COMMUNITIES OF THE AFFLICTED: CONSTITUTING LEPROSY THROUGH PLACE

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ABSTRACT

With the promotion of Community Based Rehabilitation (CBR) as a solution to health-related issues across the global South, leprosy colonies have long been out of vogue for NGOs and State institutions alike. Such colonies, however, have endured. As is being increasingly recognised by those working in the leprosy field, such places have played a particular role not only in the provision of leprosy-related care, but also in forging new and collective identities for people affected by leprosy that might otherwise not have been possible. In this article, I draw on ethnographic fieldwork in one such colony in coastal Andhra Pradesh, South India, and explore the values invested in it as a particular kind of place; its geographical location on the peripheries; and its architecture and layout (inspired in part by colonial sanatoriums) which have particular implications for how leprosy and its ramifications are constituted and managed.

Key words: Christianity; community-based rehabilitation (CBR); India; leprosy; therapeutic landscapes

Running title: Constituting leprosy through place

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Media teaser

Leprosy colonies have long been out of fashion, but their resilience suggests they offer something that community-based rehabilitation does not. This article explores what that might be.

This article emerges out of the convergence of two problems that continue to concern me in my work with people affected by leprosy in a South Indian leprosy colony. The first relates to the persistence of leprosy colonies – institutional or self-run therapeutic communities for those afflicted with the disease – despite the facts that leprosy is both curable and, at least by World Health Organization (WHO) definitions, globally eliminated. Even when I first undertook fieldwork in India back in 1989, however, 17 years before India achieved its elimination prevalence target of fewer than one case of leprosy for every 10,000 members of the population, I was told by those working in the field that community-based rehabilitation (CBR) was the only way forward. "How can you expect to capture the true experience of people with leprosy," one leading leprosy fieldworker – who ran a leprosy project in a major city – asked me, "if you only visit leprosy colonies? You need also to see how leprosy is being managed *within* the community."[1] Yet, more than two decades after that correspondence took place, leprosy colonies have remained remarkably resilient, in India and elsewhere[2] even to the extent that several people with responsibility for leprosy programs, to whom I spoke informally at a recent international leprosy congress, were beginning to consider seriously whether they might offer a solution for cured but disabled people affected by leprosy who are now suffering age-related conditions.[3] What was it about leprosy colonies – particularly the one I had worked in – that made them endure, despite efforts to affect a shift in leprosy care?

My second, related, concern was that while my earlier work had focused on social relationships between those I worked with, including leprosy affected people, their families and medical professionals, I had done less to problematize the relationships between those people and the *places* where those relationships were forged and played out in meaningful ways. Although Bethany, the main site of my field research in 1999-2000, looms large in my published research, it does so envisaged mainly as the stage on which my informants' lives

were played out: important, but relatively unproblematic. As other scholars in medical anthropology have demonstrated, however, places in which healing takes place are not simply backdrops, but might a) continuously come into being through interactions with those who dwell in them; and b) be important to the healing process in their own right. In respect of the first point, that places are constituted through being lived in, I draw in particular on Ingold's general notion of what he calls "the dwelling perspective" (Ingold 2000:chapter 10). From this phenomenologically-inspired viewpoint, places are not backdrops at all, in that they do not exist *a priori*, but come into being around those who inhabit them (2000:153). People and places are mutually constituting and, over time, reconstituting. As examples of the second point – that places might be seen as having powers *beyond* those who dwell in them – we might turn to David Parkin's (1991) description of the empty ritual capital of the Giriama of East Africa, the Kaya, as a source of ritual power, or to Ron Barrett's (2008) more recent exploration of Aghori medical practices in India, which explores the importance of particular places – especially the river Ganges – to healing.

This notion of places of healing in terms of place *as* healing suggested a possible response to my initial question of why leprosy colonies persisted despite the supposed elimination of leprosy.[4] Could the changes to people's lives that had occurred in and around these places be not only about the treatment they had obtained and the relationships with others they had forged there, but also linked in some way to the places themselves? Without leprosy colonies, would their medical treatment have been as successful (or otherwise) as it has been? In the context of what might be described as a post-leprosy era, with CBR still the dominant model of NGOs concerned with rehabilitation of those affected by leprosy, these are the questions that I set out to explore here.

I begin with some general background on leprosy elimination and the role of CBR, before moving on to a description of the terrain on which my subsequent analysis draws. The

latter is a retreat, perhaps, to the conventional framing that "informs the way the anthropologist brings his or her study into 'view' " (Hirsch 1995:1), but offers important context. I then shift to explore, ethnographically, the ways in which my field site was constituted as a special kind of therapeutic space. In particular, I revisit the *Bethany ki lopala* and *Bethany ki bayata* – inside and outside – distinction that my informants drew upon so regularly in talking about their lives, to argue that the community was not only a place where treatments were made available, but a place which reconstituted its inhabitants in particular ways.

