Editorial: Popular concerns about medical research projects in sub-Saharan Africa – a critical voice in debates about medical research ethics

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Vampire stories are, then, confusions and misunderstandings of the best kind: they reveal the world of power and uncertainty in which Africans have lived in this century. Their very falseness is what gives them meaning: they are a way of talking that encourages a reassessment of everyday experience to address the workings of power and knowledge and how regimes use them. (White 2000)

Introduction

Popular concerns about blood-stealing, trade in body parts, surreptitious birth control and the deliberate spreading of disease are common across sub-Saharan Africa, and there are indications that they are becoming more common in pace with the process of deprivation that economic and political destructuring has, over the last quarter century, set in motion across most of the continent (Comaroff & Comaroff 2000).

Such stories are commonly referred to as 'rumours' - by those who observe and dismiss them, but also by those who, usually with due scepticism, pass them on to others. With its connotation of hearsay and gossip, the term is often used in contrast to 'truth', much like the equally problematic distinction of 'belief' and 'knowledge'. It is our aim in this paper to move beyond the dismissal of these stories as 'mere' rumour, based on erroneous belief or traditional superstition, and to appreciate them as modern commentaries on social relations that involve, and extend far beyond, scientific medical research. If we nevertheless use the words 'rumour', 'story' and 'concern' synonymously, we follow the historian Luise White's understanding that rumours, such as vampire stories in 20th-century Africa, 'are neither true nor false, in the sense that they do not have to be proven beyond their being talked about; but as they are told, they contain different empirical elements that carry different weights:

stories are told with truths, commentaries, and statements of ignorance' (White 2000). By telling these stories, relating them to empirical facts in a given locality and at a particular moment, and intertwining them with other seemingly unrelated tales, people make new connections and reveal hitherto unseen links, weaving wide, often global connections into local patterns of relatedness (Geissler 2005). When, below, we speak of 'rumour' we are not expressing *our* scepticism; rather, we are reflecting the scepticism of those who tell these stories: *their* ambiguity towards formations of knowledge and power that reach deep into their everyday lives, and which are set in a world order that provokes their doubts.

Medical research and the 'trial communities' it constitutes by linking scientists and subjects, institutions and funders, media and publics, is one of the networks of global connections that has been particularly prolific in the generation of rumours (P.W. Geissler and C. Molyneux, in press). The sort of rumours mentioned above, particularly those about blood, are often directly related to medical research and health interventions. During 15 years of involvement in medical research in Africa we have repeatedly encountered such rumours. From friends and colleagues we have heard many more reports of such rumours, sometimes impeding recruitment to research, affecting adherence to interventions and even threatening the continuation of whole research projects while more commonly providing a background noise without direct impact (Geissler 2005; Molyneux et al. 2005a; Pool & Geissler 2005; Fairhead et al. 2006; for a rare note in a medical paper, see Nchito et al. 2003; for the potential detrimental impact of public debates see most recently Singh & Mills 2005). Most of these rumours follow a relatively limited number of themes, while also showing regional and locally specific variation. On a more general level they merge into related genres such as urban legends and oral traditions (Burke 1998; Ellis & Ter Haar 2001),

whereas local expressions are usually related to particular events.

Various explanations have been proposed. While medical researchers, especially in the past, have tended to interpret them as expressions of ignorance of medical science and the research process, or as the persistence of tradition, social scientists have often seen them as forms of popular resistance (Atieno Odhiambo 1974; Ceyssens 1975). Without totally rejecting such explanations, we suggest that these rumours also contain local interpretations of medical research ethics - especially relating to the problem of resource transfers and flows of value (see Varmus & Satcher 1997; Angell 2000). The frequency and urgency of these rumours, and their potential effect on medical research and public health interventions, implies that they should not be ignored, and we argue that engaging with them could enrich medical research ethics debates and improve relations between medical researchers and study communities.

To supplement our own experience of rumours relating to seven separate medical research projects in Africa, we carried out a small e-mail 'survey' among African colleagues and researchers involved in medical research in Africa (the results will be published separately). We received reports from 29 colleagues referring to rumours relating to 30 different research projects in 14 African countries over the last 20 years. Due to the sampling frame, most of the reports came from English-speaking, strongly researched countries in southern and eastern Africa. The literature makes clear, however, that these rumours are found across Africa, in countries with different histories and political, social and economic structures (Musambachime 1988; Lewis 1993; White 1995).

