

## What Makes a Disease Marginal - Tracing the History of Kalaazar<sup>1</sup>

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*More than a century after kalaazar first struck Bihar in an epidemic form, the disease not only persists but also appears to be discriminating against the poorest of the poor - the Dalits. [...]*

*Apparently 90 percent of the victims belong to the socially marginalized section. The disease is estimated to have killed over 200 Dalits, including children, in the last two years. It used to earlier affect the backward caste Yadav community and the Bhumihars, a powerful landed upper caste. But the situation seems to have changed.[...]*

*"Kalaazar is killing poor Dalits, mostly from the Musahar and Paswan community, more than others in the state," said C.P. Thakur, an expert on the disease and a former central health minister. Dalit activist Misri Manjhi said that out of 250 houses in Musahari Tola (a Dalit settlement) in Goanpura village under Phulwarisharif, 90 were in the grip of kalaazar. "Over two dozen people have died due to the disease in the last two years (in the area)," Manjhi said. Kalaazar has also hit children in this Dalit settlement. "Around 20 children are suffering from the disease," he said.[...]*

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<sup>1</sup> This is the final text of the paper published in Harshad Thakur, ed., *Kala Azar – Emerging Perspectives and Prospects in South Asia*, (Delhi: Mittal Publications, 2011). An earlier version was published in Zachariah, Srivatsan and Tharu (2010).

*In Phulwarisharif's Musahari Tola, Dalits suffering from kalaazar were not given medicines by the government and no pesticides were sprayed either, people complain. The Patna High Court in April had taken serious note of the fact that the state government had not initiated measures to provide proper medical care to kalaazar patients or to fight the disease.[...]*

*In Bihar, kalaazar dates back to 1882 when a disease called 'kale dukh', or black sorrow, was recorded in Purnea district[...].*

“From kalaazar's black shadow on Bihar dalits”

by Imran Khan, Indo-Asian News Service Patna, May 3 2006 (IANS)

### *Introduction*

Kalaazar or Indian visceral leishmaniasis (VL) is an important public health problem today. About half the world's cases of VL occur in India. On an average about 100,000 new cases occur every year and several million people in India are at risk.

Although kalaazar is a serious public health issue, it remains a marginal disease. It affects the poorest and least developed parts of the country. The disease is concentrated in specific geographic pockets, 90% of cases occurring in Bihar and the rest of the cases in adjoining Uttar Pradesh, West Bengal and Jharkhand (Singh et. al., 2006). Even in these parts, 90% of its victims are the poor and socially marginalized. In the news item cited above, C.P. Thakur, formerly a union minister for health and family welfare, refers

to Kalaazar's profile as a predominantly dalit disease. Kalaazar's marginality is reflected in the national budget to tackle the disease, which in 1993-94 was Rs. 28 crores.

Compared to the AIDS budget of Rs. 450 crores (2005-06) and TB budget of approximately 1000 crores (2005-06), even after correcting for inflation and changing medical expenditure profiles, the kalaazar budget is clearly minimal. Why do AIDS, TB, or ischaemic heart disease for that matter, have such a high status and profile compared to kalaazar?

In order to answer this question, we need to think about disease from a historical perspective that permits us to look beyond the 'hard core' of medical knowledge.

Normally we understand disease as a set of symptoms, signs, laboratory abnormalities that are specified by the name given to the disease category. The progress of scientific knowledge in relation to the disease is usually described in relation to advances in understanding the pathological processes, etiological factors and improved laboratory diagnosis, treatment and prevention. The historical development of knowledge in relation to any disease is generally constructed in relation to a series of scientific steps (scientists, experiments, dates of publications, meetings) that enabled these advances in biomedicine to take place, but always within the framework of medical science. In such a perspective, there is no place for the history of actual practices of healing and cure, medical institutions, and healthcare policies that provide the ground within which the progress of scientific medical knowledge actually takes place. Medical knowledge usually relegates

such history to an incidental and anecdotal role but always outside the boundary of the development of pure scientific knowledge.

There is however another way of looking at medical knowledge that has emerged in the seventies, and this is the historical or more precisely, genealogical perspective.<sup>2</sup> In the context of our present study of kalaazar, this perspective argues that in order to understand the marginality of this disease (or indeed the characteristic profile of any disease), we need to go beyond the standard historical descriptions of the development of medical concepts, to the history of the institutions, policies and practices that attempted to deal with the disease on the ground. It is only such a history that will allow us to understand why different diseases evolved along different trajectories. Why contemporary medicine's engagement with different diseases has led to varying approaches and resulted in differing levels of scientific progress, practical effectiveness and social consequences. This chapter attempts to analyse how the cultural and administrative context of different periods, played an important role in shaping the

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<sup>2</sup> While there have been many historical studies of medicine that outline new discoveries, medical progress and great practitioners, what we are pointing to is something different. Michel Foucault's studies in medicine from the sixties onwards excavate institutional, conceptual and epistemological discourses of modern medicine. These are not stories of progress and brilliance that celebrate the wonder of modern medicine, these are studies of specific medical and administrative conditions, constraints and facilitations of research, treatment and policy that led to the structure of nineteenth century medicine. Such a history is not hagiographic or progressive, but should be seen as a critique of mainstream histories of progress in order to understand better medicine's function today. Foucault calls these studies *genealogies*. In some ways, what this chapter attempts is a genealogy of kalaazar that explains its characteristic profile today. See Foucault (2004, 2003 and 1994) for a better understanding of the development of this perspective. Also see Tharu (forthcoming) for a discussion of the philosophical importance of the concept of practice in general, and specifically medical practice in the broad sense of engagement with illness, for an deeper understanding of the kinds of medical intervention discussed in this essay.

concepts related to kalaazar at different points in its history, but also in the success and failure of different treatment policies and practices.

