians and 2 community outreach workers), treatment and detection centres (1 nurse at a specialised treatment centre, 3 working at treatment centres attached to a general hospital and 1 at the higher-level provincial hospital, and 1 nurse working at a health centre equipped with a treatment centre) and provincial coordination (2) and supervision (2). Ad hoc complementary information came from ten interviews with HAT programme staff at the central level and nine with staff of members of international organisations, all mostly conducted in August 2017.

The main lines of questioning in the case of South Sudan included the relation to HAT technologies and the history and networks of HAT control and research. In DR Congo, the political economy of HAT research and control and frontline workers’ experience and perspective of the ‘near elimination’ of HAT were the key themes. A Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist is found in the supplementary material.

The analysis started with the coding of the Bandundu material (which sought to include participants of different ages and profiles), focussing on the skills and expertise of health workers, their acquaintance with the processes and technologies of global health, and their professional trajectories. An iterative approach was used, reading through the material first to define key categories, and then coding the material using NVivo. The South Sudan material was then analyzed using the same lens and put in perspective with DR Congo. The analysis focused on systematically describing the trends and mechanisms at play in each category and comparing the situation between the two

settings. The ethics committees of the universities of Edinburgh and Lubumbashi authorised the research.

3. Findings

In both South Sudan and the DRC, there was a clear perception that HAT control is a long-term and collective struggle. The interviewees referred to *generations* of HAT workers and conveyed the sense of feeling part of a larger history and in a mission for their country. In South Sudan, for instance, a HAT manager explained the importance of building a HAT ‘success story in my new-born country’ [South Sudan 2, 2015].

3.1. HAT frontline workers: skills development

Besides learning-by-doing, which the participants repeatedly stressed as crucial, we identified five often complementary means of acquiring HAT skills: (1) academic training; (2) HAT programme ‘in-house’ and (3) third-party training on specific tools and approaches; (4) placements and formal internships in HAT mobile teams and/or HAT referral centres; and (5) placement in and support to clinical trials.

Medical and nursing schools in the DRC have long included HAT diagnosis and patient management in their curricula. However, as a DRC HAT provincial coordinator explained to us [DRC 9], the information in non-specialised curricula often remained outdated. It did not allow students to properly comprehend what ‘modern HAT work’ entails –i.e. the most recent drugs and treatments. In (South) Sudan, the interviewees explained that either the curriculum described HAT as a ‘historical thing’ [South Sudan 1, 2014] or even that, as a former director of the HAT programme said, ‘we never talked about HAT, it was not part of the curriculum’ [South Sudan 2]. The latter is because the only option for those who undertook medical studies during the war was to go to Khartoum, in the north, where HAT is not a concern. Some master’s level education in public health in Kenya became available after the war, funded by the American Centre for Disease Control. It covered HAT but was only available for a handful of people from the Ministry of Health. In the DRC, formal education in HAT at certificate, masters, and PhD levels was sometimes possible at the Institute of Tropical Medicine in Antwerp and as part of the research projects [DRC 8].

Further training opportunities differed between the DRC and South Sudan. In DRC, where the PNLTHA was widely described as a ‘solid vertical programme’ (Falisse & Mpanya, 2022), staff members starting in a frontline position went through a one-week clinical course [DRC 4] organised by the research and learning department of the PNLTHA and the relevant provincial PNLTHA coordination. The National Institute for Biological Research (INRB) provided support for the laboratory part of the course. Additional training sessions, which seek to upskill staff members with the latest diagnosis and treatment approaches, are also organised in-house by the PNLTHA for those already in post [DRC 7]. Similar opportunities did not exist in South Sudan where international organisations were directly involved in HAT control activities and where investment in HAT at a national programme level was sometimes described as ‘political’, since HAT did not affect the areas of origin of most southern political leaders.

