Nuancing ‘leprosy stigma’ through ethnographic biography in South India

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Summary
Synoptic life history accounts and case studies of people with leprosy have tended to follow conventionalised narrative forms, with the onset of leprosy causing a violent rupture in otherwise positively construed life courses. Many of those I worked with in India, well-versed in relating their stories to donor agencies, were also aware of the power of such narratives to access funding. While case studies can be informative about the politics of representation, then, they often obscure as much as they reveal about the lives of those described within them, emphasising leprosy-related stigma at the expense of other forms or drivers of social exclusion. Drawing upon a series of interviews with a leprosy-affected man I have known and worked with for 25 years, this paper demonstrates how more nuanced – and, from a policy perspective, more useful – accounts might be achieved through intensive biographical interviews carried out over time. In particular, analysis of such biographies, set against the wider backdrop of ethnographic research, allows for a more subtle reading of leprosy-related stigma, contextualised in relation to a range of intersecting socio-political, cultural and economic concerns.

Introduction
This paper draws both on several years’ ethnographic fieldwork with people affected by leprosy in a self-established and run leprosy colony in South India and, in particular, a series of intensive biographical interviews with one of the men who lived and worked there: a cured leprosy-affected man who, as I set out in more detail below, I have known and worked with in various capacities for 25 years. Such a research methodology, the paper argues, is valuable because it offers a route through which to account for the socio-cultural, historical, economic and political contexts within which negative social responses to leprosy – sometimes summarised as the ‘leprosy stigma’ – are constituted, and within which they occur.

This approach – which I term ethnographic biography – is distinctive from, and addresses some of the problems inherent in, the more conventional case history approach adopted in many studies of people affected by leprosy that claim to be qualitative. These kinds of synoptic life history accounts of people affected by leprosy have tended to follow...
conventionalised narrative forms, with the onset of leprosy described as causing a violent rupture in otherwise positively construed life courses. Many of my informants in Anandapuram Colony (a pseudonym) on India’s south-east coast, as well as in leprosy colonies in Hyderabad and, further north, in Haryana, were well practiced in telling their stories to the representatives of donor agencies and other potential patrons. As a consequence, they were also much more aware than those I worked with from non-leprosy backgrounds of the power of such narratives to obtain access to funding and other resources. These stories are in themselves informative about the politics of representation, and might even be seen as part of a project of identity formation. In terms of capturing the lived experiences of people affected by leprosy, however – and, consequently, in understanding the impact of the leprosy stigma – they often obscure more than they reveal.

By contrast, ethnographic biographical accounts, I shall argue, not only illuminate the experience of leprosy, but help to shed light on a wide range of issues pertinent to life more generally in post-independence India. Although the growing popularity of life-history accounts has sometimes been linked to wider disciplinary shifts in anthropology from ‘structure’ to ‘agency’ and from ‘culture’ to ‘voice’, such stories can also serve to bridge the gaps between these polarities, documenting not simply the capacity of individuals to act, but the converging contexts in which those actions are shaped. As Arnold and Blackburn put it:

\[\text{[L]ife histories should not be seen as... a narrowing down or even a disavowal of grand themes... Rather, life histories enable us to render more intelligible precisely the complex of forces at work in modern societies and to reflect further, and from more solid foundations, on many of the major themes that dominate the subcontinent – gender, modernity, colonialism and nationalism, religion, social changes, family and kinship, and interrelationship between self and society.}\]

The paper also explores the distinctiveness of such a research methodology, which, although far from new, arguably remains under used, both in South Asian ethnography and, more particularly, in studies of the social experience of leprosy. The paper also sets out to challenge the assumed utility of a concept like stigma for gaining an holistic understanding of the life experiences of people affected by leprosy. A close focus on stigma, I shall argue, limits the ways we understand the lived experiences of those affected by leprosy by placing too much emphasis on a disease identity at the expense of a) other intersecting identities – such as gender and caste – and b) other intersecting life experiences particular to the individual concerned.

I begin, then, by returning to some earlier recordings of Mohandas’s life story, both to illustrate some of the shortcomings of standardised life story accounts, and to offer comparative data against which subsequent renderings of the same man’s life might also be read.

**REPRESENTING MOHANDAS**

‘Although Mohandas had a high school education and good job prospects, after contracting leprosy he spent the next 20 years hiding from the shame it brought him by working for tips as a porter on Madras Central railway station. Reunited with his father,
who also had the disease, he came to Anandapuram where his schooling was finally made good use of in the community’s central office. Now, with 10-years’ office experience, he’s been put in charge of the day-to-day running of all Anandapuram’s development programmes. The £50 a month [this charity] provides for Mohandas’s salary helps to ensure that your donations are well used – and that a leprosy patient’s skills aren’t wasted.’

