

Drug toxicity and cost as barriers to community participation in HAT control in the Democratic Republic of Congo

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Summary

INTRODUCTION Active case-finding programmes by mobile teams are the cornerstone of West African Human African Trypanosomiasis (HAT) control. Low attendance rates of screening and low uptake of treatment after diagnosis are major problems. The objectives of this survey were to explore community perception of HAT, to assess acceptability of control activities and to identify barriers amenable to intervention.

METHODS In September 2004, we conducted 33 focus group discussions with beneficiaries of the HAT control programme among various ethnic groups in two ecological settings (savannah and fluvial) of the Democratic Republic of Congo.

RESULTS The population had a very detailed knowledge and understanding of HAT transmission, utility of screening, symptoms and treatment. Melarsoprol treatment was feared for its side effects. The sudden death of previously asymptomatic people during treatment was attributed to witchcraft, to which one becomes more vulnerable when the diagnosis is disclosed in public. Lack of confidentiality was also a problem because HAT carries a stigma as a mental disease. Lumbar punctures, especially when performed in public, were disliked but less feared. Financial barriers were a major obstacle for many patients.

CONCLUSION Less toxic drugs, lowering financial barriers and improving confidentiality would have considerable impact on the participation in population screening for HAT.

keywords Human African Trypanosomiasis, accessibility, acceptability, community participation, perception, *T.b. gambiense*, Democratic Republic of Congo

Introduction

Human African Trypanosomiasis (HAT) is a slowly progressing fatal disease with few or no specific symptoms in its initial stage (Burri & Brun 2003). Patients who consult when the disease is already well advanced may have irreversible brain damage and require more expensive and dangerous treatment. They also pose a threat to the community owing to the fact that they were infectious to tsetse flies for a prolonged period (WHO 1998). Therefore, the population at risk is screened by mobile teams at regular intervals to find cases as early a stage as possible.

Active case finding was successful in several countries in the past decade: reduction of HAT prevalence to very low levels was achieved in Uganda and Sudan (Paquet *et al.* 1995; Moore *et al.* 1999; Moore & Richer 2001). In the Democratic Republic of Congo (DRC), the HAT population screening programme had a good impact in the northern Equatorial province but its effect was limited in

other provinces such as Bandundu and Kasai in the period between 1998 and 2003 (Lutumba *et al.* 2005b). Robays *et al.* (2004) showed how much of the potential impact of population screening is lost because of low participation rates and patient delay after diagnosis. The compulsory nature of the HAT screening of colonial times was abolished after independence. In the period from 1997 to 1998 population attendance rates of HAT screening in DRC were on average 75% but showed large variability ranging from 20% to 99% (Robays *et al.* 2004).

Few studies focus on the perception that people have of the screening programmes, of treatment facilities and of HAT care and its relation to health-seeking behaviour. Gouteux & Malonga (1985) describe how high cost of treatment leads to patient's refusal of care. Odiit *et al.* (2004) assessed patterns of health-seeking behaviour for sleeping sickness caused by *Trypanosoma b. rhodesiense*. Other studies focus mainly on community participation in vector control (Gouteux & Malonga 1985; Leygues &

Gouteux 1989; Okoth *et al.* 1992). A better understanding of the factors that determine attendance in active screening is needed to identify the bottlenecks and make a HAT control programme overall more effective.

We studied community perception of HAT and the acceptability of interventions amongst beneficiaries of the HAT control programme in DRC to identify barriers amenable to intervention and to propose possible improvements. We considered focus group discussions (Merton *et al.* 1956) as the most appropriate method assuming that in a rural setting group dynamics play an important role in decisions about participation in public health interventions.

Methods

Study area and control programme

Bandundu was chosen because it is the province in DRC where most cases were reported in 2004 and where the national control programme implements a large active case-finding programme. Focus group discussions were conducted in 12 different villages that were purposively selected in four health districts, Bandundu (district), Nioki, Mushi and Bagata (Figure 1). The villages belonged to one of two different types of ecology. In the savannah setting (eight villages), people live mainly from subsistence farm-

ing, often encroaching into nearby forest. In the fluvial setting (four villages) people supplement subsistence farming with fishing and sometimes engage in petty trade on the river banks.