BACKGROUND: LEPROSY ELIMINATION AND CBR

To those unfamiliar with the World Health Organization's categories, the discourse on leprosy elimination is misleading. According to the WHO, by the end of 2006 the prevalence rate of leprosy in India had dropped to 0.88 per 10,000 – below the 1 per 10,000 rate at which leprosy is considered eliminated.[5] Progress towards this had already been reported on World Leprosy Day 2006, when India's press declared that India had achieved the "globally accepted level of elimination" (*The Hindu* January 31, 2006). However, many leprosy organizations – and, indeed, the evidence of my own fieldwork – would question the optimism of both the WHO and the Indian state. Among others, leprologists Lockwood and Suneetha (2005; see also Staples 2005) have argued that there is no firm evidence that leprosy will die out at a predefined level of prevalence, and that global and nationwide statistics anyway distort local realities by including countries and states where the prevalence rate is virtually zero. With antibiotics alone insufficient to control infection, Lockwood and Suneetha argue that leprosy might better be seen as a "chronic stable disease" rather than an "acute infectious disease" susceptible to elimination strategies (2005: 230). And even if a prevalence rate of below 1 per 10,000 *was* sufficient, the National Leprosy Eradication

Program (NLEP) in India, while celebrating the national decline in prevalence rates, also notes that the central states of Bihar and Chhattisgarh, plus a few additional isolated pockets, were still reporting rates of over 1 per 10,000 in 2011 (http://nlep.nic.in/about.html). In addition, there are many people who, although cured of leprosy and, therefore, removed from the statistics, have been permanently impaired by the condition and continue to need support. Put simply, the apparent contradiction of elimination having been achieved and the continued existence of leprosy colonies is not as paradoxical as might first appear.

What is more surprising is that leprosy colonies have *also* been resilient against the international tide of community-based rehabilitation (CBR): a Western inspired approach that has dominated projects for disabled people in the global south since the late 1970s (Whyte and Ingstad 1995:22). Grounded in western notions of empowerment, access and human rights (ILO, UNESCO, UNICEF & WHO, 2002) – and in keeping with a more general shift in development to 'bottom-up' approaches (Pottier 1993) – CBR promotes the rehabilitation of disabled people within the context of their home communities. As an NGO leprosy rehabilitation officer on a major urban leprosy project told me when I interviewed her in 2000, mirroring the official orthodoxy:

Our main aim is not to disturb leprosy patients from their communities. Once they are outside they tend to go begging and lots of social problems develop which are expensive for us to deal with. If we can help them in the early stages of their disease it is much safer and society will accept them. Their lives will be changed for the better, their family's attitude will be different and their children will grow up as healthy citizens.

Whereas since the colonial era people with leprosy had been treated in sanatoriums and colonies, developments in treatment for the disease – with the discoveries first of Dapsone and then Lamprene, now used together as central components of Multi-Drug Therapy (MDT) – meant there was no longer a medical imperative for segregating patients from mainstream

society. Not only was it possible to render leprosy non-contagious in a very short time, but, if treated early enough, patients would display none of the physical signs associated with the condition, and so were less likely to be stigmatised by the disease.[6] Such approaches, which could be (and now have been) integrated into general health care provision, were also attractive because they were relatively cheap. Institution-based rehabilitation (IBR) was out; CBR was in (Gokhale 1994:331; Gopal 1999:3).

There are a number of reasons why, despite the apparent attractiveness of CBR, such programs have had less impact than one might expect given their prominence over more than three decades. The first is practical. As Deepak (2003) notes, the integration of leprosy services with general provision will only be effective if it is adequately resourced, but a shift to CBR is often about saving money. A reduction in specialized care for people affected by leprosy, he argues, has seen a corresponding decline in their care, with pilot studies in South India suggesting that those with physical impairments were more reticent about participating in CBR projects than those without. For older patients whose care has been through institutions, CBR has little to offer.