Mohandas’s conventionalised life story, as captured in both the 1995 fundraising pamphlet quoted from above, which I produced for a UK charity that supports Anandapuram, and a longer newsletter feature which told the same account in more dramatic detail, were – like many stories about people affected by leprosy – written as exemplars of the leprosy life trajectory. They recount the rejection, suffering and shame that is assumed to result from negative social reactions towards leprosy, followed by reintegration into the leprosy colony, often accompanied, at least in missionary accounts, by conversion to Christianity. They are then rounded off with a ‘happily ever after’ ending, often contingent, as in this case, on continued funding support. Because such stories follow a familiar structure, they reinforce one another and the genre, making it a difficult one to break out of, either by the tellers or recorders of these narratives. As a consequence, when I interviewed people in Anandapuram and other leprosy colonies elsewhere in India about their lives, these were the kinds of stories they generally told me. They recounted past abuse from relatives who no longer wanted to drink or eat from the same cups and plates as their leprosy-affected spouses or siblings; cruel jibes from neighbours; the impossibility of finding employment; and their difficulties in finding marriage partners. Separation – induced by the stigma – always followed, and although the leprosy stigma continued to plague their lives, positive developments had also very often taken place, proving, in line with messages promoted by all the major leprosy aid agencies, that leprosy was curable, only mildly contagious, and no logical block to getting married and having children.

For the purposes for which they were written, these stories clearly have some value. Presented to the right people, they encourage empathy and sometimes result in funding. Indeed, the story from the pamphlet cited above was published, along with two other similar life stories, under the heading ‘Three very good reasons for supporting [the charity].’ They offered examples of what can be achieved by leprosy-affected people if they are given support; parables spreading the message that the only barriers facing those affected by leprosy were social ones. The stories also enabled both the story tellers and those who read them to feel positive about what has happened: life could be better than it once was in spite of – or perhaps even because of – leprosy. A common trope in other life story accounts I collected from leprosy patients, particularly those of older women, was the expression of gratitude that they had contracted leprosy, because through the disease they had got to know ‘the true God.’

When stories of this kind are taken literally as objective representations of reality rather than particular stories told to effect change – and are used unproblematically as the basis for developing policy – difficulties arise. Donors end up bemused at the disjunction between the intent of their programmes, developed to help people with leprosy, and the results. Why, when people interviewed say all they want is the opportunity to work and to stand on their own feet, for example, do such programmes so often fail in terms of the donors’ objectives? One of the reasons, I would argue, is because such case studies convey only a formulaic, highly stylised and, for the most part, decontextualised version of reality. The dominant
narratives about leprosy on which they are based are frequently internalised by those who go on to tell them as though they were memories of personal experience, in much the same way that many of our perceived memories of events in early childhood are more likely memories of others’ accounts of those events. Indeed, it was not uncommon, more than 10 years after I had written them, for people to quote back to me almost verbatim things I had written in community publicity materials about their lives, their memories shaped not only by the events themselves but by my recording of them in a particular way. Such stories also, as Niehaus notes, conflate ‘representative models, normative notions which ascribe meanings to actions, and the specific acts performed by individuals’. Whilst people largely accepted these accounts as representative of their own histories, however, more detailed ethnographic research shows that there is often a disparity between official accounts and their day-to-day subjective experiences.

What I posit here as a way around these problems are more detailed, unstructured life history interviews, conducted over a longer period, and which re-interrogate respondents over time and in different places. In combining these accounts with ethnographic observations, they come closer to what Frank describes as ‘cultural biography’ than either simply ‘life-focused’ or ‘story-focused’ accounts. As such, because they are written-up less to illustrate a particular point or have a particular effect, and more to provide a rich, fine-grained account of someone’s life from which insights might subsequently be extracted, they are also less constrained by the form through which they are mediated than, say, the fundraising pamphlet vignette or the illustrative case study in a more wide ranging academic article. This is not, of course, to suggest that any account can appear unmediated altogether, nor is it to suggest that they are truer, in an absolute sense, than those presented through other genres. Indeed, self-reflection on the presentation of these accounts as well their content is a vital component of understanding them. Linde argues that in creating our life stories, we also create a narrative coherence which does not exist in reality, but which is necessary in order to develop a coherent sense of ourselves. By taking informants’ stories in parts, however – spread out over time – discrepant versions of the same person’s life can also be allowed to co-exist.

In the next section I set out the background to the interviews I started with Mohandas for my current project in 2009, drawing out what was particular about the kind of interviews undertaken. The subsequent section offers a highly truncated rendering of Mohandas’s account – an account which, in its own way, is as edited as the case study accounts I critique above. Necessarily selective though the current account is, however, I have consciously included elements that go against the grain of what Mohandas presents as the over-arching narrative thrust of his story, and which hint at a more varied – and consequently more telling – picture. The final section analyses the material I have presented, to compare it with other forms of life story, and to argue why such an approach has a more general applicability in providing more meaningful accounts of the social aspects of leprosy.

