

## **Making Up Leprosy in India**

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This chapter argues that the everyday experiences of people affected by leprosy in India – in common with other diseases in other places – are significantly shaped by actions at multiple scales, beyond both the biological effects of the disease and local explanations. These activities and discourses include, for example, dominant narratives in global health that are disseminated by bodies such as the World Health Organisation (WHO), or the interpretation at state and local levels of national and international health interventions and policies. When these narratives are acknowledged at all, there is a tendency to see them as effects of contemporary transformations clustered under the umbrellas of ‘globalisation’ and/or ‘neo-liberalism’. Such effects also tend to be seen as having the most significant impact on urban cosmopolitan elites: on, in other words, a relatively small proportion of the population. Here, however, I demonstrate that stimuli, beyond those immediately obvious, have long since been important; certainly since the colonial era, as the archives on leprosy policy amply demonstrate. This challenges the idea that diseases, and the cornucopia of local reactions to them – what we might think of as the social experiences of disease – are understood and experienced predominantly through vernacular idioms that are somehow separable and distinctive from those of biomedicine and health policies designated as international and national levels.

The lives of many of the people I worked with in rural South India – inhabitants of a self-run leprosy colony in coastal Andhra Pradesh, which I call Anandapuram<sup>1</sup> – had been fashioned not only by Indigenous ideas about disease causality but by global activities relating to leprosy that dated back at least a century. The facts, for example, that they were mostly converts from Hinduism to Christianity; that they had spent years as residents in mission hospitals before being unceremoniously discharged, despite no longer having homes to which they could easily return, in the mid to late 1950s; that they were so successful at begging in urban centres; and that funding from charities for income generation and social welfare programmes was on the decline in the present – *all* of these events were the consequences of complex interplays between ideas and actions at multiple scales.

Scholarship in medical anthropology has already demonstrated how the global is *always* remade in the local and that, in a liberalising India, the local, the global, and everything in between the two are becoming increasingly intertwined. My argument here, however, is that in respect of leprosy, at least, there have always been more than local influences at stake in determining how the condition is experienced. Related to this, I document how leprosy is framed, talked about, and understood within particular hegemonic narratives or, to borrow Foucault's phrase, 'discourses of truth' (1994, p. 31), which are themselves shaped beyond the contexts in which they are applied. One of those 'discourses of truth' is constituted by the stories used to frame the trajectory of particular diseases. Epidemic narratives, in particular, have come to mould the approaches taken by global policy makers to managing leprosy, despite the fact that leprosy is usually considered endemic in regions rather than epidemic. I begin with a review of how 'epidemics' have come to be defined in relation to global health, before exploring how epidemic narratives have, over the course of more than a century, helped shape the ways in which leprosy is responded to in the present. The resulting policy, co-produced by multiple stakeholders, has, I demonstrate along the way, had a profound impact on the everyday lives of those diagnosed with the disease in India.

## **Epidemics**

Epidemics have been defined as 'the occurrence ... of health-related events clearly in excess of normal expectancy' (Last, 2001, p. 60). However, although epidemics are defined as such by the act of counting, they can also 'be made to appear or disappear (accounting and recounting), depending on the interests of the state or investigators' (Herring & Swedlund, 2010, p. 18). Who, precisely, the 'state' or 'investigators' are, in the case of leprosy in India, warrants further unpacking, since there are a number of complex agents – from grassroots NGOs and the larger aid agencies that often fund them to the various levels of the Indian government and the international bodies, like the WHO – with, as it were, skin in the game. Each of these agents has interests in making leprosy more or less visible at different moments, and it is their collective actions, often in unforeseen ways, that shape the ways people on the ground in India see and experience leprosy. Getting the label of 'epidemic' attached to a condition can also have a lot to do with its capacity to get the attention of or to terrify a wider public (Leach & Dry, 2010, p. 1).

Epidemiologists recognise that outbreaks of diseases do not simply happen but, as the global Covid-19 pandemic made clear, result from complex entanglements between the economy, demographics,

and microbes (Barrett, 2010, p. 83). Anthropologists have further demonstrated that not only are the social and the biological inextricably intertwined, but that each constitutes the other. Epidemics, Shirley Lindenbaum (2001) argues, shape society: the Black Death, for example, led to new ways of understanding God or explaining the meaning of death; cholera led to new notions of public health; Covid-19 – at least in the global north – has brought about rapid changes in how people engage with online technologies. As Lindenbaum puts it, epidemics are ‘lightning rods for eliciting the particular terrors that monitor the social forms and cultural values of different communities’ (2001, p. 364). But societies also constitute their epidemics, as Charles Briggs shows vividly in the case of a cholera epidemic in Venezuela in the early 1990s (2010, p. 39).