Kalaazar has largely been the object of empirical histories of the spread of the disease and governmental efforts (or lack thereof) to control its spread in epidemic form. Part II of this paper traces this well-known history of the disease in colonialism through a review of the literature about the colonial government's initial investigations into the causation of kalaazar, its public health policies, the discovery of the parasite and the sandfly transmission experiments. The purpose of Part II is to point to a profile of colonial governmental thinking about disease, health, treatment and responsibility. We argue that this profile emerges through the administrative and political history of the disease category in colonialism, and survives in ways of thinking about the disease today.

Part III of the chapter examines the initiative and work of Upendra Nath Brahmachari, an Indian doctor whose work presents a shift in the ethical and political framework of thinking about kalaazar that occurs in the context of the nationalist movement in the early twentieth century. Brahmachari's intervention, driven by concern and the felt need to provide a cure for a condition causing mass death, established the field of pharmacology in India. Working to provide universal access to treatment, from within the colonial establishment, he subverted the colonial monopoly on drug manufacture, in effect giving birth to the national pharmaceutical industry in his garage.

In recorded fragments of his thinking, we also recognize the new ethic of service that emerges with nationalism.

In the last part of the chapter we examine the recent work of C.P. Thakur and Shyam Sundar to explore the modern configuring of kalaazar. How does “kalaazar” today relate to the history of the disease in the colonial period and in early nationalist thinking? As an answer to this question, we attempt to sketch the profile that constitutes the marginal status of kalaazar in our time. To sharpen this profile, we compare the imperatives that drive medicine’s initiatives in kalaazar with those in two other contemporary diseases with different historical trajectories: a) Ischaemic Heart Disease, where tertiary care specialization and the pharmaceutical sponsored clinical trials have provided the impetus for a market driven model of provision of treatments and b) AIDS, where patient activism has provided a model for provision of equitable and accessible care.

## **Part II: A review of colonial history**

### *The devastation wrought by kalaazar epidemics in nineteenth-century British India*

The first recognized epidemic of kalaazar is recorded to have occurred in Jessore (now in Bangladesh) in 1824. This outbreak is reported to have led to a mortality of no less than 75000. From Jessore this disease is said to have spread to Nadia in 1832, as well

as 24 Parganas. It reached Hooghly district in 1857 and Burdwan district in 1862 (Sengupta, 1947: 281-287). In 1862 the disease is reported to have occurred in Jageer, Dacca district, where there were innumerable deaths and a once populous town ceased to exist at the end of four years. The mortality was apparently so great that the dead were left in their houses or thrown into the river. Further to this, an epidemic was reported from north Bengal in 1872 and Bihar in 1882. During epidemic years the population used to fall by 15-30%. The decline of the kalaazar epidemic was noted by the recovery of population.

P.C. Sengupta, tracing the history of kalaazar in 1947, wrote:

The spread of disease to Assam followed in the wake of British conquest and the opening up of communications by the road and steamer services of Bengal. The first outbreak was reported in 1875 from the Garro hills where the local population called it the "sarkari bemari" or the British government disease. The map by Rogers shows the spread of disease into Assam during the last quarter of the nineteenth century. Kalaazar is reported to have caused terrific havoc in Assam during the period; of the affected people over 95% died and this led to serious decimation of the population, over 25% of the population dying in some districts (Sengupta, 1947: 281-287).

These epidemics have to be seen in the context of a series of wars that occurred between the British and Burmese kings in the early nineteenth century. The British had obtained control over Assam and the land was under-populated after these wars. The

establishment of tea plantations in Assam was envisaged to meet the colonial revenue crises. The British passed a set of rules reclaiming wasteland in order to make tea cultivation attractive. European planters cleared forests and established the plantations. It is estimated that in 1914, Rs. 302.3 millions had been invested in joint tea stocks, the majority of investment coming from England. Such was the economic importance given to the tea industry in Assam. In this context, local labour was considered recalcitrant and unwilling to work for low wages. Labour was recruited from outside the region. The indenture system was created to give the planter widespread penal sanctions where the breach of contract by the worker would lead to criminal prosecution (Breach of Contract Act, 1859 and amended Act, 1865).

It is against this back drop of massive foreign investments, clearing of forests, establishment of tea plantations, large scale labour movements and the system of indenturing that we need to understand the impact of the kalaazar epidemic on the British government. The depopulation due to kalaazar in Assam was so severe that the planters could not get local or indentured labour to work. The plantation economy came to a virtual standstill (Dutta, n.d.). The British government needed to find a solution to the problem of kalaazar if the tea industry was to survive.