INTERVIEWING MOHANDAS: METHODOLOGICAL CONSIDERATIONS

I first met Mohandas in early 1985, when he came with his father to Anandapuram leprosy colony’s central office – from which a range of social development and welfare programmes were administered – looking for work. He was a new member of the leprosy colony, although had been receiving various forms of leprosy treatment, on and off, for the previous 15 years. I was there in my final days as a gap-year volunteer, having spent six months helping with correspondence, giving English classes and setting up a small printing press for producing the
very kinds of newsletters and publicity materials that propagated the kind of life trajectories described above. Following this brief encounter, I met him again in August 1986, when I returned to the village for a second stint as a volunteer, and when Mohandas – now married and working in the office as a book keeper – came to meet me in Bombay (now Mumbai) and accompany me on the 700 mile journey back to the colony. We worked together over the next six months as colleagues; he helped me when I returned again to do my first, fledgling undergraduate field research in 1989; and we worked alongside one another again in 1996, by which time he had taken charge of administering the colony’s social development and welfare programmes. By the time I returned as a full-time anthropologist for a year in 1999–2000, he had resigned that post – taken over by a succession of local outsiders – to return to his previous role as financial controller. He worked for me, sporadically, as a research assistant during that period, as well as serving as a major informant.

In 2005–2006, when I began work in a new field site in Hyderabad, Mohandas was no longer working in Anandapuram, and he had left a temporary job with an NGO in Chennai to stay with me and my family and work as my research assistant full-time. On my subsequent trips to Anandapuram – in the summers of 2007 and 2009, to carry out research on suicide in the community – he continued working with me in this capacity, the latter visit also including around 30 hours of taped interviews about his own life.

My current project, then, draws on my own, first hand knowledge of Mohandas’s life as I have seen it unfold over the past 25 years; my records of fragments of it, from a range of sources, strewn throughout my fieldnotes; and more than 30 hours of unstructured interviews recorded during my 2009 visit. I also interviewed and talked to those close to him. In 2000, along with others in the village, Mohandas also kept, at my request, an informant diary and, when we were in Hyderabad, kept a separate set of field notes so that I could compare our perspectives on the same events.

In terms of our most recent interviews, we usually spoke – in sessions lasting between 30 minutes to around 3 hours, but usually about an hour long – on the verandah of the Mahila Mandal (women’s society’s) building. It was a relatively neutral, shaded place on the outskirts of the village, and while we were disturbed often, we attracted less attention than if we had spoken at Mohandas’s own house, where neighbours would have congregated together very quickly.

Importantly, we also spent around 10 days travelling back to some of the places that featured in Mohandas’s earlier narratives: to his birthplace in Tamil Nadu; to the various locations where he and his family had lived and where his father had opened up canteens and fast-food stands; and to the station platform where he spent more than a decade (1974–1985) working as an unofficial porter, hotel tout and sometime tourist guide. In several of these locations we also had chance encounters with people who had known and lived with Mohandas and who had featured in his oral accounts, offering the opportunity to qualify or enrich what he had already told me.

It was this literal reconstruction of Mohandas’s movements through space by going back to the places where he had spent formative time and which he considered important in his life trajectory that was innovative about this particular approach to recording life stories. These journeys also gave shape and colour to his narratives: I could literally visualise where the events he described had taken place and, sometimes, the people who they had happened to in ways that his words alone did not allow. On many occasions this changed my understanding of Mohandas’s recollections of particular events. For Mohandas himself, going back also transformed the ways in which he recalled – or reconstructed – the memories he had been
drawing upon. Elements of the story that appeared missing from earlier accounts were forthcoming on location, as were anecdotes about people not previously mentioned.

This is not, of course, to say that the newer versions of his stories were necessarily always more accurate. He was still, to be sure, involved in editing and representing his life in certain ways and to particular effect, often self-consciously framing his life as being, in his words, ‘just like a cinema film’. For example, having read Q & A when he lived with us in Hyderabad in 2006 – the Vikas Swarup novel on which the more recent film *Slumdog millionaire* was based – Mohandas often compared his life self-consciously to that of the Ram Mohammad Thomas, the main protagonist.14 During my 2009 visit, on train journeys between the places where he had lived, he also read parts of my copy of Gelya Frank’s *Venus on Wheels*, an anthropologist’s biographical account of Diane DeVries, an American woman born without arms or legs.10 ‘Her life reads just like mine!’ he said. When I expressed surprise that he, as an Indian Brahmin man who had been affected by leprosy should find much in common with a white, working class suburban American woman born without limbs, he explained that DeVries, too, had had an ‘up and down sort of life’, in which things did not just get progressively better or worse in a linear trajectory, but shifted back and forth in a much messier, less narratively convenient, fashion across time. Such exposure to these and other genres of story telling – such as Tamil and Telugu popular cinema, and the Tamil detective novellas to which Mohandas was partial – clearly shaped the form that his stories took, offering him templates through which to construct his own account. It was certainly a different kind of narrative to those I collected, for example, from my less literate informants, or from those less accustomed to my particular ways of working. Mohandas was relatively unusual among his generation in the village, for example, in knowing his precise date of birth. Nevertheless, our most recent interviews were certainly richer than earlier accounts and, because they were stretched out over much more than a single telling and were not necessarily told in chronological order, they were no longer obliged to conform to the over-arching narrative structure that Mohandas gave to the overall story of his life. Details could be checked by comparing accounts given in different contexts.