In making these arguments, both Lindenbaum and Briggs draw on Rosenberg’s (1992) contention that official perspectives on, and responses to, epidemics are structured by particular dominant narratives: reactions formulated by pre-set templates that are already ‘well established in media and public discourse, and in the arguments and strategies of international agencies and many governments’ (Leach & Dry, 2010, p. 4). These narratives, in turn, influence the form that epidemics take. Rosenberg identified four stages – or Acts, to use his dramaturgical metaphor – that structure the trajectory of an epidemic. First, they start at a particular moment in time – what others have called the ‘outbreak narrative’ (Wald, 2008, p. 2). For whatever reason, a disease comes to be seen as a much bigger problem than it was previously. Particular historical events, rather than just the increase in numbers diagnosed with a condition, might precipitate this moment. Second, the epidemic proceeds onto a stage limited in space and duration, and the dramatic tension increases as the epidemic plays out. Third, it becomes a crisis of individual and collective character (the moral aspect of an epidemic, within which particular people are made culpable for the spread of disease). Fourth, and finally, it drifts towards closure.

In exploring the historical journey that leprosy has taken in India (and it has not been a unilinear one), I too draw on Rosenberg’s four stages to explore how well the disease and its official representation by health policy makers might have found fit with – or been shaped by – this narrative template. My argument is that some of the problems that have been encountered by public health policy in its response to leprosy have to do with the fact that those responses have been over-determined by fixed narrative templates rather than by paying adequate attention to other stories told about leprosy, such as those of people living with the disease. As Dry and Leach

point out (2010, p. 15), the narratives of powerful actors and institutions tend to dominate policy and, in doing so, obscure alternative narratives. They also shape the experiences and beliefs of people affected by leprosy on the ground. Being discharged from hospitals in the late 1950s after many years of being inpatients, for example, or the decline in NGO funding for social welfare projects post 2000, had profound effects for those I worked with in Anandapuram. These occurrences were also, I suggest, consequences of framing leprosy within particular dominant narratives.

To make my broader case – that leprosy policy in India is influenced by more than the situation facing health services in India – let us first go back to the India of the end of the second part of the 19th century.

### Historical shaping of leprosy

The first major recorded investigation into leprosy in India was undertaken in 1862 by the Royal College of Physicians. Published in 1867, it concluded that leprosy was probably hereditary. Although this refuted the Biblical image of leprosy as highly contagious and spread by touch, by the mid-19th century, the anti-contagionists among medical scientists ‘had the upper hand in the long running debate with contagionists over public health policy’ (Edmond, 2006, p. 54). The prevailing view was that solutions to public health problems lay in environmental and sanitary reform. Such views, as Edmond notes, met less resistance than they otherwise might have because, following the abolition of slavery, the rights of colonial subjects were becoming a serious concern. The Mutiny of 1857 had shaken the colonial authorities, marking the beginning of a trend towards less interventionist policies (Kawashima, 1998, p. 68). The experience of other epidemics, notably the bubonic plague (1896–1897) and, later, the Spanish influenza pandemic (1918–1918), likewise shaped policy. As the historian David Arnold explores, draconian measures aimed at curbing the spread of plague, enshrined in the Epidemic Diseases Act of 1897, met with such hostility from the public that persuasion, rather than coercion, came to be the dominant approach (2015, pp. 113–118). Public health policy is made in particular socio-political climates.

Henry Vandyke Carter, HM Surgeon General in the Bombay Army and a name that dominates the literature on leprosy during that era, drew similar conclusions to those of the Royal College of

Physicians. In 1874, he published three reports. All of them shared the broad finding that leprosy ‘... is decidedly an hereditary complaint ... capable of being propagated by intermarriage, and by marriage of the affected with perfectly healthy people’ (1874a, p. 16). As such, leprosy was not prone to spreading in the way usually associated with epidemics, but it was nevertheless already subject to similar moral framing. Leprosy, Carter warned, could lead to moral degeneration (1874b, p. 23). As with the plague and influenza (Lone, 2020), its spread was also blamed squarely on the ignorance and insanitary practices of the local population rather than on structural inequality and poverty. ‘Absence of fear of leprosy’, wrote Megan Vaughan, in relation to colonial Africa, ‘was seen as the mark not of humanity but of the extreme primitiveness of such societies’ (1991, p. 80). While top-down intervention was deemed necessary to control disease, culpability was always firmly situated at the bottom. This was also the case elsewhere for other diseases. Delaporte et al., for example, noted how, in trying to counter the cholera epidemic that hit Paris in 1832, one class sought to control another, which it saw as powerless but dangerous: ‘The ruling class cast the working class as a threat to public welfare, as both carriers of disease and fomenters of risk’ (1989, p. 8). As with other diseases – including, for example, HIV/AIDS in the latter decades of the 20th century – the control and cure of leprosy in 19th century India were framed not simply as matters for biomedicine to deal with, but in terms of the *behaviours* of those with the disease. Treatment for leprosy, Carter told us, should include ‘... mental discipline, rectification of injurious habits and the enforcement of self-control’ (1874c, p. 192).

