Towards a Critical Medical Practice

Reflections on the Dilemmas of Medical Culture Today

Edited by Anand Zachariah R. Srivatsan Susie Tharu

On behalf of The CMC-Anveshi Collective



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Table of Contents

Pre	face	ix
Abl	breviations	xiii
	Introduction: The Dilemmas of Medical Culture Today Anand Zachariah, R. Srivatsan and Susie Tharu	1
Sec	ction I: Genealogies of Medicine in India	35
1.	What Makes a Disease Marginal: Tracing the History of Kalaazar Anand Zachariah and R. Srivatsan	39
2.	PTSD, DSM and India: A Critique K. S. Jacob	57
3.	Medicine and Government: Histories in the Present Susie Tharu	69
	CTION II: HEALTH IN THE TIME OF DEVELOPMENT: IMARY HEALTH CARE, NUTRITION AND POPULATION CONTROL	93
4.	Working the Contradictions: Three Decades Sara Bhattacharji	97
5.	Andhra Pradesh: Ground Level Observations A. P. Ranga Rao	109
6.	The Career of Hunger: Critical Reflections on the History of Nutrition Science and Policy Veena Shatrugna	116

preventive health programmes, this chapter investigates the historical formation of modern medicine in the governmental mode. Modern medicine, it argues, is structurally answerable to government policy, and in recent time increasingly to the logic of tertiary medicine and not to the call of the sick patient. This is a key aspect of its current crisis. Short discussions of PTSD and cholera elaborate this genealogy.

What Makes a Disease Marginal Tracing the History of Kalaazar

Anand Zachariah and R. Srivatsan

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 per cent of the victims belong to the socially marginalised section. The disease is estimated to have killed over two hundred 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.

 $[\ldots]$ "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.

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 $\it kale dukh$, or black sorrow, was recorded in Purnea district. [. . .]

Kalaazar's Black Shadow on Bihar Dalits, Imran Khan, *Indo-Asian News Service (IANS)*, Patna, 3 May 2006

INTRODUCTION

Kalaazar or Indian visceral leishmaniasis (VL) is an important public health problem. 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 per cent 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 per cent of its victims are the poor and socially marginalised. 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 tuberculosis (TB) budget of approximately Rs 1,000 crores (2005–06), even after correcting for inflation and changing medical expenditure profiles, the kalaazar budget is clearly minimal. Why do AIDS, TB, or IHD 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 health care 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 1970s, and this is the historical or more precisely, genealogical perspective. 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. History will tell us how 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 both in shaping the concepts related to kalaazar at different points in its history, and 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 epidemics. Part I of this chapter 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 the second part 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 II of the chapter examines the initiative and contribution 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 recognise the new ethic of service that emerges with nationalism.

In Part III 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) ischemic heart disease (IHD), where tertiary care specialisation 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 I

A REVIEW OF COLONIAL HISTORY

Kalaazar Epidemics in Nineteenth-Century British India

The first recognised epidemic of kalaazar is recorded to have occurred in Jessore (now in Bangladesh) in 1824 with a mortality of around 75,000. From Jessore it spread to Nadia (1832), Hooghly district (1857), Burdwan district (1862), North Bengal (1872) and Bihar (1882) (Sengupta 1947: 281–87). During epidemic years the population used to fall by 15–30 per cent. The scale of mortality is noted from the report that the town of Jageer ceased to exist at the end of the epidemic that started in 1862.

These epidemics have to be understood in the background of a series of wars that occurred between the British and Burmese kings in the early nineteenth century that enabled the British to establish control over Assam. The British used the under-populated land in Assam to establish tea plantations in order to meet the colonial revenue crises. Rules to facilitate reclamation of wastelands encouraged European planters to clear forests and establish tea plantations. Sizeable private investments were made from England into the tea industry.² As local labour was considered recalcitrant, the British established a system of indentured labour that enabled them to obtain labour from outside the region at low cost.³

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 indenture 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" and using the notion of "cultural factors", according to which, local factors in the topography and climate of India caused the

disease (Kar 2003). 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.