### *Studies of the causation of kalaazar in colonial India*

A recent study has pointed out that medical experts in the late nineteenth century explained the occurrence and spread of the disease using the “miasmatic theory”<sup>3</sup> and using the notion of “cultural factors”, according to which, local factors in the topography and climate of India caused the disease (Kar 2003). With its abundant forests, extensive marshes, alluvial soil and humid climate, Assam became something of a textbook example of a miasmatic country. Disease was also linked to local customs that the British found strange: “uncultivated lands, a native system of house ventilation, local cuisine, choked up drains, stagnated tanks, ill-maintained roads, opium eating, burial procedures, indiscriminate bathing, scatological habits”, etc (ibid). In order to deal with the problems of disease, the miasmatic country needed to be tamed through “reclaiming wasteland, restoring lost energy of the people and reforming the climate”(ibid). Thus in nineteenth century colonial discourse, the problem of Kalaazar was as much cultural as medical. Its remedy was seen not just in terms of treatment or prevention of the disease, but of clearing the forests for commercial cultivation, locating the carrier of the disease, and initiating the cultural reform of the people. The establishment of plantations, and the new order they would bring to the land and its people, therefore received implicit support

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<sup>3</sup> Miasmatic theory originated from the time of Hippocrates and held that disease was a result of a noxious form of bad air or miasma that came from decomposed matter. In the 18<sup>th</sup> century there was the intense study of the relationship between meteorology (temperature, humidity, rainfall) and disease. In the 19<sup>th</sup> century, Cholera and black death were held to be miasmatic diseases. The experience of the tropical climate in the colonies with heat, humidity and rainfall and high mortality convinced European physicians of the relationship between hostile climate, environmental putrefaction and disease, strengthening the miasmatic theory.

from the theory of a disease that had not yet become pure biomedical category. Indeed, as we shall argue in this section, the emergence of the biomedical category is nested in this cultural perspective of the disease.

The strange fever epidemic was described in Tura, the headquarters of Garo Hills District, as marked by fever and general febrile conditions, rapidly deteriorating organ function and death by 'malarial cachexy' (Kar, 2003: 2-4). The category of 'fevers' in Assam between 1881-85 contributed to 54% of all deaths. However, both the practitioners and the sanitary commissioner found this category of undifferentiated fever inadequate. Was kalaazar a separate disease or a local name for malaria? Initially the miasmatic theory prevailed in the sanitary inspector's 1882 report, "kalaazar is a cachexia produced by malarial fever deriving its peculiar characteristics from the region where it prevails" (ibid). However as the disease moved out of Bengal into completely different geographical regions, it became clear that a miasmatic explanation was not sufficient and finding a suitable explanation became a critical issue that would have implications for the ethical and political justifications of the colonial state itself.

It was in the context of this confusion in names and causation that the sanitary officer of Assam in 1888 made a request for a special officer to come and investigate the causes and nature of kalaazar. However, while his request was for an investigation of kalaazar, the economic interest of the colonial government was in understanding the diseases of the coolies. Thus, "the need of the hour was not an examination of kalaazar among the hill tribes and plains peasantry, but an investigation in further detail of the

causes of anaemia which prevail among the coolies on the tea gardens. The scientific observer of the 'coolie's anaemia' or 'beriberi' – causing so much havoc, may well be employed to enquire into kalaazar also”(ibid).

G.M. Giles was the medical officer sent to investigate the disease. He found that the majority of cases had ankylostoma in the stools. He suggested that kalaazar and beriberi were two names for the same disease, “ankylostomiasis”. Giles explicitly challenged the miasmatic theory with his conclusion that kalaazar was an infectious disease brought in by imported coolies, thus: The “occurrence and spread of ankylostomiasis were due to the introduction of the Indian coolie in large numbers into a country where these cases were unknown”. However, he also brought a specifically racial perception to kalaazar, stating, “ankylostomiasis is one of the most infectious of diseases for people in a low-grade civilization while the danger is almost nil for Europeans in India”. Thus, for Giles, it was principally the cultural backwardness of the Assamese that had to bear the cross of susceptibility to kalaazar even though he proposed a theory of kalaazar as an infectious disease. He argued further that, “The disease in the colony is not a deviation from the normal, rather it reveals the natural, becomes instrumental in return to the origin, functions as a cipher for the truth of the native identity” (Kar, 2003: 2-4). What is interesting in this analysis is that while it proposes a theory of infection, it immediately dilutes the responsibility to find a cure by proposing a racial/cultural predilection to the disease.

Giles findings were unacceptable to the colonial government: if kalaazar was due to government-initiated movements of coolies, Britain was creating a man-made disease crisis. The implied solution was to stop coolie movement, which would have jeopardized the tea economy of Assam on the one hand and would have laid the responsibility for the known epidemics at the colonial government's door on the other. Not surprisingly, Giles report was rejected outright and Melitus, the secretary to the chief commissioner of Assam, chastised him for failing to appreciate the influence of climate, acclimatization, immigrant sickness and morbidity. He argued that it did not require coolies to introduce an intense fever epidemic into a malarious country like Assam (Kar, 2003: 2-4). The government went on to institute a second study of kalaazar causation within 6 years, deputing Leonard Rogers, a junior doctor in the Indian Medical Service (IMS), to enquire into the causes of kalaazar in 1896. He is reported to have conducted a 10-day trek along the northern banks of Brahmaputra in Assam, examining cases and performing blood counts, malarial smear and stool examinations using the facilities of the Nowgong district hospital.

### *Segregation in the tea plantations*

Roger reported that he found that the majority of patients positive for malarial parasite and he could find no clinical difference between patients with malaria and those with kalaazar. He therefore concluded that kalaazar was a severe form of malaria. Rogers

supported the miasmatic theory. However, he also found evidence of an infectious<sup>4</sup> cause, which he called “site infection”. His by now classic research findings suggested that the soil was the reservoir of infection. Along with a plantation medical officer he performed elegant segregation studies to show that removal of coolies from houses having kalaazar victims could effectively prevent the disease. He showed that when a fresh arrival of coolies were housed in new quarters 400 metres away from the coolies lines, they did not contract kalaazar, whereas 16% of those new coolies inhabiting old houses did. They further moved unaffected coolies from houses where kalaazar had occurred to new areas and again showed that this measure prevented occurrence of the disease.