Thirteen mobile teams are active in the province, each with its own, well-defined action radius. They make excursions of 20 days each month, going from village to village. The team sends 2 days prior notice by a messenger to announce their arrival, to discuss organizational matters with the local village chiefs and to mobilize the population. The people are screened with the Card Agglutination Test for Trypanosomiasis (CATT) (Magnus 1978) and all persons with a positive CATT test who are parasitologically confirmed are referred to a HAT treatment centre. When we conducted our study, every person screened had to pay a small fee for the 'screening card', and for HAT treatment a contribution corresponding to the value of one basket of manioc was asked from the patient. Median participation rate in HAT screening in the villages studied was 75% ranging from 49% to 92%; for two of the villages no data were available (Source: monthly reports of mobile teams).

Selection of the participants

Upon arrival in the village, we contacted the village authorities, explained the purpose of the study and

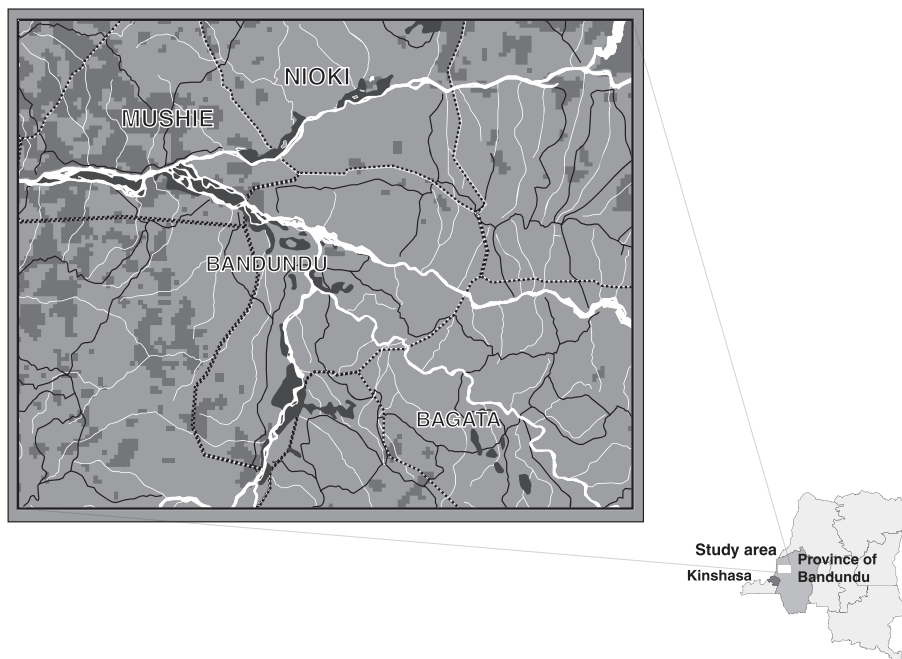


Figure 1 The four health districts in the study area in the province Bandundu, Democratic Republic of Congo.

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asked permission to proceed. We invited persons to participate in the study at different times of day in order to have a sufficient representation of those who work in the fields. Focus groups were stratified by sex and age group (equal and above *vs.* below 40 years) to avoid that the discussion would be dominated by male and more senior persons. We aimed at having four groups per village but did not always manage because of time constraints.

Question guide

A question guide was developed listing a set of prompts to trigger discussion as described in Dawson *et al.* (1993), translated and back-translated into both Kikongo and Lingala and pre-tested in four focus groups in the rural part of Kinshasa province prior to the study. These test-run focus groups were tape-recorded, transcribed and translated. A preliminary analysis was done and results were discussed in the research team. This allowed us to develop the final question guide that was used in the study. The question guide focused on three main issues: (i) the perception of HAT; (ii) acceptability of screening by mobile teams and treatment; (iii) access and barriers to screening and treatment.

Focus group discussions

A Congolese anthropologist from the University of Kinshasa facilitated the focus groups in Kikongo (20 focus groups) or in Lingala (nine focus groups), depending on setting where the focus groups were conducted. Focus groups lasted on average 46 min and were conducted in a quiet place near the centre of the village. He was assisted by an epidemiologist from the Institute of Tropical Medicine and a secretary who took notes during the focus group sessions. Each focus group discussion was recorded with a digital tape recorder. Immediately after each focus group, the research team met to discuss briefly the wording and understanding of the questions as well as obtained results and impressions, circumstances and difficulties of the field work.

Analysis

The tape recordings were literally and exhaustively transcribed in Kikongo or Lingala by the Congolese anthropologist and fully translated in French. Transcripts were checked for errors by a second person and corrected. A codebook was derived from the research themes and from themes emerging from the data using QSR N6[®] software for qualitative data analysis (QSR International Pty. Ltd., Melbourne, Australia, 2002).