In terms of interview technique, my initial approach was simply to ask Mohandas to tell me about his life; an approach which, I hoped, would reveal what was important to him rather than impose my own narrative structure on events. In our earliest sessions, he followed the format that he had used in the past: he summarised the entire story chronologically, neatly compressed into about an hour. It was a tale of a positive beginning wrecked by the onset of leprosy, followed by his remarkable ascent from vagrant station porter to chief functionary of an NGO. This was useful in telling me what was important to him – or at least what he thought was important that I should know about – but it clearly skipped over key events in order to focus on what he saw as central themes. The story also ended in around 1995, before things went awry again and the positive ending – which rounded off the story so well – was spoiled.

My subsequent approach, then, was to go back to particular points in the narrative and to get him to elaborate upon them. I would begin, for example, by saying something like ‘I want to ask you a bit more about life in your mother’s village . . .’ and let him take the story in any direction he wanted, inserting prompts which in turn elicited more responses. Usually, I see from my transcriptions of our interviews, these interjections were just single words denoting themes, such as ‘Food?’ ‘School?’ ‘Friends?’, or simple questions along the lines of ‘When?’ ‘And?’, or even ‘So?’. After each interview I transcribed and studied the recordings to draw out further, more probing questions, and to pinpoint anything that was unclear. In this way,
the interviews became more and more detailed, and covered shorter and shorter periods of history, each time.

Mohandas’s story

In the longer term, I plan to write a book length biographical account of Mohandas’s life. For my current purposes, however, a necessarily brief synopsis of his story will suffice to draw out the differences between what I would term ‘ethnographic biography’ and the shorter case studies that currently form the mainstay of qualitative data on the lives of people affected by leprosy in most academic accounts.

Mohandas was born a Brahmin (widely recognised as the highest, or most ritually pure, social ranking in the Hindu caste hierarchy) in a small village in the southern Indian state of Tamil Nadu in 1950. His parents were distantly related, their marriage providing a solution to problems faced by both partners’ families. His maternal grandmother was widowed and had no money for her daughter’s dowry, just an acre of land in her village. His father’s family, meanwhile, were keen to marry him to stop him ‘going here and there’. ‘He’d been a wanderer,’ as Mohandas put it, ‘he never went much to school’. This was in contrast to his younger brothers, two of whom became school teachers and the third a priest. Marriage, it was hoped, would force him to settle down. As Mohandas’s mother was an only child, her husband went to live with her and her mother in her village (although the expectation was that brides would go to live in their husband’s family homes, exceptions to this ideal were fairly common). Already, I might interject here, the story is rather less auspicious than the start described in more synoptic narratives, in which Mohandas’s background is presented in grander fashion, the facts that Mohandas was born of high caste and with a bright future stretching out ahead of him given the greatest prominence. Such scene setting was most likely a device to emphasise the fall that comes later.

In earlier versions of Mohandas’s story, his father absconded on the discovery that he had leprosy, a seminal event implying that the shame was too great and he wanted to spare his family the stigma of leprosy. There is no doubt some truth in this but, as it emerged during our ongoing interviews, this was not the first time his father had absconded. In addition to his youthful wanderings, after marriage he had first left home when Mohandas was six. He had gone to a relatively close-by temple town, only summoning the family there when he was admitted to hospital with cholera. He left again soon after he was discharged, and was away when Mohandas’s only sister and his maternal grandmother both died of small-pox, contacting them a year or two later to say he had set up a business in another town, and that they should join him there. The business was not a success, however, and they all returned to the temple town, which is where Mohandas’s brother, ten years his junior, was born. Most of Mohandas’s schooling was in the same town, up to tenth standard, although he missed the final exams and had to retake them later in Madras (now Chennai). Their father left again when his new snacks business ran up debts that he could not pay off. This time he returned after a year or two to shift the family to Madras, where he had rented a house and set up a handcart selling sweets and savouries. A year later, with finance from Mohandas’s mother’s maternal aunt and her husband, who was a senior tax inspector, he established a meals mess for students. Like all the other businesses, bar the handcart, it made a loss and, after holding out for about a year, Mohandas’s father left for the final time in the late 1960s. This made for a total of four major documented departures, none of them specifically related to leprosy,
although Mohandas thinks his father knew he had the disease when he left for the last time, and that this might also have shaped his decision.