Types of rumour

Our anecdotal data do not enable us to quantify the incidence of particular concerns, their prevalence in specific populations, or the intensity of belief in them. It is not our concern, at this point, what proportion of research projects encounter rumours, nor which proportion of a particular population believes them or even acts according to them. Our aim is not an epidemiology of rumour, but rather to present a range of cases and ask whether these rumours could add a voice to research ethics debates. In trying to extract what appear to be general themes and common concerns, we necessarily reduce the local and historical particularities of people's situated concerns. It is our hope that this editorial, with its broad generalizations, will raise interest and provoke more detailed anthropological and historical studies of specific sites and relations and partic-



Figure 1 The 'Lions from Europe' by the Zairian painter K. M. Tshibumba. They were said to roam colonial Congo at night, catching black people, stripping them of all their belongings and killing them (from Fabian 1996).

ular moments and processes in which concerns like these take shape and effect.

Before we discuss the rumours in more detail, let us make it plain that we think it is necessary to look at these rumours, in this editorial and in further research, not in order to criticise the work of scientists, or even biomedical science as such, but to critique the unequal distribution of the benefits of science. This in our view is the thrust of the rumours themselves and that of medical anthropology, moving beyond the 'critique of biomedicine' that has occupied our discipline for a good while.

Blood and organ stealing

Rumours about blood stealing, which we have personally encountered in Kenya, Zambia, Mozambique, The Gambia, Tanzania and Uganda, are the most widespread. They have been reported in sub-Saharan Africa since colonial times (White 2000). The blood-thieves in colonial rumours were often described as white people or their black collaborators, who often wore uniforms and operated at night using European technology - cars, fire engines, torches, medicines, electricity, syringes (see Figure 1 for a Congolese artist's imagination of such creatures, the 'White Lions') - to extract blood from local people, which they then either sold or transformed into other commodities, such as medicines (Pels 1992; White 2000). Very similar descriptions have been reported from Latin America (Samper 2002). In rumours related to medical research, it is the foreign researchers and their local assistants or collaborators who steal the blood, though the purpose is the same. These rumours are found across sub-Saharan Africa and arise from research into malaria, viral infections including HIV/AIDS,

helminth infections including filariasis and bilharziasis, vaccinations, nutrition, and even from entomological and anthropological studies that involve no blood specimen collection (Pels 1998; Nnko *et al.* 2005). Indeed, 'research' seems to be generally associated with the collection of blood and the attendant ambiguities.

A closely related group of rumours involves organ theft. These rumours, although more common in central and South America (Scheper-Hughes 1996; Campion Vincent 2002; Samper 2002), are still significant in Africa – for example the heart thieves of Madagascar (Jarosz 1994), or the skin thieves of Tanzania (Sanders 2001). We have directly encountered fears about the theft of placentas in Kenya and anxieties about skin thieves in Tanzania (see Nnko *et al.* 2005).

Another related cluster of rumours, more common in southern Africa, points to 'Satanists' as the end users of blood or body parts. Either acting independently or directly linked to medical research institutions, they allegedly use blood and body parts in sacrifices to generate wealth. Such rumours appear to have become more frequent, possibly spreading, along with more mundane forms of commerce and travel, from South Africa, over the past decade (Comaroff & Comaroff 1999; Nchito *et al.* 2003).

Disease and demographic assault

Other rumours focus on the deliberate reduction of populations through spreading disease, reducing fertility or outright genocide. HIV/AIDS figures prominently in this connection, and fears of being infected with HIV merge with fears of being diagnosed HIV positive. In some rumours, fears are expressed of scientists purposely spreading HIV, sometimes supported by the speculative hypothesis on the origins of AIDS in oral polio vaccine research (Hooper 1999). Sometimes it is thought that HIV test results are used to identify and incarcerate HIV-positive individuals. Even demographic surveys or genealogical studies are sometimes associated with planned genocide (Geissler 2005).

Some rumours portray research or medical interventions as a form of surreptitious birth control aimed at assaulting a population's 'life-force' and future. We have encountered such rumours relating to vitamin tablets in Kenya and Zambia and nevirapine antiretroviral therapy for pregnant women in Mozambique. These stories are often linked to the suspicion that (white) Americans or South Africans are attempting to eradicate (black) Africans in order to posses their land and riches, or that national elites are trying to reduce the populations of their (ethnic or political) enemies. Researchers are some-

times alleged to make common cause with the perceived enemies of the studied community (Geissler 2005). Since colonial times, blood collection, regular treatments (such as vitamin supplementation or malaria prophylaxis) and interventions targeting specific age or gender groups (such as vaccination), have been suspected of reducing the fertility of young girls (e.g. Bradley 1980; Feldman-Savelsberg *et al.* 2000).