Ethical aspects

The study protocol was approved by both the ethical committees of the Ministry of Health of the DRC and the Institute of Tropical Medicine. Participation in the focus groups was entirely voluntary; confidentiality of the results was guaranteed within the limits of a group discussion.

Results

Although focus groups were stratified by gender and age, we did not find major differences in the opinions expressed by male *vs.* female and by older *vs.* younger participants. The only difference we observed was that young female participants were a little less at ease with expressing opinions.

Perception of disease in general

The disease is well known in the population and seen as a major problem. Most of the time people use a literary translation of the term sleeping sickness: '*maladi ya mpongi*' or '*maladi ya ketol*'. Sometimes the disease is referred to as '*disease of the lumbar puncture*' (*bokeli ba lo* or *piqure de dos*) or as '*trypa*'. In one village (Ladi), the term '*tonga ya Ngankuin*' was used for the disease, meaning '*the injection of Ngankuin*', the name of a medical assistant who in the early seventies administered a series of Arsobal[®] injections that caused numerous deaths. People spontaneously use the term 'tsetse fly', either in French or by local names. Sleeping sickness is considered a '*disease of God*' (*maladi ya nzambi*) implying that it is treatable by western medicine as opposed to '*diseases caused by people*' – as a result of witchcraft (in Kikongo: *ndoki*). '*If they inject you and you get better, you know it is not witchcraft but it is a disease of God*'.

In these communities, psychiatric problems are usually associated with sorcery '*if somebody defecates in his own clothes he becomes just like somebody who is possessed*'. Patients or family members ponder who may be the cause of the problem, and nearly always identify a member of the extended family. So, when somebody in the family develops sleeping sickness, first '*we think often that witchcraft (ndoki) is involved*'. *If a child falls sick people start saying: 'Oh, the uncle put a demon into the child*'. Families may consult a traditional healer, usually somebody with visionary powers (*nganga*) to determine who may have caused the disease. A formal diagnosis of sleeping sickness by the health system changes this aetiologic attribution. '*If the nurses find the disease, the uncle is found innocent*'. This pattern came back in nearly all focus groups. However, if death occurs during or after HAT treatment,

the issue gets more complex. In some cases, death is then seen as *post-hoc* evidence that the disease was in reality caused by witchcraft, in other cases only the death will be attributed to witchcraft while the disease itself is still considered as sleeping sickness.

Symptoms

Personality changes and behavioural problems are the symptoms most frequently mentioned and elaborated upon and clearly strike the participants most. The person becomes difficult to deal with, quarrelsome, aggressive, starts to insult people and talks excessively (*tuba tuba*). The latter is often the first symptom mentioned. Reference is made to mental illness. *'He becomes just like somebody with a mental problem'*. Moreover, former HAT patients are not taken seriously after cure because of the loss of decorum they suffered during the disease. This loss of decorum is a cause of long-lasting stigma and shame. *'People say "don't listen to him because he came back"'*. The expression *'coming back'* was used here in the sense that mental faculties were lost at one point and later recovered.

The lethargy and idleness caused by the disease are seen as major problems, as is loss of weight and general physical deterioration. Descriptions of the sleeping disorders from which the disease derives its name are much less frequently given, such as excessive sleeping, insomnia and the night/day inversion that is a typical feature of the disease. Other symptoms mentioned are fever, skin problems such as itching, swelling of the skin, skin lesions and scratching, headache, swollen glands (described as 'little balls') and infertility. Sporadically the focus group participants will describe symptoms that are only culturally but not biomedically related to the disease.

Prevention/protection

Screening by the mobile teams is cited as the principal way of individual protection against disease. However, participants did not spontaneously connect population screening, reduction of the infectious pool and protection conferred at community level. This concept, which is crucial to the reduction of HAT transmission, is poorly understood. Neither did the participants make the connection between earlier case detection and the use of the safer first-stage drug pentamidine instead of melarsoprol.

Participants ask often for more fly traps and are aware that they protect against disease. In some villages flies are a major nuisance, one farmer told he needed to drink local alcohol before he went to certain fields to be able to tolerate the tsetse flies. Killing the flies by hand and chasing

the flies are also cited as a way to protect oneself. In two villages, elderly people remembered the campaigns in the past where pentamidine prophylaxis was administered to the whole population (Burke 1971) and asked why they were no longer organized.