The main formal non-academic training opportunities in South Sudan came from external partners. The NGO Médecins Sans Frontières (MSF) provided key HAT basic training, especially during the civil war when nearly all sleeping sickness foci were in rebel-held areas. It also enabled opportunities for local and cross-border learning, particularly when the war and post-war autonomous agreements prevented the Southern Ministry of Health to engage with other national programmes formally. HAT expertise, however, remained rare, and Malteser NGO staff members explained how they struggled and worried that they would deplete other parts of the country from crucial capacity when they needed to recruit HAT experts to re-

start their programmes in 2014 [South Sudan 3, 2014]. By contrast, in the DRC, after turbulence in the 1990s, the national HAT programme had recovered the upper hand in HAT control operational activities by the early 2000s (Falisse & Mpanya, 2022), with NGOs relegated to financial and research support.

Both countries benefitted from the biennial WHO international HAT course targeted at health cadres –and to which the PNLTHA would typically send two to four doctors. Such training and attendance at WHO and global HAT platform events were described with pride by frontline workers from both countries. Most interviewees stressed a personal connection to global health institutions and feeling part of a wider HAT global health community because of it. The HAT platform, an offspring of work at the global health level to improve coordination and advocacy in HAT facilitated by DNDi, helped build in-country research and policy skills and facilitated the circulation of national HAT experts to neighbouring country programmes. Many came from the DRC to the great pride of the interviewees, who took it as a testament to Congolese HAT expertise.

The training by external partners around HAT drugs and diagnostics clinical trials was especially significant in the DRC. The training activities and the advice and supervision provided during the trials covered research (e.g. ethics, research design, reporting) but also organisational and clinical work. These interactions constituted an important opportunity to share and exchange knowledge and evolve practices, notably with the multiplication of the number of trials from the early 2000s. The large DB289 trials of the early 2000s are a prime example of such ‘training through clinical trials’, with an international researcher present in the DRC describing them as ‘massively improving the diagnostic skills and ability to treat patient rationally’. Some of the respondents explained that research programmes were their entry points to a career in HAT [DRC 10], and after serving as a researcher or a research assistant, they moved into control and leadership opportunities within the PNLTHA. The journey also sometimes went the other way round (Mbo et al., 2020). These exchanges, and the embeddedness of research into control programming (Falisse & Mpanya, 2022), were very significant for HAT skills building in the DRC. Clinical trials were less numerous in South Sudan but FIND-sponsored research projects on rapid diagnostic and PCR tests included important provisions for lab staff to receive theoretical and experiential training at the Juba Training Hospital and a new national reference lab. Interestingly, at the time of research, there were no plans to extend such training opportunities to frontline health workers who were thought to be experienced enough –as a Malteser staffer explained: ‘the RDTs are just like malaria, so they don’t need to spend time teaching HCWs, and everyone at Yei hospital, at least, knows very well how to recognise [syndromic] cases of HAT’.

Last but certainly not least, actual practice (learning-by-doing) was widely recognised as the most important way for HAT workers to develop their skills; indeed, many of the interviewees started as HAT programme interns [DRC 3] during their studies and those who switched to HAT work later in their career usually started with an internship period. Here again, the practices diverge between South Sudan and the DRC. In the DRC, the main placements were (and still are) directly organised by the PNLTHA, and new recruits are required to undertake an internship. For frontline staff, it is 3–6 months in a specialised detection and treatment centre or a mobile unit, while for cadres at the provincial and national level, the 3-6-month internship is spent rotating between different services (central services, provincial coordination, and mobile units). In South Sudan, NGOs also occasionally organised such placements in hospital HAT departments for nursing and medical students. Most opportunities for a supervised exposure to HAT, however, remained less formalised –and the main chance for training has typically come through participation in the active screening campaigns:

‘Active screening is a fantastic way of training people, because you’ve actually got cases. It’s much better than getting people to sit in a classroom and talk about it in theory where it goes in one ear and goes out the other. ... obviously we haven’t found as many cases as we expected, but there’s still a very high value in doing if it’s put the spread of the disease back a few years. MSF isn’t going to come back here, I wouldn’t have thought, for 5 or 10 years.’ [South Sudan 4, 2015]

3.2. Maintaining HAT skills over decades

South Sudan and the DRC offered different career options for those trained in HAT. In South Sudan, careers involved circulating between NGO- or donor-supported programmes that did not always have a HAT-focus. They largely depended on the funding available through NGO and government channels. HAT specialisation also provided a route for some doctors, medical officers, nurses, and laboratory technicians to move into NGO or Ministry HAT programme management positions (when they were available). At the time of writing (December 2021), HAT programme coordination was still split between a consultant position funded by FIND and a ministry position supported by WHO.