Rumour as insufficient knowledge

A common explanation of these rumours is that they are misunderstandings of scientific or other 'Western' practices, such as autopsies (Baker 1946), surgery (Evans-Pritchard 1960), blood donations (Atieno Odhiambo 1974) or even drinking red wine (Trant 1970). This view takes a clear-cut distinction between things 'African' and 'Western' for granted, and assumes that once local people become familiar with modern technology and Western practices the rumours will abate. A related explanation ascribes them to 'traditional beliefs' relating to witchcraft and the supernatural. While many of the stories we discuss here are probably also rooted in pre-colonial African ideas about power and the supernatural, this type of explanation implies that tradition is limited, irrational and superstitious, that these beliefs from the past will eventually be replaced by rational, modern knowledge once education and development become more widespread.

This sort of explanation is based on a simplistic notion of 'modernization' that posits a single, scientific modern rationality as the end point of historical progress. It also ignores the echo in far-fetched stories like those cited above, of very real abuses of medical science in economically deprived countries in the past (Eckart 2004) as well as in the present (e.g. Sheper-Hughes 2000; Petryna 2006).

Moreover, explanations in terms of ignorance and (mis)understanding overemphasize the importance of knowledge. Ensuring that study communities understand medical research procedures has sometimes improved acceptance (e.g. Doumbo 2005), but lack of knowledge in itself cannot adequately explain the rumours. For example, it is not uncommon to find scientifically educated members of study populations spreading rumours. Rumours sometimes occur in urban settings with higher levels of schooling and exposure to modern technology (e.g. Feldman-Savelsberg et al. 2000), and they can arise around very familiar interventions – such as school milk donations. Even medical technologies that are popular among local populations, such as injections, can provoke rumours, given the right context (Birungi 1998). Moreover, bloodstealing rumours have even been observed in the complete absence of blood sampling or medical technology, as we

have experienced in relation to anthropological research in Tanzania (Nnko *et al.* 2005).

Rather than seeking explanations for these concerns in terms of knowledge, or the lack of it, we should look to the realm of social relations, and how they are produced in and changed by medical research and the historical transformations it is part of. The image of the 'White Lions' (Figure 1) depicts the perpetrators of evil deeds dressed in protective gear, operating from the outside of human settlement, moving along the road to somewhere else, striking and getting away without further interaction. These traits - uniforms, gloves, goggles, hard hats, motorcars, roads, cities and the lack of discernible personal features - have characterized stories like this throughout the last century and across Africa (White 2000). They relate to a crucial dimension of the social relations they describe: the experience of being touched by someone who himself does not want to be touched, seen by an unrecognizable figure, and known by somebody unknowable. This trait is tangible in the medical emphasis on the avoidance of touch, protective dressing, gloves and uniforms, but the fear of contact, which 'White Lions' seem to share with medical scientists, and which in turn provokes their 'subjects' anxiety, might be a more general trait of African experiences with modernity. The fearsome fear that marks the encounter between touched and untouchable, known and unknowable, is set in wider webs of power and resources, and this is, we argue, where we have to look for the meanings and purpose of rumour.

Rumours about relations

Some earlier authors have, in this vein, interpreted blood stealing and similar stories as 'myths of the oppressed' (Ceyssens 1975), social critique (Wachtel 1994; Burke 1998; Campion Vincent 2002) or resistance (Samper 2002). While these interpretations in terms of 'resistance' help to explain why rumours are at times associated with a rejection of medical research, they fail to account for the fact that most of the time research does not lead to resistance, and when it does, this is seldom outright rejection and the facts that often, despite rumours, members of study populations are eager to join research. Moreover, they construe the social situation in which rumours arise as crude confrontations between scientists, or other experts and authorities, and African villagers. Such limited interpretations overlook that the actual relationships between scientists and communities are often surprisingly cordial, despite rumours and in contrast to tense economic and political contexts, and they fail to consider the extensiveness and complexity of scientific, colonial and post-colonial global networks.

Often the underlying concerns can be shown to be associated with the traumatic history of colonialism. For example, colonial violence was central in Kenyan teachers' interpretations of blood stealing (Geissler 2005); rumours of blood thieves in Madagascar were 'entwined with memories' of colonial war and violent exploitation (Cole 2001); and White (2000) even re-wrote the social history of colonial occupation based on such rumours. Yet, although they are rooted in the colonial past, rumours are very much part of the African present, in the same way that medical field research is. While one source from which rumours spring is indeed a particular confrontation between known and unknown, as reflected in Figure 1, this moment of encounter is located in wider networks, and situated in a long historical trajectory. Thus, rumours about medical research debate the local within the global, and the present within its history.