However, it was as Carter’s studies were being published in the early to mid 1870s that Dr. Armauer Hansen was being credited with having identified the bacillus *Mycobacterium Leprae* in the tissues of people affected with the condition. This discovery began to tip medical opinion towards the view that leprosy *was* contagious. J. M. Cunningham, the Government of India’s Sanitary Commissioner and a vocal critic of Carter, argued as a consequence that leprosy was, indeed, contagious (Buckingham, 2002, p. 147). E. C. Bayley, Secretary to the Government of India, joined in the attack, which appeared to be getting personal, in 1876. He commented:

Dr Carter seems to be getting rather beyond a joke. So far as I understand his researches have hitherto been utterly fruitless and useless to science. I am disposed to hint that the Government of India thinks that Dr Carter’s special deputations should now cease, otherwise he will go on being deputed and writing accounts of his deputations for ever to no reasonable use.

(cited in Buckingham, 2002, p. 149)

Bayley's remarks are a good example of the fact that public health perspectives on a disease are politically constituted. Commentary on leprosy was also about institutional politics and struggles; in this case between the Indian medical service and the sanitary department. Importantly, the colonial records also demonstrate that such perspectives are seldom homogenous and coherent, even though they often come to be presented as such.

Hereditary or contagious, Carter and others continued to argue for segregation of those with leprosy (Carter, 1876, 1884). With Hindu society blamed for making outcasts of those who had the disease, segregation into asylums, with men and women separated, was considered desirable, even when fearful of fuelling indigenous unrest prevented commentators from demanding that it should be compulsory (Cunningham & Lewis, 1877, p. 30). It is also worth noting that opportunities for segregation were only made possible by Christian missionaries' willingness to set up leprosaria. Biblical understandings of leprosy, as the missionary literature bears witness to, presented 'the leper' as a rich opportunity for demonstrating Christian love.

Positions on segregation were regionally quite variable, however. The under-secretary of state to the Government of India wrote to the Secretaries of State governments in 1877 to ask whether gender segregation of patients was being strictly enforced. In Madras (now Chennai), there were men diagnosed with leprosy locked up in separate wards at night (C. M. Thompson, Selection 1896, p. 2), while in Bombay (now Mumbai), police were informed if incarcerated lepers absconded (*ibid*). Elsewhere, though, no special rules were practised, and in some asylums affected people were allowed to cohabit with their marriage partners and sometimes even to marry. As I pointed out earlier, however, positions on segregation were shaped not only by biomedical knowledge but also by factors such as post-slavery concerns about the rights of colonial subjects and post-mutiny fears of rebellion. The authorities' perceptions of public opinion drew in particular on their relations with higher castes and major traders, a relatively small section of society, and their pronouncements reflected their fears of introducing measures that might be challenged by these groups and provide a platform for the nationalist movement (Buckingham, 2002, p. 162ff). For example, the Madras Mahajana Sabha – an organisation made up predominantly of middle-class merchants – prefigured the logics of those who later resisted plague controls on the population when they urged that restraints on leprosy sufferers in employment should only be those that 'will least interfere with their freedom of action' (Suntharalingam, 1974, p. 192 cited in Buckingham, 2002, p. 166). They argued that fines rather than confinement should be imposed 'to prevent lepers from following the

occupation of vendors of articles, of dress or of food and drink' (Suntharalingam, 1974, p. 192). There was a subtle balancing act to be done between protecting the population – and particularly the colonial powers – and guarding against mutiny. 'Attempts to eliminate "tropical diseases" were tightly coupled', as Herring and Swedlund explained it, 'with colonial ideologies and projects ...' (2010, p. 15). Indeed, the very fashioning of leprosy as a *tropical* disease – one that distinguished it from the diseases of westerners, that made it *other* – conveniently overlooked the fact that leprosy had earlier flourished in Europe and still existed there in pockets.