Mohandas’s own departures were not as strictly leprosy-related as earlier accounts suggested either. He stayed at his first job, acquired with the recommendation of the uncle who had financed his father’s past businesses, only a month. ‘I suppose,’ he explained, ‘It was because I was young, about 17, and this wasn’t really the time for working, it was the time for wandering. One day I was late, missed the train, so I stayed away, hung around with friends and played cards. I didn’t go again the next day, just left the house at the usual time and came back at the right time in the evening, but then my mother found out I hadn’t been going, and shouted about how I would spoil my uncle’s reputation. So I walked away. I took money to go to the cinema, but ended up on a train to Calcutta.’ Even before this, as it finally emerged as Mohandas pointed out places he had spent time in on our seven-hour bus journey back from the town he grew up in to Chennai, he had been prone to leaving home every now and then, staying away for a few days at a time and sustaining himself by helping out on tea stalls, where he would offer to wash glasses for a little money or a meal.

After a few escapades in Calcutta, he ended up back in Madras Central station, where he stayed for a while – helping out on a woman’s banana stall outside the station. He was found there by a relative a few months later, and returned home. Soon after, his uncle fixed him up with another job in a knitwear machinery factory in Bombay, where he went to work as a storekeeper. He had been there for seven months, sleeping in the storeroom where he worked, when the watchman suggested that he should get his thickened earlobe checked out by a doctor.

He did, and he was diagnosed with leprosy. He didn’t even return to the factory to take his suitcase, he said, but went from the hospital ‘to the station and started that kind of life again’. He didn’t return to the hospital to take the prescribed treatment either: ‘what was the point? My life was over!’ A year or so later, however, his condition worsened, and one of his platform friends, a successful ticket tout who eventually established an equally successful travel agency, got him checked in to a leprosy hospital he had heard of in Gujarat, sending him spending money throughout his stay there. He got bored of the routines after about six months – boredom, followed by flight, emerging as a significant motif in Mohandas’s life story – so, when the watchman wasn’t around one day, he walked out and came straight back to the station in Bombay. In addition to unofficial portering and finding passengers seats on busy trains, he also ran a card school for a couple of years, and made additional income as a hotel tout, taking tourists, especially foreigners, to cheap nearby lodges. The hotel owners paid him commission, and the tourists gave him tips, so it was, he told me, a good and interesting way of making money and improving his English.

Mohandas presents a rather rosy picture overall of life on the station: ‘When I was on the station I felt free. I had nothing at all, but also no burdens. So maybe it’s better not to have anything.’ These comments, however, were uttered by a man subsequently burdened by debts and the needs of a wife and two children, and it was clear – from Mohandas’s description – that platform life was also hard. His time working on the stations coincided with the 21-month state of emergency declared by then Prime Minister Indira Gandhi in 1975 and, although he made little direct reference to this wider context, it was during this period that he was arrested and imprisoned several times before being released without charge. With usual civil liberties suspended, such occurrences were commonplace during this period. Along with his friends he also underwent a vasectomy when it was encouraged by the state’s family planning
programme. Such events were recalled without rancour: they were, as he put it, just the way things were for people like him.

After four or five years on the station, he was again ready for a change and decided to return to his native Tamil Nadu. He went back to work on Madras Central Station, where, sometime later, he met his younger brother – also leprosy-affected and working there as an unofficial porter. This was a pivotal event in all tellings of Mohandas’s story, and when we visited he showed me the two trees under which the two men, who had been estranged for many years and had not recognised one another, finally made the discovery. It is a story his brother is also fond of telling. After several more twists and turns – his stories include colourful sexual exploits, incidents of violence, and visits to places he had never been to before as a tour guide for foreign tourists he met off trains (‘I could read the Tamil signs on things and they couldn’t, so I could pretend I knew all about the ancient wall carvings!’) – the two brothers were finally reunited with their father in 1980, when Mohandas spotted him on the platform.

Their father had spent the first three years after his departure in two leprosy hospitals, and had met and married his second wife – also a Brahmin leprosy patient – in the second one. Together they had moved to a Roman Catholic run leprosy colony, where they converted and spent the next few years, before shifting to Anandapuram, which was much closer to the hospital where, by then, they were receiving treatment. The regime in Anandapuram was also more liberal: as a self-run colony, they could come and go as they pleased, and begging was not prohibited. They were living in Anandapuram in a mud and thatch house they had constructed and were making a living from begging when Mohandas met him on the station, and he persuaded both his sons to become members of the colony and to visit him there periodically. The brothers had also contacted their mother at around the same time: once her husband and both her sons had departed, she had gone to live with the maternal aunt and husband who have already featured in this story, by then relocated to Bombay, helping them to rear their children and running the household. Mohandas and his brother visited her every so often over the years that followed, although she was never told that her husband had remarried.