Rumours can be seen as discussions of current events, though rooted in and using idioms from the colonial and pre-colonial African past. Rather than being misinterpretations of reality, they explore 'commonly held ideas concerning the nature of reality' (Ellis & Ter Haar 2001). They are similar in many respects to newspapers and television - they convey information and news, while also being a form of entertainment. In the francophone countries of central Africa, they are referred to as radio trottoir - pavement radio - while English-speaking East Africans like to refer to village gossip as our BBC. Referring to Latin America, it has been argued that 'rumours arise in situations where there is a general lack of reliable, unambiguous, or trustworthy news about events that are of vital importance to a community'. They are 'collective representations of fears and anxieties' (Samper 2002). In colonial Africa, White (2000) said rumours were part of a transcolonial movement which produced 'independent, though parallel local idioms that express local issues and concerns'.

Rumours and the mystery of wealth

Rumours are closely linked to what has been described as the mystery of money, wealth and capital – how it is acquired and reproduced. They are related to the suspicion, widespread in sub-Saharan Africa, of extraordinary wealth of unclear origin (Geschiere & Konings 1993). This is a moral issue, because not all ways of acquiring money are respectable and because wealth is not equally or fairly distributed (Ellis & Ter Haar 2001). Moreover, in many African societies, it is considered that wealth should continuously circulate between people; static, accumulated wealth has negative moral connotations. In pre-capitalist African society, wealth was often measured

in living beings – cattle and people (children, marriage alliances) – and linked social ties between individuals and groups, as well to the spiritual world. Circulation of wealth on one level, then, requires the movement of wealth on another one, and material transactions, the production of wealth and the (re)generation of life-force are closely intertwined (see e.g. Taylor 1992; Ellis & Ter Haar 2001). For example, when President Hastings Banda tried to set up a blood bank in Malawi there were rumours that this was in order to supply the apartheid regime in South Africa with blood in exchange for political support (Ellis & Ter Haar 2001).

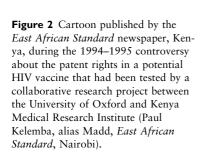
Against this background, stories about blood, ostensibly collected for research, being sold or otherwise used for the material benefit of Western scientists, help to explain differences in wealth and other inequalities that local populations perceive between themselves and medical researchers. Similarly, rumours about the deliberate spreading of HIV, surreptitious birth control and genocide help to explain, through a logic of limited good, how researchers increase their own wealth by reducing the (human) wealth of study populations.

Rumours and contemporary ethics debates

Inequality is also at the root of recent debates on the ethics of medical research in Africa – from the controversy about standards of care in African ARV trials (Angell 1997; Lurie & Wolff 1997; Varmus & Satcher 1997), through claims of double standards and scientific imperialism (Wilmshurst 1997), to the discussion about making interventions that result from research 'reasonably available' to researched populations and local communities (Participants 2002). Figure 2, a Kenyan cartoonist's rendering of the complex

and fraught networks surrounding research collaborations, underlines that inequalities of power and wealth are not only an issue between scientists and economically poor study participants, but pertain to all relationships that constitute the 'trial communities' of overseas medical research, comprising subjects and scientists as well as funders and publics, media and politics. More recently, these debates about the impact of inequality have given way to a broader discussion of benefits (and what these benefits entail) in medical research collaborations between economically rich and poor societies, and have led to a focus on the issue of fairness as a dimension of ethical research.

Although African researchers and philosophers have contributed to these debates (Tangwa 2004; Doumbo 2005; Mkhize 2005), they have been conducted mainly by academics and scientists from the economically rich countries of the North. The voices of the ostensible beneficiaries of better ethical practices – the local research populations and the communities from which they are recruited - have not often been heard. In various studies research participants have been asked what they think of particular projects, research institutions or informed consent procedures (Leach et al. 1999; Fairhead et al. 2004; Molyneux et al. 2005b), but few attempts have yet been made to involve them in discussions of the key ethical issues that exercise the Western academics who debate on their behalf [although Molyneux and co-workers in Kilifi, Kenya, are engaged presently in very promising, innovative operational research in this regard (Kamuya et al. 2005)]. For example, research populations are not usually asked which benefits they would consider appropriate and what level of benefit they would consider fair (Participants 2002).





Given local unfamiliarity with the conceptual models and terminology of the international medical ethics debate and the lack of direct engagement of study populations in discussions about ethical concerns, local communities make use of their own models and terminologies to express and debate their concerns. They use a collective set of narrative elements, plots, themes and images that have been used to facilitate discussion of colonial and post-colonial inequality and exploitation. The rumours described above can be seen as giving expression to and allowing debate about ambivalence relating to the advantages (free treatment) and disadvantages (giving blood) of participation in research, and issues of inequality and the fair distribution of benefits (see Geissler *et al.* 2005).