It was an event on the opposite side of the world in Hawaii, however, that really started to ring alarm bells and demand action from the colonial authorities in India, a clear indication that public health decisions are seldom *just* about the populations subjected to them. In April 1889, Father Damien de Veuster, a Belgian Roman Catholic priest who had worked for 16 years in a leprosy colony in Hawaii, died after contracting leprosy. Although, as we now know, leprosy is not fatal, the very fact that Father Damien became publicly known to have *had* the disease offered strong evidence that leprosy was *not* hereditary and that, if he could contract it, then so could anyone. Previously the threat had been limited; it was about managing the potential for moral decline among native sufferers. Now it posed a potential threat to people beyond Indigenous inhabitants of the colonies. The title of a pamphlet penned by Archdeacon H. P. Wright – 'Is England in Danger?' (1885) – made explicit a central question that guided colonial health policy in India.

Leprosy was being characterised for the first time, at least in some quarters, as an *epidemic* that was striking right at the heart of Empire. Note, too, the military metaphors that were deployed in this discussion: leprosy was something that could, in Wright's description (1885), 'slay' whole populations. Other, more recent, missionary pamphlets I came across, with titles such as 'Battle against Leprosy' (Martin, 1985), used the same tropes. This, again, was connected to the abolition of slavery: leprosy was seen as spreading in the colonies to which indentured labour from India had been sent to take on the jobs vacated by slaves.

In response to the heightened interest in the disease that followed Father Damien's death, a National Leprosy Fund was instituted in India, which appointed a Leprosy Commission to tour India in 1890–1891. Such activities, as the philosopher Ian Hacking (1998) shows, in themselves help to constitute a disease in a particular kind of way, as a particular kind of object. The findings of that

Commission, that leprosy was only mildly contagious and that legislation either enforcing segregation or restricting marriage was thus unnecessary, resonate surprisingly closely with contemporary biomedical opinion (1893, p. 265). Nevertheless, perhaps as evidence that the narrative arc into which leprosy was being fitted carried more weight than scientific findings *per se*, 6 out of 11 members of the special committee that was convened to review the conclusions of the Commission's report were strongly opposed to the suggestion that the disease was only mildly contagious. Instead, they reported, *contra* the tone of the report, that 'isolation is the best means of preventing the spread of the disease ... [and a] system of obligatory notification and isolation ... is recommended to all nations' (Currie, 1909, p. 1361, cited in Gussow and Tracy, 1970, p. 435). The development of germ theory, as Laura Otis (1999) points out, *increased* fear of 'the other' rather than tempered it.

However, this fear of leprosy at this time – as for subsequent epidemics – seemed to be being stirred more by the colonial authorities than by concerns of the general population. The Chief Commissioner himself warned that compulsory segregation would be 'repugnant to public opinion' and, in 1889, the Surgeon General to the Madras Government had noted that the 'lower classes do not seem to have any special dread of associating with a leper, beyond that which might be due to his loathsome appearance' (Selections, 1896, p. 29). The Leprosy Commission that toured India in 1890–1891 concurred: 'That the native ordinarily does not fear the disease', says the report, 'may easily be gathered from the fact that in bazaars leprosy vendors are not rarely found selling food or sweets' (1893, p. 265). Even as late as the 1940s, we are told, in a manual on Indian village health, that: 'Untreated lepers remain infective and at present there is nothing, *not even public opinion*, to prevent their mixing freely with their families and the public' (Norman-Walker, 1944, p. 41 *my italics*).

While this jars with the more contemporary view that the leprosy stigma is a consequence of superstition and backwardness rather than public health policy, it remains consistent with the perspective, still perpetuated in popular media, that leprosy is spread by ignorance and a lack of education. Explaining recent surges in the numbers of people diagnosed with leprosy in some of India's poorest states, for example, 'ignorance has been blamed for delays in new sufferers seeking treatment', reports Dean Nelson in the British newspaper *The Telegraph* (Nelson, 2012). Comments following a *Guardian online* piece (24 March 2011) on the same topic likewise targeted superstition and misunderstanding as the causes of leprosy's persistence in India. In either case, what was



perceived as Indian – or, more specifically, Hindu – society, bears the blame. It is portrayed *either* as ostracising those with the disease or as irresponsibly blasé about the risk of contagion. To what Indians themselves *actually* thought, as opposed to colonial representations of their thinking, we shall return.

Staying for the moment with the archives, what we have seen played out through the colonial reports of the late 19th century are what might be seen as the first three stages of Rosenberg's drama of an epidemic. We have a disease that fairly suddenly comes to be seen as a much bigger problem than it was in the past – 1889, with Father Damien's death, was a watershed moment (even though, in reality, the moment was much more dispersed and less linear). The commissions, reports, and actions that followed, and the institutional politics that are played out through the correspondence of the various colonial authorities involved, certainly conform to the increase of dramatic tension that Rosenberg identifies. So, too, does the disease become characterised as a crisis of individual and collective character (Rosenberg's third stage): it is utilised to say something about the general Indian public – it highlights *difference* – as well as something more specific about those who actually have the disease.