In the DRC, the well-functioning vertical programme allowed more stable HAT careers to develop at both the frontline and coordination levels, inside the programme, as this mobile unit leader explained:

'I am a health technician and the head of a mobile unit. I started working in 1972, I worked as a nurse microscopist and then afterwards when the programme found that I could have responsibilities, I was appointed head of the mobile unit.' [DRC 7]

The mobile teams' holistic exposure to multiple facets of HAT work also facilitated upskilling or retraining of people in new positions. HAT workers remained, by and large, separated from the rest of the Congolese health system. Their connection to global health actors further accentuated such a distinction by creating a social network outside the Ministry of Health.

A second element that distinguished HAT careers in South Sudan and in the DRC was the sense of purpose and vocation. In South Sudan, several people talked animatedly of the many initiatives of the 1990s and early 2000s, but by 2014 HAT was seen as a disease of interest to a few rare healthcare workers [South Sudan 6, 2014]. A South Sudanese member of an international NGO explained:

'HAT was dying as a disease control programme. It actually died. Because it was supposed to continue as a control programme, but as soon as it was handed over [by NGOs] we didn't see much effort in terms of diagnosis, treatment, education. No one was talking about it anymore.'

He concluded, cynically but echoing many NGO informants, 'for things to work in this country, it needs an NGO.' A return to armed conflict since December 2013 had unfortunately reinforced this perception among many.

On the contrary, in the DRC, the informants demonstrated a strong sense and pride of being part of a 'HAT family' (also see Falisse et al. (2020) on this point) –and one that has expanded to become more global in recent years. As a provincial coordinator stressed [DRC 9], this HAT family builds on both the sense of sharing a common purpose –the elimination of the disease– and the nature of work, especially in the case of the mobile unit staffs who 'spend more time with their unit than with their [biological] family'.

3.2.1. The changing nature of HAT work during elimination

Health workers in both countries understood HAT infrastructure as fragile and aid-dependent. For instance, in the DRC, international support allowed a salary top-up of US\$ 85–165 per month for mobile unit staff (depending on their position), plus an additional US\$ 6/day when in the field. This amounted to more than official pay, which is also regularly delayed (sometimes by years). In South Sudan, an NGO manager summed up the view held by many of an almost cyclical process where funding dwindles as cases go down and then rebounds because short-term planning leads to a resurgence in case:

'The country was fragile, and all HAT programmes were internationally run. The funding depended on prevalence. HAT prevalence was both going down, and very difficult to gauge accurately. From an equity point of view, however, treating even a small number of cases is economically justifiable, because of the knock-on economic costs. Nevertheless, most actors left because of the cost concerns. As they left, prevalence went up.' [2013]

The fragility is not only financial. In the DRC especially, frontline workers expressed a clear concern regarding the teams' and individuals' own abilities to maintain their technical expertise in HAT. As the head of a treatment centre explained:

'Our teams diagnose less and less and, therefore, the laboratory workers get less and less used to having trypanosomes [to work with]. It becomes a trap for someone who can go a year without seeing trypanosomes; there is now a much higher risk that they will miss a trypanosome that would be in his field [of view, within the microscope]. So capacity building becomes a challenge that can compromise the evolution towards elimination.'

In the last two decades, the nature of HAT work has changed substantially, owing to the epidemiological situation, medical advances, and programmatic changes. All benefited from substantial global health attention and funding (Falisse & Mpanya, 2022; Mbo et al., 2020), involving the inclusion of HAT in the global NTDs movement and collective drive towards NTD elimination.