These rumours are modern debates about ethical practice in a context in which experiences of alienation and exploitation form the backdrop of medical research. In White's (2000:5) words on colonial rumours:

Such confusions offer historians a glimpse into the world as seen by people who saw boundaries and bodies located and penetrated ... a world of vulnerability and unreasonable relationships.

The fact that both political-economic exploitation and medical research are debated through the same idiom may be because medical research played a role in the local presentation of colonial and post-colonial rule, or because medical research is seen as being similarly unfair and exploitive. The stories invert the idea of scientific research as disinterested work for the common good – a narrative that has shaped the self-representation of tropical medicine since its inception – and portray it instead unfavourably as an enterprise that takes more than it gives, siphoning off valuable substance or gaining advantage in the competition for the world's riches.

We are not arguing that local communities and study participants do not see in most cases benefit, often substantially, from publicly funded medical research; nor do we doubt that most study subjects regard medical research as useful (both immediately and ultimately) for themselves and their community, because they quite obviously do. Our point is that rumours give local populations a way of commenting on medical research as part of a wider system of exploitative appropriation of value. Thus, rather than a rejection of science, modern interventions, or outsiders, rumours could be seen as ways of talking about the ethical challenges of new situations and their wider context. In the wider frames, there is much cause for concern, and medical research acts as a catalyst around which these take form. Therefore, inspite of important progress in the filed of bioethics, and contrary to claims to the opposite, there remains a profound 'need to worry' (pace Emanuel *et al.*, 2004:936). African stories help us to keep these worries alive.

Consequences for medical research

In field research settings in Africa rumours of the type discussed here frequently arise. When they do, projects respond by intensifying community sensitization and providing additional information, for example by showing community leaders around the laboratory so that they can see what happens to blood samples. Rumours usually subside and research continues. We are not aware of any medical research project in Africa that has actually had to be stopped because of rumours alone, though there have been some that came close to disaster. Moreover, local communities and study participants do not necessarily believe the rumours that they spread, in the sense that they would directly motivate their actions. Rather than providing hard-and-fast facts, rumours enable people to debate current events and concerns, and in order to do this it is not necessary that everyone actually believes them.

It is therefore tempting to conclude that rumours are not a serious threat to medical research and can simply be ignored, or countered on an ad hoc basis when they arise and prove troublesome in relation to a particular project. We think that this would be a mistake. Rumours can exercise motivational force, even among people who do not necessarily believe them, and our cursory survey of colleagues involved in medical research in Africa shows that rumours are widespread and can have serious consequences for medical research, especially clinical trials, but also for social science research. Perhaps more importantly, rumours are a symptom of a potentially problematic relationship between community and researchers. The ambivalence expressed by rumours can, even without having more direct effects, prevent an open dialogue between scientists and study communities, which is needed for successful research or long term trial sites as well as for the sustainable implementation of health research findings.

Moving beyond the immediate practical concerns of medical researchers, we suggest the following. First, both medical researchers and those engaged in discussions about the ethics of medical research should take rumours seriously because, in the absence of direct debate with local communities, they provide one way of learning about their perspective on medical research and the tensions that arise within field research settings. Problems or conflicts with study populations are rarely made public or mentioned in scientific publications unless they have direct consequences

for the data (Nchito *et al.* 2003). Rumours are an expression of local communities' responses to research and the more general relationships of dependence and inequality on which this is based, and this voice deserves to be heard and taken seriously.

Second, research participants and local communities should be actively included in the ethical discussions about the medical research that they are involved in rather than being merely the subject of these discussions (see Kamuya et al., 2005). This involves taking local concerns and priorities seriously. For example, recent discussions about the fair distribution of benefits resulting from research should include local perspectives on what should count as benefits and what it means to be fair.

Third, this process could be facilitated by anthropological research aimed at understanding the local, national and international social relations that shape medical research and the debates that arise from them. Rather than being ignored as extra-scientific contextual factors, relations between researchers and study subjects should be made part of scientific investigation, reported in scientific publications, and contribute to research ethics debates and good practice. Needless to say, responses to and concerns with this kind of anthropological research should undergo the same scrutiny and ethical reflection as medical research.

More democratic local community involvement, combined with the scientific study of the social, cultural and historical relationships in which research is embedded, could contribute to the development of 'ethics-in-the-field' (Doumbo 2005). The rumours discussed here suggest that in order to improve the ethics and the practice of medical field research in Africa, we have to recognize its study subjects as interlocutors in ongoing global ethics debates, not as mere objects of ethical responsibility.

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