What we miss, however, is the fourth and final stage: the 'drift towards closure'. The narrative demand for such closure, even when such closure cannot plausibly be achieved, is what, I argue, has driven subsequent international *and* local leprosy policies. And it is this framing of leprosy within a narrative template formulated to imagine the trajectories of epidemic diseases that has, I suggest, caused so many problems for sufferers of the condition. To explain what I mean by this, we need to move beyond the colonial era to consider what happened next.

## **Leprosy in India post-independence**

Leprosy was publicly recognised by the post-independence Indian Government as a health problem through its National Leprosy Control Programme (NLCP), launched in 1954–1955. The scene facing the authorities then was rather different to the one that had initially troubled colonial medicine, when there was no effective cure, and when containment by segregation was touted as the most effective way of curtailing the disease. By the 1950s, Dapsone – an anti-bacterial drug which had first been synthesised in 1908 – came to be recognised as an effective anti-leprosy drug. A retired leprosy

doctor I knew, one who had worked for the Christian leprosy hospital in which most of my interlocutors had been treated, told me:

Before the late 1950s, early 1960s, work with leprosy patients was about care rather than cure: bandaging wounds, massaging with oils ... The hospital was a colony environment with a diverse profile of people living in families, some of them doing work around the place. They were given food rations and they cooked for themselves. But then Dapsone came on as the major control drug – which meant that people could be cured – and that coincided with a change of management at the hospital. They observed a cycle, that people were cooking and burning their hands where they had no sensation, so they decided that food should be cooked and served centrally, and that the patients should stay in wards, not in families. This was a big shift in disease control: with patients not allowed to stay there as families, many of them left and set up [their own squatter colonies]. I'd say that [these were] really the natural outcome of [local mission hospital] policy at the time.

In many cases, leprosy sanatoriums also started releasing patients on the basis that they were cured and no longer in need of their support. The fact that many of those living in such places had become institutionalised and had no home to return to was the key reason that my oldest interlocutors founded the squatter settlement in which I came to do fieldwork 25 years later.

Although many people were or became Dapsone resistant, Clofazimine (trade name Lamprene) was identified as effective against leprosy in 1959 and, by 1981, multi-drug therapy (MDT) had been introduced by the WHO. It usually included Dapsone, Lamprene, and Rifampicin (the antibiotic), and proved highly effective against the condition, curing people in some cases within six months. It is still the form of drug treatment in current usage, although a vaccine is being worked on.

The renaming of India's leprosy programme as the National Leprosy Eradication Programme (NLEP) in 1983 thus came on the heels of this advance in drug treatment for leprosy and, with it, a commitment from the then Prime Minister, Indira Gandhi, to eradicate leprosy from India by the year 2000. In 1991, at the 44th World Health Assembly the global community also resolved to eradicate leprosy as a public health problem by the new millennium. So here, finally – a full century after leprosy first became identified as a major colonial public health problem – we have what

could be characterised as the beginning of the final act in the epidemic narrative: the combating of the disease. The possibility of imagining eradication, I suggest, comes not just from advances in drugs to treat leprosy, but also from the wider context created by the eradication of smallpox a few years earlier in 1977: the notion of freeing the world from infectious diseases had become a possibility of thought in the wake of this development. Diseases now *could* be eradicated.

By the time I began fieldwork in Anandapuram in 1999, this millennium deadline was about to pass unmet, even though the definition of what 'elimination' meant had been qualified by the WHO as meaning a prevalence rate of less than one case per 10,000 members of the population; a prevalence rate at which, according to the WHO, leprosy would eventually die out naturally. This remained the goal at the third International Conference for the Elimination of Leprosy in 1999, when the Global Alliance for Leprosy Elimination was also launched. At that time, there were around 800,000 new cases still emerging every year (lepra.org.uk).

The WHO claimed that leprosy had been *globally* eliminated by 2000, because the average international prevalence rate had dropped below one per 10,000 members of the population. Rates in several countries, however, India included, remained stubbornly above this figure. Launching its new initiative, the 'Final Push Strategy', the WHO declared that, having eliminated leprosy at global level, its target would now be to 'eliminate the disease at a national level from every country in the world by the year 2005' (WHO, 2003, p. 10). The NLEP fell in line with this international strategy, beginning to integrate its leprosy services, as the WHO strategy required, into its general healthcare provisions. Such a strategy would not only be more cost-effective, the WHO claimed, but also offered a simplified approach to both diagnosis and treatment that could be provided closer to the patient (ibid: 7). Such measures were being discussed, at ground level, during my 1999–2000 fieldwork, when leprosy workers I met were fearful of losing their jobs. They expressed concern that non-leprosy specific health workers were likely to have the same prejudices against people affected by leprosy as the general population. Leprosy charities were also uncertain about the future: even if the disease had been entirely eradicated, those already disabled with the disease would be around requiring support for a long time to come, but there was a fear that positive headlines reporting leprosy's demise (which, like Mark Twain's prematurely reported death, were an exaggeration) could lead to a substantial reduction in funds available for existing patients. Cured but physically impaired people affected by leprosy themselves expressed similar fears: there was a concern among my interlocutors that elimination of leprosy would eliminate their own identities as excluded members