Acceptability and accessibility of the screening

Participants know that the mobile teams come to screen for trypanosomiasis and correctly describe the sequence of technical procedures, from neck palpation and puncture, taking of blood samples for testing, to the use of the microscope. They see participation in screening as a way of protecting themselves from the disease. However, some group members confused the HAT screening with the activities of mobile vaccination teams. The fact that one must pay for the screening card is badly accepted, and people often mention that it used to be free in the past. The price for a screening test is meant to be symbolic (participants mention amounts ranging from US\$0.05 to US\$0.4 per person) and entitles individuals to participate in subsequent screenings but participants complain that total cost for a large family can sum up to US\$1.5 and that this money is not readily available.

In the past members of the mobile teams got a premium when they found a HAT case and in some villages the suspicion was mentioned that because of this financial incentive, healthy people are declared sick or that even sleeping sickness is induced by programme staff.

Lumbar punctures are disliked and patients experience the procedure as humiliating, especially when done in public. Participants mention they experience pressure and coercion by local authorities to comply with the lumbar puncture that is performed for follow up of treatment. The reasons for these lumbar punctures are not well understood and often is seen as the beginning of the treatment. When asked how to improve HAT screening, participants advised avoiding the planting season indicating that opportunity cost is a barrier, but closer analysis revealed that participants' primary fear is that they will miss the entire planting season if found to be ill. Public disclosure of sleeping sickness is a problem because it leads to stigmatization, feelings of shame, community pressure and coercion to comply with treatment even if they cannot afford it. *'If they catch you with the disease and you cannot pay for the treatment, they go accusing you by the state..., the state may even come to arrest you.'*

In one focus group, it was mentioned that public disclosure of a HAT diagnosis makes the person vulnerable to attacks from sorcerers. Some participants proposed to do house-to-house screening instead of gathering all the people in one public place.

Access to treatment

Accessibility of the treatment is mentioned as the most important barrier in nearly all focus groups. Participants make an explicit link between affordability of the treatment and their motivation to come to the screening sessions. They question the usefulness of attending screening if they cannot afford the treatment anyway. The official price asked for HAT care at DRC treatment centres is the equivalent of one basket of manioc. This amount of manioc may not be readily available when the family needs the money, so it needs to be harvested and processed (soaked in water to remove the aminoglycosides) before it can be marketed. *'She must dig the manioc and put it in the water, this takes time'*. Their main resources come from agricultural products and sometimes fishing but rapid monetizing of produce is often not possible. Families will then sell assets such as goats or sheep, stocks of groundnuts, clothes or furniture. Moreover, payments for HAT care are perceived as unpredictable, excessive and unfair. The health personnel are suspected of running their own business and make money out of HAT care for their own account. The cost recovery system is perceived as hard and merciless and there is a general perception that if one cannot pay, the programme will let one die. *'Before they will treat [you], you need to have money, a lot of people die because of the money. Even these people (shows a house) died because of the money'*. Participants refer to past times when treatment and screening was free as the *'time of the Flemish'*, indicating the previously very direct and visible involvement of the Belgian Cooperation in HAT control activities.

Transport and distance to the treatment facilities are perceived as less problematic than the hardship of staying away from home and family who can provide material and psychosocial support. The fear of dying alone or dying outside the home village is also a strong factor impeding patients to access HAT care. Lack of food is seen as a major problem for HAT care because of the belief that one needs to eat well to cope with the treatment. Some participants fear or distrust food and water in certain places.

Side effects of treatment

Participants have a detailed knowledge of the side effects of melarsoprol and its brand name, Arsobal[®], that is commonly used. Problems such as the irritating effect of the injections, swollen legs and difficulties in finding a vein are often attributed to the use of 'big needles'. Health staff is blamed for this and accused of being rough and careless. One participant expressed this with the quote *'Nurses*

become Samsons' (after the biblical warrior). Participants can accurately describe the symptoms of arsenic encephalopathy such as trembling and paralysis. They are mostly struck by the fact that patients so suddenly get worse and that even previously symptomless persons can have a severe and sometimes permanent deterioration of their mental state after treatment.