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, it became clear that a miasmatic explanation was not sufficient and finding a suitable explanation became a critical issue for the colonial state.

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 . . . of the causes of anaemia which prevail among the coolies on the tea gardens. The scientific observer of the 'coolie's anaemia' or 'beriberi' . . . may well be employed to enquire into Kalaazar also"(ibid).

G. M. Giles the medical officer deputed for this investigation 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". Giles 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). While the analysis proposes a theory of infection, it immediately dilutes the governmental responsibility to find a cure by proposing a racial/ cultural predilection to the disease.

Giles' findings were unacceptable to the colonial government. The government went on to institute a second study of kalaazar causation within six years, deputing Leonard Rogers, a junior doctor in the Indian Medical Service (IMS), to enquire into the causes of kalaazar in 1896.

ANAND ZACHARIAH AND SRIVATSAN

Rogers 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 cause,5 which he called "site infection" suggesting that the soil was the reservoir of infection. Along with a plantation medical officer he performed elegant segregation studies to show that when a freshly arrived batch of coolies were quartered 400 metres away from the coolies lines, they did not contract kalaazar, whereas 16 per cent of those new coolies inhabiting old houses did. In addition, movement of unaffected coolies from houses where kalaazar had occurred prevented the occurrence of kalaazar.

Based on the successful experiments, Rogers recommended a policy of surveillance and segregation of the coolies from the affected area. Following these measures, kalaazar ceased to be a major problem in the tea plantations. It 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. 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 in 1903, William Leishman identified microscopic bodies similar to tryponosoma (which were known to cause sleeping sickness) in the spleen of an Irish soldier from Dum Dum who died of fever after returning to England and almost simultaneously Charles Donovan working in Madras General Hospital made a similar description. This was the first time that a pathogenic organism for kalaazar had been identified and the name Leishmania Donovani was given to them. Rogers too confirmed these findings and went on to demonstrate that Leishmania Donovani could be cultured in the test tube. These findings changed the entire way in which the disease was conceptualised.

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 n.d.).

Transmission Studies of Kalaazar

Following on Rogers' suggestion that kalaazar was an insect-borne disease, 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 to demonstrate transmission of the parasite from the sandfly to the animal host (Sengupta 1947: 281-87). Subsequent to this, Swaminath, Shortt and Anderson published an experiment that demonstrated transmission of kalaazar from sandflies to man (Swaminath, Shortt and Anderson 1942: 473-77).

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 relative mapping of disease and insect distributions to examine the causation of kalaazar is clearly a precursor of epidemiological studies that begin in the early twentieth century. 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 Bengal Presidency. This may have led to a proper explanation of the relationship between the kalaazar epidemics and the political history of the tea plantation industry. From this perspective, a seemingly pure research interest is governed by implicit boundaries of the political and administrative context within which it is conducted.

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, emphasis added). We may try and read in this acknowledgement the silenced voice of the tribal, which appears to be attempting to say, "We had no choice but to submit to a life-threatening trial".6

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 II

DEVELOPMENT OF DRUG TREATMENT FOR KALAAZAR:

A TWENTIETH CENTURY NATIONALIST AGENDA?

In medical history writing, Upendra Nath Brahmachari is an almost forgotten 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.⁷

Brahmachari who was working for the Indian Medical Service at the Calcutta Medical College and the School of Tropical Medicine found that tartar emetic that was advocated for treatment of kalaazar was associated with increased toxicity and lacked uniform effectiveness. Based on his knowledge of chemistry he worked towards synthesising non-toxic antimony preparations and in doing this he synthesised 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 n.d.).