of the population. 'What will become of people like us?' as one elderly man expressed it to me. 'They tell us that leprosy will be gone. But we'll still be here, and we'll still need support'. For those whose lives had already been radically changed by leprosy (and its management), the prospect of elimination was something to fear as much as it was to celebrate.

Nevertheless, the statistics continued to move, albeit slowly, in what, from a global health perspective, was the right direction. By 2003, according to the WHO, there were only 600,000 new cases emerging every year and, by the end of 2005, India had achieved a national prevalence rate of 0.95 per 10,000: below the 'elimination' target. The final act in Rosenberg's epidemic narrative appeared at last to have been played out. 'India achieves leprosy eradication target' screamed a headline in *The Hindu* newspaper on 31 January 2006, below which – under the caption 'Fighting the scourge' – India's then president, Abdul Kalam, is pictured inaugurating the Anti-Leprosy Fortnight in New Delhi. As is buried in the fourth paragraph of that same story, however, six states – Bihar, Chhattisgarh, Jharkhand, Orissa, Uttar Pradesh, and West Bengal (between them making up more than 40 per cent of the population) – still had prevalence rates of between 1 and 3 per 10,000. In the same way that global averages scaled the leprosy statistics, so did nationwide figures miss the point that plenty of new cases were still being identified in parts of the country. In 2009, of the 244,769 new cases reported across the world, 133,717 of them still came from India (Patro, Madhanraj, & Singh, 2011), and press reports were reporting similar numbers more recently (130,000, according to *The Guardian*, 127,000 according to *The Hindu* – which also noted that the prevalence rate in Chhattisgarh was still 1.69). Newspapers and other media that had celebrated the NLEP's success in bringing leprosy under control in 2006 now expressed horror that cases were still emerging at an apparently high rate and rising.

2018 saw the launch of the Global Partnership for Zero Leprosy, a coalition of groups that, as its website proclaims, are 'committed to ending leprosy'. Its action framework sets its ultimate goal as being not only to eradicate the disease but all associated disability, discrimination, and stigma, although – other than being after 2025 – no definitive date has yet been set for this. Act Four continues.

## Emic narratives

There is not space here to offer a detailed exegesis of what might be thought of as more locally specific beliefs and actions in relation to leprosy that are not captured by the selective historiography above (see Staples, 2007). Ayurvedic explanations – and those that appear in the Laws of Manu, from the same period, around 3,500 years ago – suggest that leprosy was considered a punishment (or a lesson) for violations of various forms of conduct in previous lives (Wise, 1845; Trawick, 1992): a consequence, in other words, of *karma*. Improper eating (eating the wrong food or eating it at the wrong time), bathing, or sexual transgressions all find their way into elaborate lists of proximate causes (de Bruin, 1996; Wise, 1845, p. 27). There were also more localised explanations: in the village where Berreman (1984) worked in Tamil Nadu, for example, leprosy was seen as a curse from the goddess Yellamma. My own interlocutors, however – partly because of their conversions to Christianity, although this might be a more general trend in the South – seldom made reference to Hindu notions of *karma* or talked about leprosy as a curse. When they discussed treatment, this was generally framed within biomedical idioms, within which ‘English medicines’, as allopathic medicines were termed, were seen as vital for cure. Causes, of leprosy as well as other diseases, were also described in what could be interpreted as simplified humoral terms, rooted in classical Ayurveda. Disease in general, for example, was often caused by imbalances between hot and cold in the body, and daily routines – from what to eat to when and where to bathe – were frequently designed to maintain a proper balance between the two (Staples, 2007). People also took steps to avoid the evil eye, a potential cause of misfortunes of various kinds, as well as witchcraft (see, again, Staples, 2007). At the same time, stories about Jesus curing the leper were also very popular, suggesting why conversion to Christianity had appealed to many of my interlocutors.