Secondly, projects conceived under the CBR banner have often been ethnocentric, insensitive to the fact that the rights-based model on which it draws is particularly western (Burck 1989; Devlieger 1995). Consequently, the concept of 'community' has not always been adequately problematized in the locations where CBR is to be applied. In the case of the project Ingstad worked with in Botswana, for example, the failure to translate CBR into culturally understandable terms accounted for why it was "implemented from the top down and never really managed to activate the community in the rehabilitation process" (Whyte and Ingstad 1995:23; cf. Ingstad 1997). At the same time, 'rehabilitation' also implies a form of deviance on the part of those to be rehabilitated, rather than, as many in disability studies would argue, flaws in social structure (Staples 2011). This failure to define how CBR might

translate into local contexts can also lead to it being seen as radically opposed to IBR, nullifying the validity of leprosy colonies in the eyes of those, like the head of the urban leprosy project I corresponded with in the 1980s, who are committed to CBR. If we consider them as communities in their own right, however, leprosy colonies are not necessarily at odds with CBR's aims.

Thirdly, the notion that people are best treated within the contexts of their existing community settings also assumes that the *status quo* is, for most, a desirable state. However, leprosy – like disability more generally (Harriss-White 1999:140) – disproportionately affects the poor. The majority of my informants, regardless of caste, came from materially poor, landless families. For them, the escape from the *status quo* leprosy colonies offered might well have been attractive even without leprosy, especially when the only alternatives being offered were membership of, for example, self-help groups and petty income generating schemes that usually raised only paltry sums of money.

While the above goes some way to accounting for the failure of CBR to eliminate leprosy colonies along with the disease, there are also other, more positive reasons why leprosy colonies have persisted, and I turn to this now. I begin with some basic scene-setting.

A PLACE CALLED BETHANY

Bethany is a self-run leprosy colony in coastal Andhra Pradesh, around 200 miles east of Hyderabad, the state capital. The community emerged in the late 1950s as a squatter settlement of patients affected by leprosy, who had been discharged from a nearby missionary hospital; it took its name from the village near Jerusalem identified by the New Testament as home to Simon the Leper.

Early settlers were cured of their biomedical disease but were either too institutionalized to return home (many had spent up to a decade in the hospital), or

unwelcome, either because of their association with leprosy or, having converted to Christianity during their time in the hospital, because they had married beyond the communal affiliations of their families. Shifting to wasteland across the railway line from the hospital, they built makeshift mud and thatch homes and eked out livelihoods from begging.

Like other leprosy colonies, Bethany was situated in a particular kind of space. It was not geographically isolated, in that it was less than a mile from the centre of the local town, but, like other leprosy colonies, it was on the periphery. Until relatively recently, when the municipality laid a service road into town, it was physically divided from the nearest road by the railway line which ran alongside its widest border and, beyond the rail tracks, a Christian burial ground and an expanse of now cultivated farmland. Its other three boundaries were bordered by paddy fields.

According to one of my informants, relating a story told to him by his father, a first generation settler in the village, the area now occupied by the village had once been a mixture of wasteland – *panikiraani sthalamu* – and cashew nut plantation, with the earliest settlers simply constructing mud huts between the trees. While there was some variation in people's accounts about whether they squatted or purchased land, nearly everyone concurred that, back then, it was a wild, dangerous and liminal place. Because it was so secluded, several people told me, the space was also used by men to rape women, and people had been murdered there. The peripheral character of the place also meant that, at night, it was frequented by *dayyamu* (spirits) or, in English, 'devils'. People were not clear, when I pressed them, who these *dayyamu* were or where they came from, although some suggested – and their use of the term 'devils' supports this – that they were framed within a Christian idiom as Satanic, sent to tempt people towards evil or, as in several reported cases, to possess them.

At first glance, then, Bethany looked unpromising as a therapeutic site: the *only* place where, cast out both from the hospital and their natal places, they could take refuge. I would argue, however, that it has come to be experienced as otherwise on at least two bases. Firstly, in *becoming* Bethany – and this process of transformation was a major part of the longer stories of the same people who told me of the land's dangerous qualities – the space was changed into a place which, to those who lived in it, was no longer peripheral but central. Bethany has, in terms of Ingold's "dwelling perspective," come into being around those who inhabit it (2000:153). At the same time, other places were reconfigured as dangerous and external in relation to Bethany. Like the Tamil *cheris* described by Gorringe – the peripheral village settlements to which Dalits were confined – such negatively-defined spaces can become both "havens of security" and "centres of resistance and social change" (2006: 46). This ambiguity about certain places, with their powers both to harm and to do good, makes them powerful as sites of cure.

Over the course of nearly 50 years, Bethany was transformed from a space that was dangerous to one where its occupants, relative to the outside, considered themselves safe. Over that period, the village grew from an initial 30 inhabitants to a population bordering on 1,000. Just under half the population today has had leprosy: the rest is made up of the children and spouses of former patients. Around 150 people go begging outside the village, but several income generation programs – started by foreigners who came to stay in the village from the early 1980s – now provide work for around 300 people. During my 1999-2000 fieldwork, there were no other foreigners but myself in the village and development projects were managed by a project co-ordinator appointed from within the community. However, much of Bethany's income was still channelled through overseas donors and a management committee on which they, as well as villagers, were represented. This ensured a

continued close relationship between Bethany villagers and 'the foreigner'—a shorthand category for their white, Christian patrons.