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 and by 1933 it was estimated that about 3.25 lakh lives had been saved in Assam alone due to urea stibamine therapy.⁹

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 price. Apparently there were very few hospitals in India that had not received a free gift of urea stibamine from Brahmachari. 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. It was also an important aspect of the ethic of seva to do well for one's national community, to serve what would come to be called in other circumstances 'the hungry millions', as part of the nationalist struggle.11 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 recognised that his intervention in scientific, industrial and public health practice was both singular and uniquely effective.¹²

Subsequent to Brahmachari's work, other pentavalent antimonials and aromatic diamidines were synthesised. Wellcome Burroughs developed sodium stibogluconate (pentostam), which is currently used in the treatment of kalaazar (Goodwin 1995: 339–41).¹³ As a typical example of the uncontrolled price regime in India, sodium stibogluconate in its branded form of pentostam costs US \$273 per patient whereas the generic form (manufactured by Albert David Ltd., Calcutta) costs US \$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 III

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 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 from 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 programme 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 at best secondary. Thus, Brahmachari's will to cure does not find a true inheritor in free India.

Two, the liberalised regime of the conduct of international clinical trials in India by clinical research organisations 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, it is well known that in the practice of clinical research organisations, such informed consent sometimes becomes a travesty of the ethical intention that gave rise to it.

Modern Clinical Trials and Drug Treatment through the Public Health System

Kalaazar disappeared from scientific radar screen following dichloro diphenyl trichloroethane (DDT) spraying for eradication of malaria, which accidentally killed the sandflies too, and led to the virtual disappearance

of kalaazar between 1950 and 1970. Following the discontinuation of DDT spraying, Kalaazar experienced a resurgence after the 1970s.

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. They have demonstrated increasing unresponsiveness to sodium stibogluconate over the 1980s and 1990s (Lira et al. 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, liposomal amphotericin and finally miltefosine (Sundar 1997: 133–37).

They conducted an open labelled randomized controlled trial (RCT) 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). The study was jointly conducted by Astra Medica (now known as Zentaris), which originally developed miltefosine, the World Health Organization (WHO) and Government of India. The WHO and Zentaris shared the cost of conducting the trial equally. Following the publication of the results, this drug has been included in the public health programme for eradication of kalaazar from high prevalence districts in Bihar. 14

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 (S. P. Singh 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 2006).

Conclusion

The Musahars are recognised as 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. . . . The Musahars have mostly been denied the benefits of the government's food security and employment guarantee schemes. "Kalaazar affects Musahars more than other communities because they are starving . . . 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 nongovernment organisations (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 three hundred Musahar families live in Banthu. In January, two brothers in their thirties died of extended starvation and Kalaazar. The deaths led to protests by Reghupati and fellow activists. "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," said the widows of the men who died. [...]

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."

> Edited from *InfoChange News & Features*, October 2006 By Anosh Malekar

We have argued that the disease profile of kalaazar has its roots in the administrative history of colonial rule, the commerce of the tea industry and the racial characterisation 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 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 approach of the colonial government and Brahmachari 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, the form of Brahmachari's intervention that focuses on cure has not received policy priority 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.

There are some similarities between the interventions Shyam Sundar/ Thakur and those of Brahmachari. The 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 share a similar drive to find a cure to alleviate people's suffering. And yet there seems to be a subtle difference. The political and economic context of the 1980s and 1990s provides a different meaning to the efforts of Shyam Sundar and Thakur. Their effort could be understood 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 prioritises what is called the modern sector over what may be called the 'subsistence' territories such as North Bihar. This demographic prioritisation 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. 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 stigmatised disease has changed dramatically in medical importance over a short period of time due to patient activism. Patient activism has 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, "Peoples' Struggles Producing a Curative Public Health for AIDS", this volume). The development of drug treatments with kalaazar also provides a contrast to the pharmaceutical driven model of drug development seen with ischemic heart disease. As a result of this latter model of research, we have practice guidelines for ischemic 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.¹⁵

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 mobilise 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 ischemic 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 health care concern that has historically driven IHD type tertiary care. This is not to suggest that any one kind of mode of development of knowledge related to a disease is either superior or preferable. The purpose is 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 provides critical insights into the public health problem of kalaazar today. In addition, it gives us a glimpse of some of the broader issues of medical culture that need to be tackled in the search for an appropriate medicine for our context.