On the one hand, the decrease in cases has significantly reduced workloads in hospital wards and specialised screening centres that manage patients identified by the mobile teams [DRC 3]. As a provincial supervisor (doctor) in the DRC summed it up [DRC 15]:

'The workload has decreased. Injections [for administering treatment] were a lot of work, and above all, the ward was not well equipped. I was abandoned; there was no one to come and visit me. I had to sweep up first, then talk to the patients, all that; and then give the injections.'

On the other hand, while HAT wards may have become calmer, the work of the mobile unit staff remains laborious. One of them [DRC 1] explained the situation contrasting the early 2000s when they would work a double shift –spending two months in a row in the field– and identify a satisfying 415 cases with the present situation in which they would find three to four cases at most [DRC 4]. However, as he further explained, it takes as much work, if not more, to screen and find a couple of cases in this new context. In fact, teams reported extending their shifts and 'keep pushing' to find cases to have something to show for their work.

3.3. The new central issue: Infrastructure for case detection

Substantial progress in HAT treatment has been made in the past two decades, and the general feeling at the frontline is well summed up by a mobile team leader in the DRC [DRC 6]: 'on the treatment side, we succeeded'. NECT, a safer alternative treatment to melarsopol, which had a 5% mortality rate just associated with the medicine itself, was a substantial emotional relief for HAT workers.

Once this problem was solved, however, and as the numbers of patients went down sharply, 'finding patients' –both for elimination and for the clinical trials to improve treatment further– became the defining issue of HAT frontline work. It was compounded by the declining public engagement with HAT programmes and related decline in HAT diagnostic expertise in the general population.

In the DRC, the respondents all explained that working with the population and politico-administrative authorities (who are attuned to shifting public priorities) has become harder. They cited as root causes the general reduction of interpersonal trust between people and between people and government in today's DRC (also see Falisse et al., 2020) and the lack of widespread awareness about the threat posed by HAT. A mobile unit worker captured the general feeling, explaining that:

'there was a time when people knew what sleeping sickness was. Perhaps at that time, there was awareness but today, I assure you, [...] it is not even half, it is less than half.' [DRC 1].

In South Sudan, where a return to civil war has interrupted HAT activities at the frontline and engagements with global health actors and funders, HAT workers believed there was a general decline in HAT. However, they reported having to guess the trends using their local contextual knowledge of endemic population behaviours; both control activities and data collection are

difficult, and insecurity often prevents engagement with the population. As a WHO focal point explained:

‘if I compare the current data and last year’s data, the numbers are kind of coming down [...] [but] It could be some patients have not been coming [...] In the endemic areas like Source Yubu which have been affected by the [Lord’s Resistance Army] rebel activities [...] people are not able to come out to seek treatment in the health facility.’

Across the board, the decline in numbers was bringing hope to the respondents but also fear. Deeply ingrained and fed by the realisation that HAT awareness is declining is the fear that ‘some patients have not been coming for treatment’ [South Sudan 6, 2013]. This helps understand two concerns of frontline HAT workers that rarely feature at the level of global HAT discussions. The first is the exclusion of certain areas from mobile screening, especially in the DRC [DRC 6; DRC 7]. It is influenced by the global health actors’ push for cost-effectiveness modelling focussing on actively screening only in areas of disease risk, but the frontline HAT workers we met struggled to understand that sufficient information exists to make such decisions when the overall coverage by mobile units is decreasing. The second is the still limited level of integration between the HAT vertical programme and the rest of the health system. As a provincial coordinator explained [DRC 18]:

‘there is also the integration element [HAT programming fitting into the wider health system], which is still stagnating, even if we are making a lot of efforts, but so far, we can say that [...] there are health zones where activities are almost non-existent [...] This means that there are many prerequisites that need to be put in place, that need to be relayed before we can achieve elimination’.