Based on the successful experiments, Rogers recommended a policy of surveillance and segregation of the coolies from the affected area. He also suggested that local villagers who were affected not be allowed to emigrate from the area. No physical contact was to be permitted between affected families and those free from the disease. Rogers’ recommendations of strict and coercive segregation were immediately accepted and implemented in all the Assam tea plantations by the plantation medical officer. Following these measures, kalaazar ceased to be a major problem in the tea plantations. It

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<sup>44</sup> The concept of infectious theory arose from the idea of contagion. Some diseases were termed contagious (e.g. Small pox) and others miasmatic in the 17<sup>th</sup> and 18<sup>th</sup> century. John Snow was the first to show that cholera was contagious, with the outbreak of cholera from the Broadstreet pump (1854). It was with the identification of the bacteria for anthrax (1876) and cholera (1883) and the formulation of Koch’s postulates that germ theory gained acceptance. The malarial parasite was first demonstrated by Louis Laveran (1880) but it was Ronald Ross who demonstrated that mosquitoes transmitted the malarial parasite. The modern day concept of infectiousness implying person to person transmission of microbes arose with the development of the identification of bacteria and parasites.

is clear that the segregation methods could be implemented only in the context of the indentured system of labour. Disease and death continued to ravage the local communities.

### *Success and failure of theory*

It would be instructive to explore the reasons behind the difference between the colonial rejection of Giles' theory and its acceptance of Rogers' proposals. Rogers had shown that though the disease was infectious, it also could be explained by the miasmatic theory. It has been recorded that he collaborated with the plantation interests in studying measures that they had implemented. The disease control practices he recommended could prevent disease among the coolies, without adversely affecting the tea plantation interests. Perhaps most importantly at the level of a colonial health policy, Rogers' proposals took the spotlight off the administrative responsibility in the disease's new epidemic profile in the nineteenth century.

Thus, clearly, the acceptance of Rogers' findings and the rejection of Giles' disease theories by the colonial state suggest that a specific medical theory was found acceptable based on its compatibility with the governmental context it had to inhabit. Since the colonial government viewed its interests in economic terms, and found itself answerable largely to its British superiors, it had little interest in or responsibility for implementing general public health measures to prevent kalaazar. It is also likely that the colonial government saw a political hazard to its authority in implementing strict

segregation measures among the general public. Thus, the security of colonial rule and British economic interests were the frame within which research was commissioned, findings evaluated, policies drafted and implemented to tackle kalaazar.

### *Discovery of the parasite*

At the turn of the century, there was much confusion regarding the category of kalaazar. Was it ankylostomiasis, beriberi or malaria? By this time, the miasmatic theory was losing ground to the infectious theory of disease and infectious agents had been identified for several diseases such as tuberculosis, malaria, cholera, plague and anthrax. It was in this background that the following events took place:

In 1903 an Irish soldier from Dum Dum on his return to England was reported to have fallen ill and died of fever. William Leishman a military medical doctor reported microscopic bodies in the spleen similar to trypanosoma (which were known to cause sleeping sickness). Charles Donovan, who was working in Madras General Hospital, on reading this report, remembered a similar case that he had seen with fever and microscopic bodies in the spleen and published it (Donovan, 1903: p 79).

This was the first time that the pathogenic organism of Leishmania had been demonstrated. The Leishman Donovan bodies (LD bodies) carry the name of both these doctors who demonstrated the causative agent. The discovery of the parasite changed the way the disease was viewed. Rogers too confirmed these findings and went on to demonstrate that Leishmania Donovanii could be cultured in the test tube. He noted that

the parasite changed its shape in culture from spherical to an elongated and flagellated organism thereby suggesting that there was a stage outside the human being probably in an insect (Rogers, nd).

These findings changed the entire way in which the disease was conceptualized. Kalaazar was not beriberi, ankylostomiasis or malaria. It was caused by an infectious agent in a manner similar to trypanosomiasis and was probably insect borne.

Rogers' identification of an infectious agent did not alter his racial view of the disease. He noted that occurrence of the disease in Europeans was unusual and that "without exception all the Europeans who were affected had a history of having cohabited with an infected native woman" (Rogers, nd).

### *Transmission studies of kalaazar*

Rogers had hypothesized that kalaazar was an insect borne disease but he was not able to demonstrate the parasite in insects. J.A. Sinton, an entomologist, noted that the geographic distribution of kalaazar mapped onto that of the silver-foot sandfly, *Phlebotomus argentipes*. It was later shown that the sandfly could get infected when it bit patients suffering from the disease. However transmission of kalaazar to patients through the sandfly could not be shown till two scientific steps were taken: a) an animal model of kalaazar was established using the Chinese hamster, and b) an appropriate method of the sandfly biting the hamster was developed in order to demonstrate transmission of the parasite from the sandfly to the animal host (Sengupta, 1947: 281-287). Subsequent to

this, Swaminath, Shortt and Anderson published an experiment that demonstrated transmission of kalaazar from sandflies to man (Swaminath, Short & Anderson 1942: 473-477).

In this experiment, sandflies were fed on cultured leishmania and then allowed to grow for 10 days. Experimental subjects were kept in contact with these infected sandflies, which were allowed to bite them for several nights. All the five subjects were successfully infected with *L. Donovanii* and then went on to develop visceral leishmaniasis.

This record of medical research in the late colonial period highlights several factors that help us understand better the characteristic profile of the disease in colonial culture.