Risks of the treatment are very well known and deaths are explicitly linked to the melarsoprol injections *'... somebody takes this injection, finished, he dies'*. Participants emphasize the unpredictability of the outcome. *'After treatment, sometimes you get better, sometimes you die'*. Melarsoprol-related deaths are remembered by the communities for a long time after the event and negatively affect people's willingness to participate in screening and to comply with treatment. The fact that apparently healthy, symptomless persons are diagnosed by the mobile teams as HAT-patients, and can subsequently succumb during treatment causes consternation and creates suspicion towards the mobile teams and their motives. One participant expressed this in the following way: *'... they [the programme staff] try to find (the disease) because they get paid for that, people come [to the screening], a person who used to walk very well is examined, they say the person has trypa [sic], he goes there [the treatment facility], they put a syringe in his body and he dies. Therefore people are afraid; they say it is them who contaminate us.'*

Participants are also aware that delayed complications and deaths can occur after discharge from the treatment facility. *'... they take treatment but afterwards they fall in the forest'*. They quote a 6-month resting period during which a number of rules and taboos need to be observed in order to avoid this delayed complications. Things to avoid according to focus group participants are hard labour, sexual intercourse, heat, fire, hot water, spicy foods and oranges. If delayed complications occur they are attributed to non-observance of these rules, blaming the victim. *'If you do not respect the principles given by Fometro, you die'* (Fometro is the name of an N.G.O. involved in HAT control).

During the 6-month recovery period the patient is followed up by members of the community to make sure that he/she respects these rules. Sometimes the need to avoid accusations of sorcery and conflict is cited as a motivation. *'... he will die [because he didn't respect the principle] and then the story will go that it was witchcraft'*. The forced inactivity during 6 months leads to an important economic loss, increases the cost for the patient and is repeatedly cited as a reason for not attending screening or treatment. *You cannot work in the fields, so you starve.*

The taboo of sexual intercourse is very frequently quoted and is a favourite discussion topic. *'If he amuses himself*

with a woman he must die, even on top of the woman'. Female focus groups evoked marital problems and conflicts with their husbands because of this. In several focus groups health workers were identified as the source of this advice. The mandatory rest period ends with the first check-up visit 6 months after treatment.

Discussion

Toxicity of HAT treatment and financial barriers to screening and care are the main concerns of the affected communities. This study was conducted in a single province so caution is needed when extrapolating the results to other regions, especially to regions outside of Central Africa. The study area has been endemic for a prolonged time with prevalences up to 5% so that most people have come into contact with the disease either directly or through a member of their family. In a new disease focus, the general population as well as the health professionals active in the area may be considerably less knowledgeable about the disease, but even 'new' epidemics usually happen at former disease foci.

Our sampling was purposive and we did not try to quantify the response given. However, when, as is the case in our study, a large number of focus groups is conducted, it is quite easy to distinguish the dominant ideas and opinions that come back (Krueger & Casey 2000). Knowledge of symptoms, transmission and treatment was often very detailed, accurate and apart from minor misconceptions, usually correct. Tsetse flies were identified as the vectors, and, in contrast to the findings of Gouteux and Malonga (1985), there was only minor confusion with other insects.

Hagenbucher-Sacripanti (1981,1983) conducted anthropological studies in Niari in Congo-Brazzaville, in communities that were socio-linguistically very close to our study population. He focused on the psychosocial and political meaning of HAT, function of the disease in the society, medico-magical rituals and divinatory interpretation. He describes how in epidemic areas the modern definition of the disease has replaced beliefs in the actions of a sorcerer-demiurge to explain the occurrence of the disease. Yet, despite this, death of a trypanosomiasis victim was blamed on witchcraft, as it was in our study. The important distinction between '*diseases of god*' (*maladi y nzambi*) and '*diseases caused by witchcraft*' (*ndoki*) was also made in this Kikongo speaking area with the same terminology as participants used in our study. Mental disorders are usually attributed to witchcraft and lead to accusations of sorcery, causing serious disruptions in (extended) families and rural society in general.

Hagenbucher-Sacripanti described the role of the 'traditional healer' (*nganga*) in HAT treatment in similar ways as our study participants. Rather than herbal medicine, the visionary power of a faith healer is consulted very early on in the disease process, to determine who is causing the disease. Tempels (1945) describes a similar role of the '*nganga*' and describes the system of accusations and reparations, especially involving more senior relatives in the extended family or lineage (uncles, *banoko*), which the participants also refer to in our study. These social tensions as a result of accusations of sorcery caused by HAT are also described by Gouteux and Malonga (1985) in Niara. The same study describes the putative role of sorcery in aggravating the disease and causing death rather than giving origin to the disease in a way that is very similar to our study. However, contrary to Gouteux and Malonga (1985) who found that belief in supernatural causes was a limiting factor for participation in vector control programmes leading to hostility and abandonment of fly traps, we found that this was no barrier for participation in screening and treatment and, in certain circumstances, even may improve health-seeking behaviour in the rural community.