Bethany, then, was become transformed into a morally positive location: safe, Christian, and intrinsically related to the people who lived there. The evidence for this change in this perception of place is seen most forcefully in the distinction drawn by Bethany people between *Bethany ki lopala* (inside Bethany) and *Bethany ki bayata* (outside Bethany), rather than Bethany, as historical descriptions of the place have it, itself being the outside to which its inhabitants were cast. I initially resisted what seemed to me an overdrawn inside:outside dichotomy, but, although there are shades of grey between the two poles, it was an enduring pairing that those I worked with used to talk about their community and actively to constitute Bethany as a particular kind of place and themselves a particular kind of people.

Although *Bethany ki lopala* had once been a place of danger, then, it was now dangerous to leave. Within its boundaries, food and water were safe. Outside, residents complained, the water made them sick, or the rice was unsuitable for their bodies. Such claims mirror those most commonly made in respect of people's natal places. South Indians, Daniel has argued (1987:62-63), experience themselves as literally *of* the place they come from, and will consequently prosper from food grown or water pulled from its soil, since its substance matches their own. Bethany is not the land from which its original inhabitants came (although a younger generation might justifiably make such claims). However, the continual reinforcement of Bethany's boundaries in relation both to 'outside' and to the shared qualities of its inhabitants – as 'one people' – has transformed Bethany into a place at least analogous to one's natal place, and, given the references so many people made to food prepared there as 'suitable for our bodies', in many respects one to which, through prolonged dwelling there, they have become substantially related. So while for Hirsch, kinship and land are mutually implicated (1995:9), in Bethany, a shared disease-based identity, recognisably

inscribed on their bodies, had constituted a new form of relatedness – through leprosy rather than of caste or of blood, although sometimes translated into the language of caste (*kustha kulam*, 'leprosy caste'), or of religious identity as Christians.

While insiders were connected to one another through their shared space and "cultural sameness" (Gupta and Ferguson 1997:32), outsiders were unpredictable. They were, for example, seen as liable to harm those marked with leprosy, either literally or, in refusing to serve them in shops or restaurants, by shaming them and hurting their feelings. In a play written and performed by villagers at my request to narrate their history in 2000, there were numerous examples of ill treatment at the hands of outsiders. A householder was depicted shooing away leprosy beggars with a broom, telling them that they are no better than her "bloodied menstrual cloth," while a ticket inspector on a train threw them off the carriage and beat them with his belt. In similar vein, one man, describing a begging trip he had been on, told me how outsiders had refused to let his group take rest anywhere other than "the place where other people went to the toilet." Outside, and outsiders, pose the greatest risks to their well-being.

By contrast, many aspects of the space that had once made Bethany dangerous had now been tamed. The trees and the undergrowth had been cut back, and the community had been physically rebuilt in an orderly fashion: straight roads with, since a building program in the 1980s, regularized brick built houses, communal, white washed buildings and well-cared for gardens – splashes of bougainvillea and marigolds, neatly bordered with bricks set at 45 degree angles, mirroring the colonial architectural arrangements of the hospitals, rather than the villages from which they came. This distinction has been eroded somewhat over the last couple of decades. I have observed a growing tendency among middle class families in the local town, in particular, to prettify the exteriors of their newly built houses by painting them in bright colors and bordering them with flower beds. But, as memories of the hospital

environment fade, and without the influence of resident foreigners on the public spaces in the village, there has also been a shift towards a local esthetic more inspired by what Pinney dubs "bazaar-kitsch" (1995) than colonial architecture. However, the very orderliness of Bethany's layout – more enduring than decorative styles – and the presence of community buildings such as the weaving unit and the clinic, continue to retain some of the link between Bethany and its inhabitants' pasts in missionary environments. Bethany still *looks* different to other villages.