Firstly, the manner in which the etiology of kalaazar was mapped on to the geographic distribution of the silver-foot sandfly is clearly one of the precursors to the epidemiological studies that begin to take hold of twentieth century medicine. Despite the elegance of the finding, the research approach appears to not have considered the possibility that the change in geographical distribution of native populations made it match that of the silver-foot sandfly, thus provoking the kalaazar epidemics of the Bengal Presidency. Such research may have led to a proper explanation of the relationship between the natural history of kalaazar epidemics and the political history of the tea plantation industry in colonialism. From this perspective, a seemingly pure research interest is governed by an implicit boundary to its investigations. It cannot ask the

obvious question: how have native population distributions shifted in relation to insect distributions?

Secondly, the colonial perspective on medical science, research and experimentation echoes in the words with which the authors conclude their article: “Lastly we must acknowledge the *self-sacrificing spirit* of the *human volunteers who submitted themselves for experimentation* and helped in the final *solution of a problem in tropical medicine* of many years standing” (ibid, ital added). We may try and read in this acknowledgement the silenced voice of the tribal using the following table of correspondences:<sup>5</sup>

Text	Voice of subject
Theirs is a self-sacrificing spirit	We had no choice but to submit to a life-threatening trial
They were human volunteers who submitted themselves for experimentation	
They helped provide a solution of a problem in tropical medicine. Progress for the empire. Advancement of western medicine	

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5 In doing this we follow the direction proposed by Guha (1983)

Such a reading suggests that both the way in which the idea of the *tribal* and that of *kalaazar* were constituted enabled the kalaazar commission to perform life-threatening experiments on Khasi tribal subjects in the northeast frontier.

We cannot rest assured in the conviction that such a callous disregard for its subjects was characteristic of a colonial scientific culture and that we would not treat our present day research subjects in this manner. Continuing evidence of this ambiguous legacy comes to us from the occasional reports of suspicious deaths in contemporary clinical trials conducted on Indian subjects today.

### **Part III: Development of drug treatment for kalaazar: A twentieth century nationalist agenda?**

In medical history writing, Upendra Nath Brahmachari is almost forgotten as the crucial figure in the development of treatments for kalaazar and the significance of his work needs to be evaluated in the context of the British government's neglect of the drug industry: a) most of the allopathic drugs were imported and were largely based on raw materials that were exported from India; and b) that the neglect of the drug industry was deliberate was evident from the fact that the government had intentionally prevented the establishment of departments of pharmacology in Grant's Medical College and in the Calcutta Medical College.

Brahmachari is reported to have trained in chemistry and mathematics prior to his medical degree and subsequently completed his PhD in physiology. He later joined the

Indian Medical Service, the Calcutta Medical College and the School of Tropical Medicine (Mahanti, nd.). On his own account, he felt challenged by the large number of deaths due to kalaazar, a disease that had no effective treatment. In 1914 Rogers had reported the successful treatment of kalaazar with tartar emetic. He had performed these studies based on the known effectiveness of tartar emetic for sleeping sickness. In Brahmachari's experience tartar emetic was associated with increased toxicity and lack of uniform effectiveness. Based on his knowledge of chemistry he worked towards synthesizing non-toxic antimony preparations. At this time Paul Ehrlich had synthesized sodium arsanic acid for treatment of trypanosomiasis. Brahmachari thought that since arsenic and antimony were next to each other in the periodic table, he could substitute antimony for arsenic. In doing this he synthesized urea stibamine, the urea salt of para-aminostibnic acid (Brahmachari, 1928). He wrote, "I shall never forget that room where Urea Stibamine was discovered. The room where I had to labour for months without a gas point or a water tap and where I had to remain contented with an old kerosene lamp for my work at night. To me it will ever remain a place of pilgrimage where the first light of Urea Stibamine dawned upon my mind." (Mahanti, nd.)

Based on his work he published sixteen papers demonstrating the efficacy and safety of urea stibamine (Brahmachari, 1928). H.E. Shortt of the Special Kalaazar Hospital in Shillong found it to be highly useful and recommended it for wide use. As a result, urea stibamine was used in Bengal, Bihar, Orissa and more distant parts of India. The public health effectiveness of this treatment was noted in the declining mortality

rates due to kalaazar in Assam. It was estimated that by 1933 about 3.25 lakh lives had been saved in Assam alone due to urea stibamine therapy. The following table shows the effectiveness of the treatment:

Year	No. of cases treated	No. of deaths
1920	7188	2798
1925	60940	6365
1930	16430	953
1935	11100	845

(Annual public health report of the Province of Assam)

It is arguable that the decline in mortality was possible only because Brahmachari undertook drug manufacture in a unit established in his own house. He provided medicine free of charge to the kalaazar commission of Assam for a long time and sold the medicine at cost. Apparently there were very few hospitals in India that had not received a free gift of urea stibamine from Brahmachari. The cost of urea stibamine was Rs. 9 rupees and 15 annas, which, though more expensive than antimony tartarate, resulted in the saved

expense of hospitalization. He subsequently set up a partnership firm with his sons involved in manufacturing and research that functioned till the mid-1960s.

How was Brahmachari's approach to kalaazar different from the older colonial approach towards the disease?

First, and most important, is the effect of his research to produce an indigenous drug to treat kalaazar. The cost of treatment became so low that it was amenable to widespread use – its indigenous cost profile made it possible to think of the whole of the diseased population. On the other hand, in common with biomedical approaches that proliferate afterwards, his drug made it possible to treat the disease without the hazardous disciplinary approaches of segregation and public health engineering aimed at prevention. Paradoxically, his invention made it possible for the colonial government to think about large-scale treatment of those afflicted with the disease without worrying about the kind of political fallouts that would follow other methods like segregation.