The screening activity in itself is well accepted in most places, but the 'symbolic' fee asked for the card is frequently cited as a major obstacle and for bigger families may add up to one or two times a household daily income. One card may serve for several screening rounds and this diminishes the overall cost, but cards tend to get lost. This may even create a group of 'core transmitters' as during consecutive screening rounds the same group of people without a card may be excluded and remain infectious. Based on these findings the national programme abolished the fee for the screening card in 2005, but not for the treatment.

Confidentiality at screening was an issue for the participants for several reasons: the important stigma surrounding a mental illness, the concept that a patient becomes vulnerable to witchcraft when his disease status is disclosed in public, community pressure to comply with treatment that may even lead to sanctions from local authorities. House-to-house screening, as was proposed by participants, may not be feasible but improving procedures such as communicating results afterwards in more discrete circumstances should be considered. It is indeed an ethically questionable practice to expose a patient in public as diseased and this aspect of population screening did not get the attention it deserves from disease control programmes so far.

There is definitely stigma attached to HAT, as ex-patients are taken less seriously because of their past behavioural problems. However, we did not find evidence

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that HAT patients are excluded from society or ostracized because of the disease, despite the fact that we extensively explored the attitude towards HAT patients in the focus group discussions. This is in striking contrast to the exclusion that is the fate of tuberculosis, lepra or other patients in some cultures. The lesser stigma of HAT may of course reflect a tendency of focus group participants to provide socially acceptable answers. On the other hand, there were some former HAT patients amongst the participants, who talked freely about their illness. In these highly endemic areas where HAT persisted for several years, almost all families have been confronted with the disease, and this most likely contributed to lessen the stigma.

Encephalopathy and deaths because of melarsoprol have a profound effect on the acceptability of the programme and this is a major reason to refuse screening and treatment. The unpredictability of these events and the fact that they occur in persons that appeared perfectly healthy before they got the diagnosis strike terror and lead to accusations of sorcery even if the disease was previously attributed to sleeping sickness. Switching from melarsoprol to the less toxic eflornithine, apart from saving lives because of fewer complications, will result in more effective control by having a beneficial effect on the participation rates and treatment compliance, factors that often render the active screening campaigns ineffective (Robays *et al.* 2004). Affordability of treatment is the most discussed issue in nearly all focus groups. The sums that the patients must mobilize are far from symbolic and access is seriously compromised. The adverse effect of cost recovery schemes on access to treatment in general is extensively documented (Gilson 1997; Wilkinson *et al.* 2001; Meuwissen 2002; Ridde 2003; Nabyonga *et al.* 2005).

A study by Médecins sans Frontières (Accès aux soins, mortalité et violence dans la République Démocratique du Congo, MSF 2005) reveals that access to health care in general is seriously compromised and that only between 33% and 55% of the people are able to obtain medical care and treatment in a primary health care structure. A study by Lutumba *et al.* (2005a) in rural Kinshasa shows that cost of HAT care amounted to 5 months of household income. Gouteux *et al.* (1987) found that direct cost of treatment in the Niari focus (People's Republic of Congo) amounted to 6 weeks of household income out of agriculture and that it was the major reason to refuse treatment. Timely care for a disease that has such a high morbidity and mortality when treatment is late or absent is in the first place an essential human right but the poor access to treatment also seriously compromises effective disease control. Putting more resources into lowering

barriers to treatment would not only be more effective but may also be cost-effective, as less resources are wasted on screening and diagnosing patients who do not receive adequate treatment afterwards. Abolishing cost recovery efforts may in the long term compromise sustainability of the control effort but today the functioning of the DRC HAT control programme depends nearly entirely on international aid money, so activities would stop anyway if aid was halted (Lutumba *et al.* 2005b).

Finally, communities seem to attach a lot of importance to the rest period during the first 6 month after HAT treatment. The strict restriction on labour and sexual intercourse is allegedly imposed by the programme staff and probably offers a way to cope with the unpredictability of the treatment outcome. However, there is no objective medical justification for these restrictions and they considerably increase the social cost and opportunity cost for the patient, including victim-blaming in case of relapse and late complications.