In other words, a risk many interviewees point to is that the key mobile teams infrastructure that supports health workers and communities to maintain HAT diagnostic expertise is being weakened while there is not a new, robust system in place yet. In South Sudan, the same question of integrating vertically-run HAT services appeared to be the only solution in the face of diminishing funding for the disease and, as in the DRC, it also raised concern. A worker in the Ministry of Health believed that HAT personnel felt integration would devalue their expertise:

‘At this time, some HAT programmes were at risk from integration. For instance, the MSF-Spain clinic in Yambio had a 32-bed ward, with separate staff, yet only 2–3 patients at a time. Meanwhile, other wards were overcrowded. State ministries allowed a trial of integrated services. Some staff were disgruntled, they felt that it was devaluing their expertise and prestige’ [South Sudan 5, 2013].

For these HAT workers, separate HAT treatment centres were valuable in that they provided vital hubs of expertise for treatment and lab work which was quite complex. Ultimately, however, within a model of emergency-oriented, externally-funded NGO service provision which dominates health system planning in South Sudan, the sustainability of such HAT centres of excellence was hard to achieve. As a result, these centres tended to close, creating vulnerabilities to keep key staff in position.

3.3.1. Diagnosing HAT

Detection of HAT has long been a time-consuming technical task, and a core skill of HAT workers. Historically, the initial screening was done by examination of venous blood or cervical gland fluid via direct microscopy. CATT tests came as a substantial improvement, especially in mobile units, but still required cumbersome logistics. Our research came as RDTs –a prime example of the sort of new technology enabled by global health mobilization– were being introduced. Our interviewees presented them as a possible game-changer, as with this NGO representative in South Sudan:

‘RDTs will be in facilities and used by health workers who never thought they could get involved in sleeping sickness. I believe RDTs will be very popular among patients at the PHCUs [Primary Health Care Units].’

RDTs are thermostable and can be used in almost any circumstance, with increased reliability and ease of use compared to CATT [DRC 10]. While they do not eliminate the need for resource-intensive parasitological confirmation, they make the initial screening easier. In South Sudan, RDTs revitalised the push for bringing people with HAT expertise back together to work on a shared programmatic objective along with an essential infusion of funding and infrastructure investments. In the DRC, RDTs allowed the deployment of smaller mobile units going on motor-bikes [DRC 18], which are able to reach the population more directly than with the heavier team (without mass events). It remains to be seen, however, how this new, lighter mobile structure addresses team and community complaints of HAT case search fatigue and the generation of health worker HAT expertise.

4. Discussion

The Congolese and South Sudanese health workers of our study made HAT work their careers. They are the institutional memory of disease control efforts (Wenzel Geissler et al., 2016). They developed specific and relatively rare skills, which in South Sudan were often acquired, maintained, and developed through work for international NGOs that long constituted the backbone of HAT control in the country. The war and the absence of a robust national HAT programme until recently means that HAT careers were often interrupted and expertise often hard to (re) mobilise. By contrast, the DRC's national (vertical) HAT programme, which consolidated in the late 1990s after a decade of disarray, coordinated and structured international HAT interventions and clinical trials in the country and allowed HAT careers to flourish, with internal promotions in mobile units and coordination structures.

Advances in HAT medicines and detection are a source of pride in global health circles (Burri, 2020) and we see such pride manifested among health workers too; they express a strong feeling of being part of a wider community through their control work but also through their association with international trials. New HAT technology relieved burdens on health workers in HAT referral centres and, to some extent in mobile teams. However, as the joint efforts of HAT national programmes and the global HAT community paid off and the number of cases decreased, the nature of HAT work changed, especially for mobile units that felt pressure to work harder to find the rare few cases amidst a context of declining public interest in the disease. The key challenge, according to HAT workers, was not so much anymore with the appropriateness of the medical technology but much more the rapport with the population, and the changing relationship with the local authorities who are key in supporting their struggle (Palmer et al., 2017). This dimension is rarely highlighted in the policy and academic discussions on HAT, but it will not be new to observers of other disease elimination campaigns such as polio (Larson & Ghinai, 2011) or leprosy as in the work of Warne and Mukhier (2021). The latter highlight, and we concur with them, the value and expertise of former patients to shore up the gradual loss of disease expertise in the field. While it may be tempting to rely solely on health worker education to elaborate new HAT health system practices, the role that publics (endemic communities) can play in prompting screening, co-creating diagnoses and therefore building expertise in healthcare workers should not be dismissed (Palmer et al., 2020). An open-door policy for testing (Palmer, Kelly, et al., 2014) seems crucial here; it may help reduce the gatekeeping role of health workers and enable populations to take a more active role in HAT symptom sense-making and diagnosis. It, however, requires a well-functioning passive screening infrastructure, which still needs to be expanded and reinforced in both countries.