Second, although Brahmachari was part of the colonial establishment, he saw his work in relation to needs of the large number of people who were suffering and dying of the disease. In his own words, "... I did not know then that providence had put into my hands a wondrous thing and that this little thing would save the lives of millions of fellowmen". How then would we try to understand Brahmachari's altruistic intervention and his drive to set up a small industry to produce urea stibamine? The spirit of the national movement during that period nurtured different desires: to do well in the pursuit of science; to make a mark for what would become Indian industry; and to establish a

critical standpoint with respect to colonial rule. Brahmachari's effort should be seen as an expression of these diverse drives and inspirations that marked the thinking of that time. Within this constitutive context however it must be recognized that his intervention in scientific, industrial and public health practice was both singular and uniquely effective.<sup>6</sup>

Finally, Brahmachari's desire to do well for ones' national community, to serve what would come to be called in other circumstances 'the hungry millions', should be seen in the context of a widespread ethic of *seva* that was part of the ethical and political formation of the nationalist struggle.<sup>7</sup> While a nationalist perspective would argue at length about the essential goodness that constituted this effort in contrast to the 'heartless strategies' of colonial rule, it would be necessary to point out that *seva* did a great deal to consolidate the ethical position of the nationalist ruling elite in the country. The nationalist ethical culture that provided Brahmachari with the stimulus to embark on his scientific voyage, to intervene for the good for his countrymen, shows in its other face, the political will to achieve the supremacy and legitimacy to govern the country.

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<sup>6</sup> The notion of practice used here draws on a philosophical argument developed in Tharu (forthcoming) that it is necessary to re-evaluate the concept of practice, as something that revitalizes and preserves the validity and effectiveness of the theoretical medical knowledge which purports to give that practice its essential meaning. In this view, studying the various adjustments and negotiations of practice in the field is a crucial endeavour if we are to understand how medicine actually works in India, and across most of the world.

<sup>7</sup>The concept of *seva* emerged as the seed crystal of social service and voluntary activism in the Indian nationalist struggle early in the twentieth century. Setting itself up as the demonstration of care towards native populations, *seva* began to function as a critique of what was seen as the callousness of colonial rule. While there were many organizations especially around Gandhi, that ran *seva* programmes, the ethic and stance of *seva* had a much wider and diffuse presence in nationalist thought. It is this broader ethic of *seva* that is being proposed here as one of the contextual factors that provide the ground for Brahmachari's enterprise. See Srivatsan, (2005),

Subsequent to Brahmachari's work, other pentavalent antimonials and aromatic diamidines were synthesized. Wellcome Burroughs developed sodium stibogluconate (pentostam), which is currently used in the treatment of kalaazar (Goodwin, 1995: 339-341).<sup>8</sup> As a typical example of the uncontrolled price regime in India, Sodium stibogluconate in its branded form of pentostam costs \$ 273 per patient where as the generic form (manufactured by Albert David Ltd. Calcutta) costs \$ 23 per patient. In contrast Brahmachari whose goal was to make urea stibamine as widely and freely available as possible, never patented this drug.

#### **Part IV: The contemporary context of kalaazar**

##### *Implications of colonial medicine for our times*

Implicit in the sandfly experiments and their search for a broader scientific solution is an absence of any concept of right of the native subject. Both the segregation experiments of Rogers and the sandfly transmission experiments indicate clearly that the biomedical category of kalaazar was developed and shaped within a coercive and somewhat disciplinary administrative practice related to colonial industry of the early twentieth century. Such an administrative practice was supported by an explicit and

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<sup>8</sup> Urea stibamine is a mixture of related compounds that require careful control of the manufacturing process. The reasons for shift away from the use of urea stibamine are not clear, but technical manufacturing difficulty has been suggested as one of them. In 1939, Stilbamidine was synthesized by Edwin and later used for treatment of Kalaazar in India. Pentostam or sodium stibogluconate was synthesized by Goodwin of Wellcome Trust, UK, studied in animals (1944) and later in clinical studies around the war (1947). It thereafter became the most widely used antimonial for treatment of kalaazar.

official ideology of a master race that was the basis of colonial rule in India. These experiments also clearly follow Western medicine's inclination towards governmental and biomedical control of infectious diseases that emerge in the non-Western world, coupled with a subsidiary concern for the cure of ill populations belonging to a subject race. It is here that we need to locate the difference between Brahmachari's focus on trying to cure all those suffering the disease, and the colonial efforts at prevention.

As we reflect on these historical events with an eye to the present, two aspects of contemporary reality present themselves: One, the weakness of the curative component in the government's primary health system that was established after independence is a sign of some continuities in perspective between the colonial state and the development state after 1947. For different reasons the colonial government and modern developmental state placed great priority on prevention- curative care was advocated as part of a strategy to prevent disease. In the case of kalaazar the colonial state paid attention to finding a cure for the disease only when it threatened to harm the white population. In the modern day state, the TB treatment program has been advocated as a global prevention strategy in the context of grim statistical picture of the TB epidemic. In both cases the patient's need for a cure is marginal, or secondary at best. Thus, Brahmachari's will to cure does not find a true inheritor in free India.

Two, the liberalized regime of the conduct of international clinical trials in India by clinical research organizations is an indication that we remain broadly within the epoch of biomedicine that began in colonial times. However, there are some changed

factors in the situation today: The ethics of international research at least theoretically insists on implementing a system of informed consent to ensure that those participating as trial subjects know what they risk. However, often in the practice of clinical research organizations, such informed consent becomes a travesty of the ethical intention that gave rise to it. Even so, the administration of medical research in the era of liberalization is not supported by an explicit and official ideology of racial superiority that formed the administrative foundation of research in tropical medicine in the colonial enterprise.