This transformed space was re-categorized as *lopala* rather than *bayata* or, as Barrett renders the latter in Hindi, *bahar*, which he translates both as outside and as a place to which pollution is externalized (2008:43). In Bethany's case, pollution is literally externalized, as in other villages, through the act of leaving the village to defecate on the far side of the railway line – the practice of 'going out' still popular despite many houses now having their own latrines – but is also done so symbolically through various actions that reinforce the village boundaries. For example, when people leave, particularly on long journeys, there are prayers to keep them safe, and when harm comes to someone outside it is often attributed to something that happened as they crossed the community's border. When the daughter of a family I knew fell off a rickshaw on the road to the beach and was hit by a motorcycle, for example, her father said it was because a certain inauspicious woman had bewitched her as she left the village. And while people were also susceptible to the dangers of witches and the evil eye *within* the community, they became particularly vulnerable to such attacks when they ventured outside. Rama Reddy, a man with learning difficulties who was considered auspicious, was able to charge people for walking across their paths as they were about to leave because they believed his blessings could protect them. Every long journey I took he would be there, hand out stretched in anticipation of my donation, to bless my departure and offer me protection by crossing the road in front of my rickshaw as it pulled away. Older

village men and women, renowned for being prayerful, would also gather to plead for God to protect me as I went on my way. The greatest dangers, once embodied in the undergrowth of this dark and peripheral location, had now, through Bethany people's dwelling practices, been relocated beyond the village boundaries. For this reason, at an NGO-workshop organized in the village to promote self-help, participants – to the horror of the organizers – included a high periphery wall around the community as part of their wish list. It was not, one of the women explained, to keep people in or to protect the public from leprosy – which is what the wall of the mission hospital had been seen as – but to keep Bethany's residents safe from outsiders. The construction of a village secondary school, so that their children wouldn't have to venture outside to continue their education in the local town, also made the list.

HEALING PLACES

The experience of a disease, as Kearns and Gesler (1998) point out, is shaped not only by a bio-medically defined condition, but also by the locations in which it is experienced. "Therapeutic landscapes," as they define such locations, "are places that have achieved lasting reputations for providing physical, mental, and spiritual healing" (1998:8). We should, therefore, move beyond space as a container to "space as an active agent in the shaping of human (health) experience" (1998:11). It is in this sense that I want to explore Bethany as a 'therapeutic landscape': a place within which the multiple experiences of leprosy are shared, lived and – importantly – either muted or rendered positive. This occurs both in a literal, straightforward sense – through, for example, the presence of the clinic, visiting doctors, the ready availability of dressings and access to medicines, and in more subtle, ongoing ways, through, for example, the particular organization of space within the village, and the spiritual values which the space has come to embody, which in turn reconstitutes those who live there. Bethany is also constituted through the relationships between people that take place there,

and makes for a more flexible understanding of place not constrained to its geographical boundaries. The agency of space does not suggest, as Kearns and Gesler's comment might imply, that those who reside within it are passive recipients of that therapeutic agency. Rather, therapeutic landscapes like Bethany come into being and change through the very activities of those who dwell in them. Place and people are inextricably entangled.

Below, I offer three broad examples of how Bethany was and is constituted as a therapeutic community, beginning with its constitution as a particularly Christian space.

Spiritual therapy

A framed photograph of Prasad, Bethany's founder, hangs prominently behind the pulpit in Bethany's church. It was Prasad, people told me, who gave the community its Christian name, served as its first Pastor, and instilled in the settlers the understanding that, regardless of where they had come from, they were as one: "one caste, one disease, one religion," villagers told me with almost mantra-like regularity.

As Bethany was unequivocally Christian from the outset, its symbols were clearly inscribed throughout the landscape. Bethany's only place of worship was the cross-emblazoned, ocher-painted church, on the border of the village, boldly facing outwards; in crosses and calendars depicting Christ in almost every household; and in the absence of icons of Hindu deities or the rangoli designs that Hindu women elsewhere painted on their doorsteps each morning. The soundscape reinforced the material imagery: every morning, from around 4.30am, the village's pastor broadcast either sermons or tape-recorded Christian songs on a PA system that reached every corner of Bethany. Regular church services, Sunday school and prayer meetings were transmitted on the same system.

As a Christian space, Bethany is seen as particularly suitable for those who have been affected by leprosy: a place which embodied a worldview that constituted leprosy not as

ritual pollution or karmic punishment, but, as some elderly women described it, a blessing through which they had found "the true God." People also contrasted the love (*prema*) they had experienced from missionary doctors and nurses in the hospital, embodied in their willingness to touch them and to dress their wounds without donning protective gloves, against what they characterized as the rejection and fear they had experienced from their own (mostly) Hindu families or, among those from scheduled tribes and castes, from the higher castes in the places where they once lived. This Christian love was seen, in itself, as a prerequisite to healing: not just of their physical or even emotional wounds – central those these were – but also a healing of the soul which, they believed, would not otherwise have been achieved. Being there (that is, not *just* being a Christian), being able to pray and to share their faith with other people in the physical space of the church was, a lot of the older people described it, central to their recovery. It also offered them an additional and more positive identity than that afforded by the ascription of 'leper'— a Christian identity continuously reinforced by self-perpetuating imagery and sounds with which they had surrounded themselves (Staples, forthcoming).