In conclusion, we can say that the barriers to HAT screening and care are not lack of knowledge. Additional health information campaigns are therefore unlikely to have much impact on participation. HAT programmes should focus on addressing the real concerns of the beneficiaries. Switching to less toxic drugs, lowering financial barriers and improving confidentiality would have a considerable impact on the participation in population screening for HAT and access to treatment.

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J. Robays *et al.* **Community participation in HAT control in DRC****Toxicité et coûts des médicaments, barrières pour la participation de la communauté dans le contrôle de Trypanosomiase Humaine Africaine en République Démocratique du Congo**

OBJECTIFS Les programmes de dépistage actif des cas par des équipes mobiles sont des points clés dans le contrôle de la trypanosomiase humaine africaine (THA). Des taux de participation faible au dépistage et à la prise du traitement après diagnostic sont des problèmes majeurs. Les objectifs de cette étude ont été d'explorer la perception de la communauté sur la THA, d'évaluer l'acceptabilité des activités de contrôle et d'identifier les barrières à l'intervention.

MÉTHODES En septembre 2004 nous avons mené 33 séances de discussion de groupe focalisée avec des participants du programme de contrôle THA provenant de divers groupes ethniques dans deux milieux écologiques (savane et fluvial) de la République Démocratique du Congo.

RÉSULTATS La population avait une connaissance et une compréhension détaillée sur la transmission de la THA, l'utilité du dépistage, les symptômes et le traitement. Le traitement au melarsoprol était craint à cause de ses effets secondaires. La mort subite de personnes asymptomatiques durant le traitement était attribuée à la sorcellerie, à laquelle l'on deviendrait plus vulnérable lorsque le diagnostic était publiquement révélé. Le manque de confidentialité était aussi un problème parce que la THA comporte une stigmatisation comme étant une maladie mentale. Les ponctions lombaires, surtout lorsque pratiquées en public, n'étaient pas bien appréciées mais elles n'étaient pas redoutées. Les barrières financières étaient un obstacle majeur pour beaucoup de patients.

CONCLUSIONS Des médicaments moins toxiques, la réduction des barrières financières et l'amélioration de la confidentialité auraient un impacte considérable sur la participation de la population au dépistage de la THA.

mots clés Trypanosomiase humaine africaine, accessibilité, acceptabilité, participation de la communauté, perception, *T.b. gambiense*, République Démocratique du Congo

Toxicidad al medicamento y barreras económicas en la participación comunitaria para el control de la Tripanosomiasis Humana Africana en la República Democrática del Congo

INTRODUCCIÓN Los programas de búsqueda activa de casos realizada por equipos móviles son la piedra angular del programa de control de la Tripanosomiasis Humana Africana (THA) en África Occidental. Los mayores problemas encontrados son la escasa participación en el tamizaje y un bajo cumplimiento con la toma del medicamento después del diagnóstico. Los objetivos de este estudio eran explorar la percepción comunitaria de la THA, evaluar la aceptabilidad de las actividades de control e identificar las barreras susceptibles a ser intervenidas.

MÉTODOS En Septiembre del 2004 se organizaron 33 grupos de discusión focalizada entre los beneficiarios del programa de control de la THA pertenecientes a varios grupos étnicos, en dos emplazamientos ecológicos diferentes (sabana y fluvial) de la República Democrática del Congo.

RESULTADOS La población tenía un conocimiento muy detallado y entendía acerca de la transmisión de THA, los síntomas, el tratamiento y la utilidad del tamizaje. Los tratamientos con melarsoprol eran temidos por los efectos secundarios. La muerte repentina durante el tratamiento, de personas previamente asintomáticas, estaba atribuida a la brujería, a la cual uno se torna más vulnerable cuando el diagnóstico se ha hecho público. La falta de confidencialidad también era un problema, puesto que la THA trae consigo el estigma de una enfermedad mental. Las punciones lumbares, especialmente cuando se realizan en público, no gustaban pero tampoco eran temidas. Las barreras financieras eran un obstáculo mayor para muchos pacientes.

CONCLUSIÓN El uso de medicamentos menos tóxicos, la disminución de las barreras económicas y una mejora en la confidencialidad tendrían un impacto considerable sobre la participación de la población en el tamizaje para THA.

palabras clave Tripanosomiasis Humana Africana, accesibilidad, aceptabilidad, participación comunitaria, percepción, *T.b. gambiense*, República Democrática del Congo