*Modern clinical trials of kalaazar and providing drug treatment through the public health system*

Kalaazar disappeared from scientific radar screen following DDT spraying for eradication of malaria, which accidentally killed the sandflies too, and led to the virtual disappearance of kalaazar between 1950-1970. Following the discontinuation of DDT spraying, kalaazar experienced a resurgence following the 1970's.

Dr. Shyam Sundar a rural physician from Bihar, and Dr. C.P. Thakur Professor of Medicine in Patna Medical College, have over the last four decades, focused our attention on the problem of kalaazar in Bihar. Dr. Shyam Sundar set up a kalaazar research centre. Dr. C.P. Thakur subsequently went onto become the Union Health Minister.

Shyam Sundar and Thakur demonstrated increasing unresponsiveness to sodium stibogluconate over the 1980's and 1990's (Lira R 1999). Over the last two decades they have carried out a series of clinical trials to establish the relative efficacy of high dose

sodium stibogluconate, amphotericin B (Sundar, 1997: 133-137), liposomal amphotericin and finally miltefosine.

They conducted an open labeled randomized controlled trial comparing oral miltefosine to parenteral amphotericin. They were able to demonstrate that oral miltefosine was as efficacious as parenteral amphotericin in curing visceral leishmaniasis (Sundar, 2002: 1739-46). This latter study was initiated in 1995 by the Special Programme for Research and Training in Tropical Diseases. The study was jointly conducted by Astra Medica (now known as Zentaris), which originally developed miltefosine, WHO and Government of India. WHO and Zentaris equally shared in the cost of conducting the trial.

Following the publication of the study results, this drug has been included in the public health programme for eradication of kalaazar from high prevalence districts in Bihar. The programme strategy detects cases through serological tests and then provides infected cases miltefosine treatment (Govt. of India).

The drug trials of Shyam Sundar and Thakur provide a different model of collaborative research practice based on local priorities (Karbwang, 2006). Both Shyam Sundar and Thakur are from Bihar. The latter was affected by kalaazar at a young age. His statements reflect his sensitivity to the experience of the disease, and to the socioeconomic profile of the disadvantaged. These local researchers have collaborated with pharmaceutical companies, government and international agencies on questions that they have defined and that are relevant to their context. They have focused on developing

locally relevant treatments and ensured that these can be made available through the public health system. Shyam Sundar established the Kalaazar Research Institute to provide treatment and research. He found that the majority of people in Muzaffarpur did not know the symptoms and methods of transmission. Only one-fourth preferred to use the public health system (Singh SP 2006). Shyam Sundar and Thakur worked towards providing improved treatment access through the government health system. Not only did they demonstrate the efficacy of an oral drug therapy, but they also established the validity of a simple dipstick method of screening (Sundar S, 2006).

### *Conclusion*

*The Musahars are recognized as a scheduled caste (SC). They survive on the margins of villages in isolated settlements. Their traditional occupation was hunting out rats from burrows in the fields. In return they were allowed to keep the grain and chaff recovered from the rat holes. In times of drought and food scarcity, the Musahars would resort to eating rats. Many Musahar families work as bonded laborers at brick kilns. [...]*

*The Musahars have mostly been denied the benefits of the government's food security and employment guarantee schemes. When they demand their rights, as they did in Varanasi district last year, the upper castes abused them and the official machinery said they were Naxalites. [...]*

*Union rural development minister Raghuvansh Pratap Singh visited Banthu village in Vaishali district of Bihar after 25 persons died of kalaazar in six months.*

*Banthu has a sizeable Musahar population and is surrounded by a host of 'VIP constituencies' represented by Singh, Ram Vilas Paswan, George Fernandes and Rabri Devi.[...]*

*"Kalaazar affects Musahars more than other communities because they are starving. The World Health Organization has set 2015 for its eradication. But as long as the Musahars continue to face food scarcity I do not see any relief from kalaazar in north Bihar," said Reghupati (who is also Singh's brother) of the Delhi-based Confederation of NGOs of Rural India.[...]*

*Fellow activist and Bihar Panchayat Help line convener Amar Thakur said the current kalaazar eradication programme was so devised that the impoverished Musahar had to spend nearly Rs 2,000 on tests to confirm the disease before they could become eligible for free treatment.[...]*

*About 300 Musahar families live in Banthu. In January, two brothers in their 30s died of extended starvation and kalaazar. The deaths led to protests by Reghupati and fellow activists. The district administration finally responded with Rs 25,000 cash compensation and a pucca house each for the widows, Sivanti Devi and Manju Devi, under the Indira Awaas Yojana. [...]*

*The cash went into repaying old loans. There was little food to eat inside the pucca houses when we visited them in early-September. "We do not know how our*

*children will survive the starvation after their fathers. Looking at how things have turned out for us, it is better if they never have to face such a future," the women said.[...]*

*The Musahars live in dilapidated mud and straw huts surrounded by pools of stagnant water during the monsoon, which are a breeding ground for the sand fly that causes kalaazar. "People need food first before they can think of hygiene or proper housing or education," Reghupati said. "Dealing with kalaazar means dealing with poverty and hunger. Nobody wants to do that in these times of globalization."*

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By Anosh Malekar

We have argued that the disease profile of kalaazar has its roots in the administrative history of the colonial rule, the commerce of the tea industry and the racial characterization of the native. Complicating this colonial profile, we have the substantial curative effects of Brahmachari's approach. He focuses on a cure for a disease of 'his fellowmen' and sets up an industry dedicated to non-profit production of urea stibamine, pointing to a new ethic that is focused on the providing a cure for the general population rather than on preventing the disease in the specific population of the plantation coolie. While the difference between the colonial government's approach and Brahmachari's indicates different forms of administrative intervention with different goals, both of these form part of the history of kalaazar treatment, giving it its characteristic profile. However, as we have noted, Brahmachari's intervention that focuses on cure has not been

successfully institutionalized in the primary health network set up by the development state in India. It is also clear that our current regime of curative medicine based on pharmaceutical drugs, of which Brahmachari's garage factory was an unwitting predecessor, also leaves much to be desired in terms of an effective regime of curative medical practice in India.