Egalitarianism

One value embodied in Bethany – popularly related to their Christian ways of being-in-the-world, but also a defining feature of wider discourse within the community – was that of equality. The accusation *varvandarini samananga chuuchutaledu!* ("you are not treating us equally!") was seen as particularly serious when levied against supervisors by participants in Bethany's income generation schemes, more damning, say, than a supervisor's counter claims of worker insubordination. Any suggestion of discrimination on the basis of caste was likewise damaging to the discriminator's credibility. Villagers were, they told me, united as a single *kustha kulam* (leprosy caste), and although caste remained significant in terms of

personal identity, within the community the category's capacity to shape relationships between groups of people had been diminished.

In part, publicly acceptable ideas about caste were propagated through public rhetoric; through, for example, the 'one caste, one disease, one religion' message that was repeated in most public meetings and religious events. Practices such as inter-caste marriage – which accounted for at least half of all weddings in the village – materially served to reproduce the idea that, as people affected by leprosy, they were all equal. When villagers travelled in groups to go begging in Mumbai, for example, and stayed together in their shared squatter camp, albeit in discrete family groups, they cooked similar foods so, as I was told, "there's no jealousy." Sameness was positively valued.

At the same time, maintaining ideas about equality were sustainable because they were embodied in the spatial arrangements of the village. When people had first settled there in the late 1950s, homes were constructed haphazardly, wherever space was available, without – unlike every other village I visited in Andhra – respect to caste. This continued when, in the 1980s, each family was allocated an equal sized plot of land on which identical two-roomed concrete dwellings, NGO and government funded, were erected. There was some swapping of plots so that extended families and former neighbours could, if they wished, remain living close to one another, but there were no conventional divisions that demarcated which streets particular families lived on. Whereas elsewhere caste divisions were reproduced by spatial arrangements that kept certain castes apart – diminishing opportunities for relationships to develop that might challenge those divisions – in Bethany relationships were mapped out by what connected them rather than by what might otherwise have divided them.

There are, of course, *other* kinds of divisions that have emerged to challenge this rather romanticized ideal of equality. Some people have bought additional adjoining plots of

land to extend their homes, for example, and although some, because of a lack of resources, have kept their houses in much the state they acquired them in, others have embellished theirs considerably, suggesting that some forms of equality – economic in particular – are not maintained in practice. Some families, whether through success in education and subsequent employment or business, or through the productive management of an inheritance, inevitably became wealthier than others, and such inequalities were reproduced over time. The general point, however, is the same: that social values are inscribed, reproduced and, over time, changed by Bethany inhabitants' engagement with their environment. The establishment and reinforcement of these values in themselves, rather than their absolute application in practices, were seen by residents as pre-requisite to their broader healing process.

Activity in public buildings – the community hall, the church, the weaving unit, clinic and school – likewise served to reproduce this public rhetoric of equality. The pastor's messages, disseminated as described above; speeches and commentary at public meetings; teaching – and non-caste specific seating arrangements – within the school; the management of disputes within the work places; and non-caste based seating arrangements at wedding feasts and other ritual events, all serve to embed the ideal, whether or not realised, of equality as a driving principle of social life within the village.

Unity

Closely related to the ideal of equality is that of unity, and it is in relation to the maintenance of unity that my point about the mutually constitutive relationship between Bethany dwellers and their community is best illustrated. As a community of people with similarly different shaped bodies – bodies that, through mutual recognition, are empathetic to one another – Bethany might usefully be compared to what Haualand (2007) describes as the development of distinctively deaf spaces, established during events such as the 2001 Deaf World Games in

Rome. Her account offers a useful perspective on how those with bodies shaped by leprosy might also experience and use their bodies in the creation of particular communities. In the case Haualand describes, a mutually recognised space is created by a group of people with shared distinguishing features – being deaf and communicating via sign language – occupying, in increasing density, a shared space in a European capital city (2007:37). While the creation of a deaf community, albeit a temporary one, occurs *because* of a critical mass of hearing impaired sign language users in a shared space, the community is not constrained by any particular geography; it is, in the widest sense, a therapeutic landscape, but one that could occur wherever people with shared characteristics might congregate in sufficient numbers.