Unlike his brother, however, who married and settled in the village fairly soon after they had all met in the station, Mohandas found it difficult to stay there for any length of time, only moving there permanently in 1985, when his father and step-mother arranged his marriage to a young, scheduled caste Madiga girl: a pairing of individuals from opposite ends of the caste spectrum and which would have been almost unheard of had the families not been affected by leprosy. Mohandas told me that his father had thought (rather ironically, given his own former propensity to abscond) that if he was married he would stay there with the family. Mohandas, by now 35, was also starting to feel too old for what he called ‘the platform life.’ The wedding followed Mohandas’s baptism at local prayer meetings, during which he was officially converted to Christianity, and the payment of Rs. 1,000 by Mohandas’s step-mother to his wife’s family. Despite her low status and a difficult life at home she was not keen to marry a man so many years her senior: she was around 14, and only started menstruating a year later. The payment to her stepfather – which Mohandas says he only learned about after the event, and was unhappy about – ensured the union took place. ‘She was very shy, very timid,’ he remembers of his wife, ‘and because she came from that group, that caste, she didn’t know how to do lots of things around the house properly.’ It was more than a year later before the marriage was consummated, and a vasectomy reversal operation and another 10 years before the births, first, of a son, and, three years later, of a daughter. His father also helped him get a
temporary job in the office, which became permanent when he found a more effective way of maintaining the accounts. Working alongside the British nurse who served as the colony’s administrator until 1995, he became her right-hand man, and was a well-respected figure in the community.

Meanwhile, however, towards the end of that period, he also starting making regular trips to see his old friends in what was now called Chennai, some of which were facilitated by the travel required of his job, and to go with some of them back to the horse races. Although Mohandas maintains that he made more money than he ever lost at the races or in card games, he ran up large debts during that time which he struggled to pay off, particularly as local interest rates were very high.

When the nurse left in 1995, Mohandas was appointed Administrative Officer – the top job in the Colony, answerable to an absent management committee and the community’s elected village Elders. His story from this point details the many difficulties in managing the role at a time when a new consciousness was developing in the village: when people would go to the police rather than the elders with their problems; when workers on rehabilitation programmes set up a trade union to campaign against low wages; and when one man – unfairly dismissed by the Elders – took his case to court. Much of his time over the next few years was taken up attending court cases and being pressed by the Elders, in his account, for money, alcoholic drinks and biryani dinners. He felt increasingly burdened by the pressures that were mounting up on him. His personal debts were spiralling out of control and he was drinking more heavily. Although a love affair with a village woman closer to his own age offered some respite, it was clear he found himself in an increasingly impossible situation.

He resigned in 1999, only to be re-instated by the Elders in 2001 and removed from the post again a couple of years later. There have been six incumbents of the post in the intervening decade. Mohandas took a job for a while with another NGO back in Chennai, but complained that it did not pay enough to cover the expenses of living there, and was keen to take up my offer of coming to work with me again in 2005–2006, when he lived with us and worked as my research assistant in Hyderabad. His father, who was begging in Mumbai, died during this period: we were back in Anandapuram for a few days when the news came through from a Mumbai-returnee. Unable to bring his body back from the other side of the country, they had had to leave him at the roadside to be cleared away by the municipality.

Mohandas returned for a while to work for the same NGO in Chennai in early 2007, this time surveying the beneficiaries of post-tsunami funding in fishing communities along the Coromandal coast. He enjoyed this work, but became bored again when it was over and he was returned to the office. He had to rent a room and buy his own food, which took up most of his salary, and it was, he said, a ‘machine routine.’ The death of his mother a couple of months later, when she was hit by a delivery van as she crossed the road to go to temple, was the catalyst that sent him back to the village once again. His mother had been looked after financially by the Madras uncle’s sons, and she left him a small inheritance that enabled him to pay off some of his debts, buy some furniture and buy some gold for his wife. He was not working when I returned to Anandapuram in the summer of 2007, but the inheritance appeared to have given him some reprieve and lifted the spirits of both Mohandas and his wife. However, both the money and the gold were gone by the time I returned to the village two years later in 2009, and he was working for daily wages as a quality checker in the community’s weaving unit (and sometimes as a research assistant to a visiting anthropologist).
Discussion

Although I have only begun to scratch the surface of Mohandas’s life stories in the summary above, there is, I hope, sufficient detail to highlight important deviations from earlier accounts; to illustrate some of the general advantages of the research method proposed over the alternatives; and to demonstrate why accounts of how people affected by leprosy experience stigma need to focus on a broader range of life experiences than leprosy alone if they are to tell us anything meaningful. As we have seen, case studies tend to yield predictable results. However, if leprosy researchers are able to draw on the insight of the biographical methods outlined here, even if they do not have time to construct a full account, they will be better placed to understand the everyday social problems people affected by leprosy face.