My friends’ hybrid explanations, however, were also complicated by the fact that while most of them claimed *not* to believe in a connection between past actions and current health – they did not, in short, profess a belief in *karma* – several nevertheless invoked such connections in telling moral tales to warn others. Guruswami, for example, an elderly, medically cured but physically impaired former leprosy patient, told a younger male friend that his own leprosy had been caused by the fact that he had slept with so many women when he was younger. Leprosy, he warned, was a punishment from God (in this case a Biblical one) for his sinful behaviour. When we were alone later and I asked him if he really thought this was the case he laughed and said that of course he didn’t; leprosy was, he said, like other diseases, caused by bacteria. My point, then, is not only that local understandings of leprosy were already infused with knowledges drawn from elsewhere – Christian

beliefs, Ayurveda, karmic explanations, and biomedicine all, already, disturb clear cut distinctions between the global and the local – but that the stories they *did* share were not necessarily presented as factual but were often used allegorically.

## Conclusion

Ideas about leprosy in India – what caused it, what the correct response to it was – and the consequences of those ideas were, as the above shows, multiple and complex. Influences included the internal politics of policymaking departments; the Biblically informed perspectives of missionary medicine; and the colonial fashioning of leprosy as a *tropical* disease in contradistinction to the kinds of diseases to which white Europeans were susceptible. Events not specific to India, such as the abolition of slavery in the 1830s, which led to indentured Indian labour migrating to British colonies across the world, had important implications for the epidemiology of leprosy. So too did the medical breakthrough that rendered leprosy curable for the first time: for my own informants, it led to the very existence of the squatter settlement that, for subsequent generations, has become a natal home, allowing leprosy and notions of ‘the leper’ to endure in space and time. Regionally specific ideas about leprosy both exist alongside and are shaped by contexts provided by the very particular confluence of different circumstances that I have described.

In terms of the ‘epidemic narratives’ discussed above, a practical answer to the question of why leprosy has proved so resilient to elimination was provided by leprologists Lockwood and Suneetha (2005), who argued that there was no firm evidence that leprosy would die out at a predefined level of prevalence rate, and that global and nationwide statistics anyway distorted local realities by including countries and states where the prevalence rate is virtually zero. With antibiotics alone insufficient to control infection, they suggested that leprosy might better be seen as a ‘chronic stable disease’ rather than an ‘acute infectious disease’ susceptible to elimination strategies (ibid). The subsequent refusal of leprosy to go away suggests that they might have been on to something. Such an image, however, does not fit well into the fourth act of Rosenberg’s narrative arc. Leprosy, like other diseases, lives on and endures in bodies (including those which have been biomedically cured), in funding arrangements and various imaginaries that resist the dream of elimination. And in the same way that medical evidence that leprosy was contagious in the late 19th century did not prevent those who had invested heavily in other arguments to cling to the idea that it was

hereditary, so too has the contemporary elimination narrative continued to frame how leprosy is understood and how policy is formulated.

## Note

1. A pseudonym.

## References

- Anon. (1896). *Selections from the Records of the Government of India Home Department, No CCCXXXI, Papers Relating to the treatment of leprosy in India from 1887–95*. Calcutta.
- Arnold, D. (2015). Disease, rumor, and panic in India's plague and influenza epidemics, 1896–1919. In R. Peckham (Ed.), *Empires of panic: Epidemics and colonial anxieties* (pp. 111–130). Hong Kong: Hong Kong University Press.
- Barrett, R. (2010). Avian influenza and the third epidemiological transition. In D. A. Herring & A. C. Swedlund (Eds.), *Plagues and epidemics: Infected spaces past and present* (pp. 81–94). Oxford, UK: Berg.
- Berremen, J. M. (1984). Childhood leprosy and social response in South India. *Social Science & Medicine*, 19(8), 853–865.
- Briggs, C. L. (2010). Pressing plagues: On the mediated communicability of virtual pandemics. In D. A. Herring & A. C. Swedlund (Eds.), *Plagues and epidemics: Infected spaces past and present* (pp. 39–60). Oxford, UK: Berg.
- Buckingham, J. (2002). *Leprosy in colonial South India: Medicine and confinement*. London, UK: Palgrave Macmillan.
- Carter, H. (1874a). *Reports on leprosy (2nd series)*. London, UK: HMSO.
- Carter, H. (1874b). *Report of leprosy and leprosy asylums in Norway; with references to India*. London, UK: HMSO.
- Carter, H. (1874c). *Leprosy and elephantiasis*. London, UK: HMSO.
- Carter, H. (1876). *Report of a Tour in Kathiawar*. Printed at the expense of the Chiefs of Kathiawar.
- Carter, H. (1884). *Memorandum on the prevention of leprosy by segregation of the affected*. Bombay, India: Government Publications.
- Cunningham, D. D., & Lewis, T. R. (1877). *Leprosy in India*. Calcutta, India: Office of the Superintendent of Government Printing.
- Currie, D. (1909). Public health report, The Second International Conference of Leprosy, Bergen, Norway, August 16–19., 24(2).