Focussing our research on the perspectives of health workers also helps demonstrate why a multi-dimensional approach to programme design is important for elimination. It is not as 'simple' as switching from a vertical to a horizontal approach to disease control. In the DRC, as in South Sudan, active screening is an approach for HAT control and a prime channel for HAT health workers to train and acquire skills (the DRC HAT programme clearly understood this as it had institutionalised internships in mobile units for new staff members). Active screening is potentially

more important in contexts like the DRC's where very few HAT patients present to treatment centres in the face of low institutional trust in static government facilities which charge high fees despite being under-provisioned, and in South Sudan's context where insecurity means patients cannot safely seek care that requires travelling long distances. Ending such programmes is seen by health workers as a major de-skilling threat and constitutes a risk of losing key engagement with community leaders and people.

This is not to say that passive screening efforts should not be pursued. Quite the contrary, and in line with a growing literature, passive screening will be key for HAT elimination and needs to be developed (Cattand et al., 2001; Palmer et al., 2020), but the DRC respondents echo the literature in explaining that the road will be long (Mulenga, Lutumba, et al., 2019). This is not dissimilar to polio and smallpox campaigns (Bhattacharya & Dasgupta, 2009; Greenough, 1995; Larson & Ghinai, 2011). In contrast, in South Sudan, the integration of HAT screening within primary care using RDTs has become a solution for a 'dying programme' by providing a policy goal and increased resources with which to value the expertise of individual HAT experts and bring them into managerial and training posts. These newly configured RDT-based programmes, however, face novel challenges in engaging non-expert health workers and communities in a new form of testing. The DRC and South Sudan experiences also echo the recommendations of Warne and Mukhier (2021) on leprosy, who stress the need to both extend disease expert training to more health workers while simultaneously valuing and reinforcing expert knowledge networks and hubs (e.g. at referral centres).

Global health strategies for HAT elimination that rely on sophisticated modelling and ever-improving testing and treatment technologies are viewed by HAT health workers in the DRC with interest and sometimes with concern. All experts in their own right, the health workers' perspective is based on an understanding developed over decades of work in HAT of what has been done well and the herculean effort it takes to rebuild structures when they have been lost. They worry about the risk of dismantling the human resource structures represented by mobile teams, and the training opportunities they have provided over decades for the DRC health workforce, which will continue to be needed to achieve true and lasting HAT elimination.

5. Conclusion

Our study of HAT frontline work invites careful consideration of the value of practical field expertise built up in teams and networks. At different times and in two countries, these networks appear both fragile and resilient, much as expertise itself can shrink, grow, die, or survive within individuals and groups. While global health actors appear preoccupied with wasting resources on screening in low-risk areas, frontline health workers see a risk calculus involving the social relations of HAT service provision and control which enable these HCWs to keep their diagnostic practices alive. There are clear limitations to our study that misses the population's perspective and only covers a small sample of HAT workers in two distinctive contexts. However, we believe that a more systematic understanding of frontline work and its various manifestations is important not only for enabling the last mile of HAT elimination but also for supporting the elimination of other NTDs that are often best known only by a small, specialised, part of the health workforce.

Note

1. <https://www.who.int/health-topics/human-african-trypanosomiasis#tab=tab_1>

Disclosure statement

Erick Mwamba Miaka currently serves as the director of the DRC's national HAT control programme (the *Programme National de Lutte contre la Trypanosoma Humaine Africaine*, PNLTHA). His tenure started after the period

under consideration in this article. Alain Mpanya and Elizeous Surur have held various appointments with HAT control and research programmes in the DRC and South Sudan, respectively.

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