Firstly, in terms of illuminating the lived experience of leprosy, Mohandas’s story shows very clearly that while the onset of leprosy has very important social implications for those affected by it, a specific focus on the disease, as is common in case history accounts, downplays its inter-connections with relationships, social institutions and other factors, while overstating the centrality of the disease to the individual’s life. Mohandas’s father’s final departure from his family and Mohandas’s sudden move from the knitwear factory were certainly triggered by the discoveries that they had leprosy, but it was their existing propensity to abscond from difficult situations – and the relative acceptability of male flight within the society in which they lived – that made it a possibility of action in the first place. Furthermore, other factors beyond a reaction to ‘social stigma’, such as the pull of freedom and the known excitement of station life, in Mohandas’s case, or the possibility of escaping debt and family obligations, in his father’s, made flight more of a probability. Ian Hacking’s notion of an ‘ecological niche’ is useful here: as he demonstrates, it is usually the convergence of particular factors at particular points in history, rather than a single factor, such as leprosy, that make possible or likely certain social phenomena. Had Mohandas and his father been women, for example, or had they been financially better off, leprosy may not have led to their respective departures in the way that it did. Wider factors have an impact on how leprosy is experienced and managed at the level of the individual, and leprosy – in all its social and biological manifestations – is only one of the many prisms through which the lives of those affected by it are filtered.

Ethnographic biographical accounts are also, necessarily, also informative of much wider social experiences. Mohandas’s story also has something to tell us about how the categories of caste, class, gender and so on are experienced and reproduced and, importantly, about how these categories intersect in individual lives. As Carol Thomas argues in her critique of social constructivist accounts of the lives of disabled people more generally, insufficient attention has been given to how different kinds of social relationships intersect, and the impact of these intersections on people’s experiences. We need to know, for example, how the experience of leprosy intersects with those, among others, relating to gender, ethnicity, socio-economic class, and, in the case of India, caste.

In terms of caste, for example, we learn that leprosy has changed how Mohandas’s relationships are constructed in relation to it: he married someone of lower caste status than in other circumstances would have been permitted by his family, let alone encouraged in the way it was. Mohandas’s frequent references to his Brahmin (and Tamil) heritage, however, offer strong evidence that caste remains important to him as a marker of identity and social...
status. Brahmin-ness, for him, manifests itself through the kinds of food he prefers to eat and in the comparisons he draws between himself and others.

His caste identity was not just something he internalised, however: he felt it also made a difference to how people responded to him, and how, as a consequence, his life took shape. The banana seller who helped him on the station, for example, trusted him, he said, because he ‘spoke and looked like a nice Brahmin boy. I had a fair complexion – not like now – and good manners, so people were respectful.’ In short, as it emerges in Mohandas’s story, caste is not about relative ritual pollution and purity and negated by leprosy, as a collectivist-type account might have it, but much more about personal identity and, in his relationships with other poor people, relative status.

Socio-economic class and, more specifically, poverty and social exclusion, also overshadow much of Mohandas’s story, further detailing the wider context against which his leprosy is experienced. His immediate family, despite his father’s repeated attempts to run profitable businesses, was poor from the outset: virtually landless, victim to disease and premature death, dependent on more economically secure relatives to bail them out, and on the peripheries of their community and wider kin group even before leprosy became a factor. Mohandas, despite his caste consciousness, was very aware that he was not part of a ruling elite and that his immediate family were the ‘poor relations’ within his wider kinship group. He saw nothing odd or particularly unjust, for example, about his arrests without charge when he lived and worked on the train station, or about the everyday violence to which he and those living alongside him on the station platform were subjected. His leprosy status might have fed into his social exclusion and his acceptance of it, but it was also formed, as it was for most people I knew with leprosy, by a more general exclusion from power and economic resources. Poor people expected to be ill-treated by those in authority and, for the most part, their strategies were about avoiding or managing that ill-treatment rather than confronting it head on. To use a popular phrase among my informants, they ‘adjusted’ to their situations accordingly.

At the same time, Mohandas’s story also has much to say about what it was to come of age in urban India in the late 1960s and to be a man in a particular patriarchal society in the intervening years; about personhood and agency; and, related to this, a tendency towards passive acceptance. In relation to the latter, it was striking in Mohandas’s accounts how much he spoke of things happening or being done to him rather than by him as an agent of change. His rising debts to the office during his tenure as project co-ordinator, for example, were presented variously as the fault of the community’s Elders – who had pressured him to buy them food and alcoholic drinks which he could not put through the accounts; his wife’s occasional purchase of jasmine for her hair from passing flower sellers; and, especially, the birth of his daughter. ‘After she was born I had a lot of problems: that’s when the drinking and everything happened,’ as he explained it.