- de Bruin, H. M. (1996). *Leprosy in South India: Stigma and strategies of coping*. Pondy Paper in Social Sciences. Pondicherry, India: Institute Francais de Pondicherry.
- Delaporte, F., Goldhammer, A., & Rabinow, P. (1989). *Disease and civilization: The cholera in Paris, 1832 (MIT Press)*. London, UK: MIT Press.
- Edmond, R. (2006). *Leprosy and empire: A medical and cultural history*. Cambridge, UK: Cambridge University Press.
- Foucault, M. (1994). Two lectures. In M. Kelly (Ed.), *Critique and power: Recasting the Foucault/Habermas debate* (pp. 17–46). Cambridge, MA: MIT Press.
- Gussow, Z., & Tracy, G. (1970). Stigma and the leprosy phenomenon: The social history of a disease in the nineteenth and twentieth centuries. *Bulletin of the History of Medicine*, 44, 425–449. Baltimore, MD: Johns Hopkins University Press.
- Hacking, I. (1998). *Mad travelers: Reflections on the reality of transient mental illnesses*. Cambridge, MA: Harvard University Press.
- Herring, D. A., & Swedlund, A. C. (Eds.). (2010). *Plagues and epidemics: Infected spaces past and present*. Oxford, UK: Berg.
- Kawashima, K. (1998). *Missionaries and a Hindu state: Travancore 1858–1936*. New Delhi, India: Oxford University Press.
- Last, J. M. (Ed.) (2001). *A dictionary of epidemiology* (4th ed.). Oxford, UK: Oxford University Press.
- Leach, M., & Dry, S. (Eds.). (2010). *Epidemics: Science, governance and social justice*. London, UK and New York, NY: Earthscan.
- Leprosy Investigation Committee. (1893). *Leprosy in India: Report of the leprosy commission in India 1890–91*. Calcutta, UK: Superintendent of Government Printing.
- Lindenbaum, S. (2001). Kuru, prions, and human affairs: Thinking about epidemics. *Annual Review of Anthropology*, 30, 363–385.
- Lockwood, D. N. J. & Suneeta, S. (2005). Leprosy: too complex a disease for a simple elimination paradigm. *Bulletin of the World Health Organization*, 83(3), 230–235
- Lone, S. (2020, April 8). What epidemics from the colonial era can teach us about society's response. *The Wire*. <https://thewire.in/history/colonial-era-epidemicsindia>
- Martin, N. (1985). *Battle Against leprosy: The story of Stanley Brown*. Faith in Action Series. London: Canterbury Press.
- Norman-Walker, J. N. (1944). *Indian village health*. Calcutta, India: Oxford University Press.
- Otis, L. (1999). *Membranes: Metaphors of invasion in nineteenth-century literature, science, and politics*. Baltimore, MD: Johns Hopkins University Press.
- Patro B. K., Madhanraj, K. and Singh A. (2011). Is leprosy 'Elimination' a conceptual illusion? *Indian Journal of Dermatology, Venereology and Leprology*, 77(5), 549–551.
- Rosenberg, C. (1992). *Explaining epidemics*. Cambridge, UK: Cambridge University Press.



- Staples, J. (2007). *Peculiar people, amazing lives. Leprosy, social exclusion and community making in South India*. New Delhi, India: Orient Longman.
- Suntharalingam, R. (1974). *Politics and nationalist awakening in South India, 1852–1891*. Arizona: University of Arizona Press.
- Trawick, M. (1992). Death and Nurturance in Indian Systems of Healing. In C. Leslie & A. Young (Eds.) *Paths to Asian Medical Knowledge*, (pp. 129-59). Berkeley, CA: University of California Press.
- Vaughan, M. (1991). *Curing their ills: Colonial power and African illness*. Cambridge, MA: Polity Press.
- Wald, P. (2008). *Contagious: Cultures, carriers and the outbreak narrative*. Durham, NC and London, UK: Duke University Press.
- Wise, T. A. (1845). *Commentary of the Hindu system of medicine*. Calcutta, India: Thacker Publisher.
- World Health Organization. Strategy Development and Monitoring for Eradication and Elimination Team. (2003). *World Health Organization leprosy elimination project: status report 2002*. World Health Organization. <https://apps.who.int/iris/handle/10665/68406>
- Wright, H. P. (1885). *Leprosy and segregation*. London, UK: Parker and Co.