Something similar happens among people affected by leprosy when they meet in Indian cities for marches and other shared events (see Staples 2003), their common bodily differences allowing for mutual recognition and a sense of community to emerge. The leprosy-impaired people with whom I travelled to one public meeting, for example, met and talked with others travelling to the same event because of recognisable deformities to the feet and hands or collapsed noses and loss of eyebrow hair. Because they shared similar experiences of living with those bodily differences, they often stepped in to lend a hand, literally, when required. People who had grown up in Bethany knew instinctively, in a way that I could only try to learn, how, for example, to offer food in ways that could be received by those without fingers, or when to step in to help with such everyday acts as hair brushing and plaiting, vegetable cutting or lighting a cigarette. These shared understandings were in themselves therapeutic, and they reinforced a boundary between *Bethany ki lopala* and *Bethany ki bayata* – inside and outside. Paradoxically, though, *Bethany ki lopala* was extended to the spaces they occupied, and shared with other leprosy-affected people, *outside* the geographical confines of their colony. The landscape here might better be seen as a "cluster of *embodied* dispositions and practices" (Clifford 1997:199, cited in Haualand

2007:41) than a distinctive space, although the shared identities both Haualand and I have described might *only* be possible because of shared values imbued through, for example, the learning of sign language or the collective experience of living in a leprosy colony.

Within the leprosy colony, shared attributes such as collapsed noses, loss of eye brow hair, patches of pale skin, muscle-wasted limbs and the absence of fingers and toes *did* offer something of the more stable "cultural sameness" that makes a place recognisable as home (Gupta and Ferguson 1997:32). Unlike the Rome of the Deaf World Games – within which the deaf community was, presumably, diluted once the games were over – or the mass leprosy meetings I attended, the shared space of the leprosy colony allowed the otherwise different to become the norm. Leprosy-shaped bodies within the colony were not usually, then, what Leder describes as "dys-appearing" bodies (1990:83-92), a term he uses to capture the subjective emergence of the body as an alien presence at particular crisis points. They were commonplace, and responses to them, because of the prolonged contact they had shared, were thoroughly embodied and automatic. Indeed, it was only in watching video footage of Bethany sometime after I had left the village that I was struck by *how* different so many people's bodies were to mainstream ideals: after a year living in the community, a fingerless hand or a foot reduced to a stump was sufficiently unremarkable to go unnoticed in everyday life.

Collectively, therefore, leprosy-deformed bodies both make the places they occupy and, through dwelling in them, values such as unity are inculcated as embodied dispositions, and are maintained or changed over time. Bethany dwellers are unified, in other words, by their bodily similarities vis-à-vis *Bethany ki bayata.*

DISCUSSION AND CONCLUSIONS

I began this article with a broad question: how might we account for the endurance of leprosy colonies in India despite the decline of leprosy as a public health issue *and* the near universal hegemony of CBR as the appropriate response to both medical and social implications of the disease? Partial explanations might be sought in the perceived failing of CBR either to challenge structural inequalities or to meet leprosy patients' stated needs, or in the fact, despite WHO elimination targets having been met, that there are still plenty of cured but leprosy-disabled people across India for whom leprosy colonies provide shelter. Such explanations are compelling. They are, however, inadequate to explain not only the endurance of leprosy colonies in India over the last half century or so, but the fact that some of them – like Bethany – continue to grow and flourish even, and perhaps especially, when they repeatedly fail to make self-help initiatives work in the way that the NGOs that fund them envisage.

In seeking answers from a rich seam of ethnographic data – predominantly from one leprosy colony but informed by work in others too – I have sought to read my data through theoretical lenses offered by an anthropology of landscape. Although my selection of ideas through which to consider my own material might not lead me to the same conclusions as those who originally posited them, such a process has been informative. By envisaging the leprosy colony I worked in as a 'therapeutic landscape' – a place which, in *itself*, offers something important to people affected by leprosy that they might not access as, for example, out-patients who remain in their natal homes – its appeal becomes clearer.

Ingold's notion of a "dwelling perspective" draws, in turn, on phenomenological theory in general and Bourdieu's more specific explanation of the enduring embodied dispositions he calls the 'habitus' (Bourdieu 1990:52ff).[7] Such a perspective allows us to see the leprosy colony as more than a place constructed and occupied as a relatively unchanging backdrop to the social life that takes place against it. Rather, the people and the place are