NOTES

- 1. 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 1960s 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 contemporary medicine's function. Foucault calls these studies *genealogies*. In some ways, what this chapter attempts is a genealogy of kalaazar that explains its characteristic profile. For a better understanding of the development of this perspective, see Foucault (2004, 2003 and 1994).
- 2. It is estimated that in 1914, Rs 302.3 million had been invested in joint tea stocks, the majority of investment coming from England.
- 3. 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).
- 4. 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 eighteenth century there was the intense study of the relationship between meteorology (temperature, humidity, rainfall) and disease. In the nineteenth 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.
- 5. The concept of infectious theory arose from the idea of contagion. Some diseases were termed contagious (e.g., smallpox) and others miasmatic in the seventeenth and eighteenth century. John Snow was the first to show that cholera was contagious, with the outbreak of cholera from the Broad Street pump (1854). It was with the identification of the bacteria for anthrax (1876) and cholera (1883) and with the formulation of Koch's postulates that germ theory gained acceptance. Louis Laveran first demonstrated existence of the malarial parasite in 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.

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

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

- 7. First, most of the allopathic drugs were imported and were largely based on raw materials that were exported from India. Second, 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.
- 8. At this time Paul Erhlich had synthesised sodium arsanilic acid for treatment of tryponosomiasis. Brahmachari thought that since arsenic and antimony were next to each other in the periodic table, he could substitute antimony for arsenic.
- 9. The table below 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

- 10. The cost of urea stibamine was Rs 9 and 15 annas, which, though more expensive that antimony tartarate, resulted in the saved expense of hospitalisation.
- 11. 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 organisations 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.

- 12. The notion of practice used here draws on a philosophical argument developed in Tharu ("Rethinking Practice(s)", in this volume) that it is necessary to reevaluate the concept of practice, as something that revitalises 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.
- 13. 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 synthesised by Edwin and later used for treatment of kalaazar in India. Pentostam or sodium stibogluconate was synthesised 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.
- 14. The programme strategy detects cases through serological tests and then provides infected cases miltefosine treatment (Government of India n.d.).
- 15. See Zachariah, "Development of the Cardiovascular Epidemic in India and Inappropriate Tertiary Care Treatment Guidelines", in this volume

PTSD, DSM and India A Critique

K. S. Jacob

Post-traumatic stress disorder (PTSD) originally described among United States Vietnam War veterans was introduced into the official Diagnostic and Statistical Manual III (DSM III) (American Psychiatric Association 1980). It has now come to be regarded as a standard long-term consequence of traumatic stress and has been identified and described from different parts of the world.

This chapter problematises PTSD and discusses the issues relevant to India. The label assumes specific etiology and distinct symptomatology. It medicalises normal human emotions to acute and severe stress, pathologises the person and invalidates his/her ways of coping with trauma. Its historical and social links are rendered invisible and the 'condition,' stripped of its original context, has been universalised. A category created after the Vietnam War is projected into the past, linked with description of other superficially similar conditions and gradually elaborated into its present form using a so-called scientific process. The diverse contexts under which the condition now exists is brought together as many strands, de-contextualised and subsequently unified into a single disease label.

EARLY HISTORY OF PSYCHOLOGICAL SYMPTOMS FOLLOWING COMBAT

Symptoms of anxiety have been described among soldiers in ancient Greek and Roman armies. However, the clinical details were first clearly documented by DaCosta during the American Civil War and described as *Soldier's Heart*. The horrific railway accidents, the World Wars and the Holocaust of the twentieth century prompted systematic descriptions of symptoms associated with traumatic stress. The dominant view during the first half of the twentieth century was that the traumatic events per se were not the *cause* of the post-traumatic symptoms. It was felt that reactions to traumatic events are transient and that only people with