What such a study also allows, as my work with Mohandas has made clear, is the kind of historical perspective that accounts based only on participant observation in the present cannot provide. In this case, an individual’s stories tell us not only about life for relatively poor, ordinary people in India since Independence in the second half of the twentieth century – stories otherwise mostly untold – but they also show how well-reported, apparently critical events, like the state of emergency in the 1970s, or the tsunami in December 2004, are experienced and remembered by people on the ground. For most people, unless they are very directly involved in such occurrences, the events that make international press headlines remain relatively peripheral.
None of this, of course, is to posit a turn towards biographical interview at the expense of researchers actively immersing themselves in the lives of the wider communities of which their informants are a part. Indeed, my analysis of Mohandas’s biography is made possible only against the backdrop of prolonged ethnographic research in the village where he has spent most of his time over the past 25 years. Nevertheless, probing biographical interviews – which operate not through aggressive questioning but through gentle persistence, and through creating contexts in which informants are less constrained by expectations of the time it should take to summarise their lives – offer unique lenses through which the interplay of social categories might be observed and better understood.

Even leprosy researchers without the time to conduct the in-depth biographies I have described here, however, can still apply insights from such an approach to provide more informative. In closing this discussion section, I summarise the practical steps researchers may take as follows:

- Be alert to the immediate contexts in which respondents live, taking detailed descriptive notes on their living conditions, family situations and access to resources, based on their observations. Photographs and sketch maps can add to this background data which, although its relevance may not be clear at the time, will often be invaluable in interpreting the data collected through interview.
- Reflect on the kind of representations interviewees offer by considering the wider contexts against which they are speaking. Are their frames of reference shaped, for instance, by local cinema or the rhetoric of local religious or political leaders? Published ethnographies on the regions in which respondents live can offer much of this wider context.
- Begin interviews with indirect, open-ended questions (simply inviting respondents to talk about their lives, for example), using the responses as prompts to formulate subsequent, more probing questions. Having a list of topics to be covered allows the interviewer to return to these at the end – or during a subsequent interview, if possible – rather than imposing their own agenda on from the outset. Leading questions should be avoided, and local terms and concepts should be used whenever possible. Questions on topics other than leprosy will produce richer data against which to understand their experience of the disease.
- Be alert to the influence of the interviewer on the kind of data produced. If a respondent believes certain answers might generate funding from the interviewer, for example, he or she might well respond in particular ways as a result. Being aware of and critically exploring one’s subjectivity is more important than trying to be objective.

Conclusion

Many studies that attempt to measure the negative social impact of leprosy are not designed to consider leprosy either in relation to multiple intersecting social identities – such as caste, class and gender – or the more specific social experiences of the kind I have described in this paper. ‘Leprosy stigma’, then, is often difficult to identify both because it is entangled with disadvantage caused by other oppressive relationships, and because those identified as ‘stigmatised’, as Hacking17 demonstrates in relation to other social labels, take on and interact with their classifications in ways that are sometimes difficult to predict. In short, the very act of labelling someone or something as ‘stigmatised’ changes the thing so labelled. Like many
other people affected by leprosy who have been exposed to leprosy donor agencies, Mohandas was aware that reference to ‘stigma’ offered a shortcut explanation for a whole range of life events that were rooted in more complex causes. Stigma, to paraphrase Goffman,\(^{18}\) can become a peg on which to hang other failings, such as the explaining away of Mohandas’s youthful propensity to abscond by reference to leprosy. Such accounts were popular among my informants because they offered short, readymade answers in place of what would otherwise have needed to have been complex explanations; because, appealingly, they cast their narrators in the roles of victims of circumstances beyond their control rather than as actors with some degree of culpability for their actions; and because, through repetition, these stories had been thoroughly internalised by those who told them as definitive accounts of their lives. As a consequence, simple surveys or questionnaires intended to measure leprosy stigma – which might, for example, ask respondents to judge the extent to which they have been stigmatised by leprosy – often do little more than reproduce the received wisdom that leprosy is stigmatised. The representation is left undistinguished from the reality.

Although qualitative case studies have attempted to flesh out or nuance the statistical bones produced by quantitative surveys, such an approach also falls prey to many of the same problems. For a start, a focus on leprosy as the central element of the lives of those affected by the disease averts our gaze from the broader socio-political and economic contexts within which leprosy is experienced. Life before and after the disease in such accounts is presented almost uniformly as good, allowing those charged with the management of leprosy to frame solutions without reference to the wider conditions of people’s existence in which the disease became a problem in the first place. The status quo is presented unproblematically as the positive state to which one might want to and should return.

By contrast, ethnographically-informed biographical accounts – which capture, as Caplan\(^{19}\) puts it, both a life and a time – can provide the wider context that many leprosy-focused studies necessarily leave out. In Mohandas’s case, as I hope to have shown, they illustrate how the onset of leprosy, as one of a range of factors that have shaped his life, was experienced and responded to against a backdrop of pre-existing poverty and social exclusion, as well as in relation to the dominant social categories of caste and gender. In turn, at a policy level, this suggests that governments and leprosy NGOs need to address broader social inequalities in order to respond effectively to the social problems associated with the disease. Although addressing structural inequalities might be beyond the scope of most NGOs, they do have a role – in part through the kind of research I have been describing – in exploring them, and are well-placed to address such issues at the level of individuals affected by the disease.

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