mutually implicated in the ongoing process of constituting the other, and – in the sense that the same ideas and values became embodied in both – the boundaries between people and place are revealed as more fluid than might usually be envisaged. If people and place were simply reinforcing of the other, we might find ourselves accused, as was Bourdieu (eg, Comaroff 1985:5; Farnell 1994:931; Shilling 1993:146), of being unable to account for social change. However, just as Bourdieu recognised a relationship between structure and individual agency and worked to collapse the radical distinctions drawn between them – highlighting, *contra* his critics, possibilities for change *within* changing constraints – so recognition of an ongoing relationship between people and place allows for a continuous process of change. Hirsch (1995:3), in focusing on the relationship between what he calls "foreground actuality" – everyday lived experience – and the "background potentiality" of social life which, he argues, together constitute the process of landscape formation, likewise allows mechanisms for change in such analyses. The gradual shift from Bethany as a liminal place of danger to a central point of safety – within which its population came to experience itself as central rather than peripheral – is ethnographic evidence of this process. Ingold's "dwelling perspective" has also been useful here: it enables us to break down distinctions drawn between the physical aspects of a place, such as roads, houses, cultivated gardens, wells, churches and other communal buildings, and its less tangible aspects – symbols, ideas, rhetoric and embodied dispositions – which are often attributed more specifically to people. In Bethany, as elsewhere, they are embodied in both.

The question, then, becomes one about whether understanding certain places as curative in themselves – rather than simply as places to which one might go to obtain healing – can tell us anything about leprosy colonies and their longevity that we did not already know. Although Bethany is not, like the Ganges, seen as externally imbued with intrinsic powers, through a mutual engagement between place and people it becomes powerful. The

on-going healing narratives I described – of Christianity, unity and equality – render Bethany a place for the re-imagination of identities more positive than those ascribed to the disease, and more positive, often, than the identities people were known by even before they had leprosy. For those of low caste and economically poor – categories into which most of Bethany's residents would have fallen regardless of their disease – unity and equality, castelessness and a spiritual identity not based on ritual purity were powerful and attractive. And although they would not have been sustainable had they not lived in a shared place, in which the missionary hospital-inspired architecture, public discourse, rhetoric and other symbols helped to keep reproducing them, they were not constrained within geographical boundaries. Dispositions that were embodied through their dwelling within Bethany were extended outwards when they left the community for short periods, and enabled them to engage empathetically with people from other such colonies (for examples of this, see Staples 2003). Quite apart from curing the physical aspects of the disease, self-run leprosy colonies of the kind I worked in allowed for an ongoing healing of all kinds of other leprosy-associated wounds.

Bethany is not, however, the realization of some kind of Utopian vision. Inequalities *do* exist – between genders, as elsewhere; between those who can and cannot work; between money-lenders and borrowers; and between the poorest members of the community and the relatively affluent. Disharmony, rather than unity, is also a feature of much of community life, often characterized by struggles between a healthy younger generation and their older, leprosy-disabled parents, or between the management of social welfare and development programs and those who worked for them (e.g. Staples 2007). My point though – and Hirsch's distinction between "foreground actualities" and "background potentialities' is again useful here – is not that Bethany endures because it has achieved unity, equality and spiritual enlightenment; rather, it is that Bethany endures because of the *potential* of these values,

shared within the community, to be realised and to bring about the social changes they desire. Nor is it to valorize the colony environment over alternative set-ups for the treatment of leprosy. The experiences of those who receive treatment as out-patients and never reveal to those around them that they have had the disease are inevitably very different to those I worked with who, because they had initially been estranged from their home environments in order to receive treatment and because for the most part they were impaired by the condition, they were particularly receptive to what leprosy colonies have to offer. Nevertheless, it is important for those implementing CBR in *any* setting to develop an understanding of the appeal that alternative, and sometimes apparently contradictory, approaches might have for those directly concerned; an understanding best achieved, as I have demonstrated, through prolonged ethnographic engagement with those on the receiving end of such approaches. In Bethany, in particular, it has become clear that the experience of place has contributed to the efficacy of their healing.

Acknowledgements

NOTES

1 Taken from private correspondence I had at the time with the leader of a leprosy project. I had been undertaking fieldwork for an undergraduate dissertation.

2 See, for example, a recent *The Guardian* article on leprosy colonies in Egypt, which ran under the headline "Egypt's last leprosy colonists resist lure of freedom" (Shenker, 11 October 2010:25)

3 The 17th International Leprosy Congress, Hyderabad, India, 30 January – 4 February 2008.

4 I am grateful here to Amit Desai, whose proposal for a panel at the Annual Conference on South Asia at the University of Wisconsin, Madison, in October 2009, was the initial impetus for this article.

5 http://www.searo.who.int/en/Section10/Section20_12162.htm

6 Rejection of people affected by leprosy occurs for a complex range of reasons, among them the fear of contagion from those who, because of their particular deformities, are identified as having the disease.

7 Bourdieu argues that action is constituted through a mixture of individually and collectively embodied constraints, and freedom, within these constraints, to act (Bourdieu 1990:52ff).

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