The similarities between the Shyam Sundar/Thakur and the Brahmachari approaches to kalaazar are striking. The sheer range of interventions—rapid diagnostic tests, epidemiological studies, treatment trials, dealing with drug companies, international agencies, setting up a research institute, working through the government health system—all of these are similar. The efforts of Shyam Sundar and Thakur in trying to provide an effective treatment are reminiscent of the work of Brahmachari. And yet there seems to be a subtle difference. The political and economic context of the eighties and nineties provides a different meaning to the efforts of Shyam Sundar and Thakur. Their effort could be seen as a new kind of activist medical practice, seen in its most successful form around the development of curative theories and practices of AIDS. Their efforts suggest that a health initiative that is rooted in a specific political situation need not be a distant dream. And yet, Thakur and Shyam Sundar's all too local initiative and its results are far from satisfactory. Why is this so?

An answer to this question emerges in the changing historical profile of health care in India. In the colonial situation, the rational solution to the problem was to take care of the epidemiological profile among the coolie population leaving the general

population well alone. In the situation in independent India, the logic of development prioritizes what is called the modern sector over what may be called the 'subsistence' territories such as North Bihar. This demographic prioritization results in a structural bias against any welfare measure in these 'backward' territories at all levels: budget, planning, infrastructure, and implementation. From the governmental perspective, so long as the problem remains endemic to some 'backward' regions of Bihar, it is on a controlled geographic margin of the modern sector— we need only to worry about the epidemics that begin to threaten the modern sector directly! Mapped on to this is the changing socioeconomic profile of those affected: away from the upwardly mobile Bhumihars and Yadavs, and towards the dalits as shown in the news extracts we have cited in the epigraphs to this essay and to the concluding section. Thus, while the kalaazar territorial demography is non-threatening, its social demography remains marginal to a nation that has a deeply rooted culture of disregard for the well being of those who do not belong to the upper and upwardly mobile castes.

The problem is better understood when we compare kalaazar to HIV/AIDS. AIDS provides a model wherein a marginal and stigmatized disease has changed dramatically in medical importance over a short period of time due to patient activism. Gay groups in US through their political force negotiated with governments, pharmaceuticals and drug licensing bodies to ensure that clinical trials were performed with patients' interests in mind (introducing concepts such as informed consent, expanded access), drugs were rapidly licensed and treatment became available to all who needed it. In Brazil, AIDS

activism figured prominently in the struggle against dictatorship, creating a strong pharmaceutical industry and a health system that provided AIDS treatment in the newly independent nation. Activism by AIDS and other related groups across the world pressured Kofi Annan to convene a United Nations General Assembly Special Session (UNGASS) on AIDS and develop the 3 by 5 initiative (to provide 3 million people across the world with HIV treatment by 2005). Indian pharmaceutical companies such as CIPLA cut anti-retroviral drug prices to 1 \$/day breaking the monopoly of international pharmaceutical companies of anti-retroviral drugs . All these have enabled the provision of universal access to HIV treatment across the world. A disease that was marginal, has through patient activism become a model for provision of equitable medical treatment. The activism and communitarian model of care have become constitutive elements of the cultural profile of AIDS today (Zachariah A, in press).

The development of drug treatments with Kalaazar also provides a contrast to the pharmaceutical driven model of drug development seen with ischaemic heart disease, where evidence based medicine provided the push for the explosion of clinical trials in the 1980's and 1990's. Only pharmaceutical companies could provide the resources for conducting these clinical trials. In the last three decades, drug companies have not only influenced the conduct and outcomes of clinical trials, but also the development of treatment practice guidelines by scientific bodies that favour their interests. Simultaneously they have determined the price of drugs that ensure that their products return a handsome profit. As a result of this model of research, we have practice

guidelines for ischaemic heart disease requiring treatments such as stent placement, bypass surgery and tissue plasminogen activator that are highly efficacious, but inapplicable and unaffordable across most parts of the world (Zachariah A, forthcoming).

Unlike the AIDS activists, kalaazar victims have not had the visibility of gay groups or the Brazilian freedom struggle, or Kofi Annan to battle with drug companies and pressure international agencies and governments to invest in research, policy and practice. The category of kalaazar today does not appear to have the political strength to mobilize governments, international agencies, pharmaceutical companies or the medical community to address it. On the other hand, when compared to the high profile tertiary care research to diagnose and cure ischaemic heart disease, kalaazar has not had the economic driver of the welfare state or pharmaceutical companies to commission scientific research and medical technology to find new and effective methods of cure. Kalaazar's cultural history does not provoke the kind of healthcare concern that has historically driven IHD type tertiary care. This is not suggest that any one kind of mode of development of knowledge related to a disease is either superior or preferable. The purpose is merely to highlight the manner in which the cultural profile determines the structure of the disease category and how knowledge and concepts related to disease are wired into the administration and practices of health care. Such a genealogical understanding of the disease as a cultural category may provide critical insights into the public health problem of Kalaazar today.

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