I was initially in two minds about editing a special issue on ‘stigma’. The term, it seemed to me, was one too often applied uncritically to bodily conditions – especially in relation to leprosy – as a vague gloss for a qualitatively diverse range of negative social reactions and attitudes, as well as a description of how they might be experienced. As such, ‘stigma’ can become a lazy shortcut for the multiple ‘social aspects’ of leprosy, preventing deeper scrutiny of the complex and sometimes contradictory experiences that are characteristic of living with the disease.

At the same time, however, devoting a special issue to the topic also offers a valuable opportunity to address precisely those issues: to interrogate how, if at all, ‘stigma’ might remain a conceptually useful notion through which to analyse the experience of those whose lives are touched by leprosy, whether as sufferers, family members or those working in the leprosy field. It also provides a chance to showcase alternative approaches to understanding attitudes towards the disease that go beyond the conventional, taken for granted wisdom which states, a) that leprosy is a uniformly stigmatised disease, and b) that education about its causes and treatments is necessarily the appropriate response to managing that stigma. A critical focus on stigma allows us to ask, for example, questions about the socio-cultural, historical, economic and political contexts in which stigma is produced. It also enables us to consider how stigma, as it is currently configured and used, might also be a barrier to understanding the social experience of leprosy. These were the kinds of questions thrown out in the call for papers for this special issue, and I have been both impressed and encouraged by the responses, which together subject ‘leprosy stigma’ to a more rigorous critique than I could have hoped for.

Several of those responses come from my own discipline – anthropology – rather than from the clinical sciences that make up the bulk of contributions to Leprosy Review, and I confess to a bias towards the long-term qualitative work for which anthropologists are best known as a route to understanding the complex socio-cultural, historical and political implications of leprosy. Such research does not begin with hypotheses to be tested – which
could overly-determine the results – but rather permits counter-intuitive findings to challenge well-worn stereotypes. A complementary approach – that favoured by researchers such as Wim van Brakel\(^1\) and represented in this collection both by de Groot et al.’s contribution and by the report on a stigma research workshop, held in Amsterdam last October – is to focus on building more finely-tuned tools for identifying and measuring stigma and, having measured it, to intervene. Taken together, I argue here, such approaches have a real potential to propel forward our understanding of how leprosy is socially constituted and experienced for a whole range of social actors.

This bias towards qualitative work should not, I hope, be taken as a signal for leprosy medical professionals, social workers, healthcare policy makers and others in the leprosy field to switch-off. For one thing, most of the contributors to this volume are also as involved in public health and/or policy as they are in their academic disciplines, and share a commitment to understanding how the lives of people affected by leprosy might be improved through intervention. For another, not only does the richness of the empirical research set out here offer important insights for all those working in the leprosy field, but it also depends on a wider audience beyond academic social scientists if those insights are to have a genuine impact on policy. At present, too many of us who work on leprosy do so within the narrow confines of our own disciplines without referencing – or even being aware of – a wider body of research that should inform our thinking and make for better policy. One of the grander aims of this special issue is to encourage more than a superficial inter-disciplinarity in leprosy research, and to demonstrate that qualitative research should be seen as more than a bolt-on extra to the hard science of clinical investigation.

My clarion call made, then, I want to use the remainder of this editorial to illustrate some of the general difficulties in approaching ‘social aspects’ of leprosy through the prism of stigma that the papers collected together here go some way towards addressing.

**Stigma trouble**

**RECONFIGURING STIGMA AND LEPROSY AS DYNAMIC PROCESSES**

A criticism levied against studies of stigma – particularly in psychology – is that they focus overly on the individual as the primary site in which stigma takes place. Yang, Kleinman and Link et al.\(^2\) argue, in contrast, that we should move away from seeing stigma as a psychological variable towards understanding it – as, they argue, Goffman\(^3\) intended – as ‘a dynamic psychocultural process’ (p. 1525) or ‘a social process with multiple dimensions’ (p. 1527). Put simply, we need to understand the everyday life worlds within which people stigmatise and are stigmatised, because, contrary to how stigma might be presented as a constant, it is not something uniformly applied to leprosy affected people across different contexts. At different stages of the life cycle and within different networks of relationships discrimination takes different forms. Feenstra, Nahar and Pahan et al. (p. 178) show, for example, that even within a particular cultural location (in their case, Bangladesh), differences in attitudes towards and by people affected by leprosy might vary across genders and age cohorts, and depending on whether they live in rural or urban settings.

‘Stigma’ also encompasses a significant range of qualitatively different responses to leprosy which, in turn, have different ramifications for those so stigmatised, but which tend to get flattened out by grouping them together within an undifferentiated category. There is, for example, a world of difference between being thrown out of one’s family home and cast...
to the margins – as social responses to leprosy are often reduced to in talk about them – and, while being materially cared for by one’s family, excluded in more insidious ways: by not being invited to take part in family decisions one might expect to be involved in, for example, or being fed away from others on plates that are washed and stored separately. Similarly, as Jacky Bonney – a trained nurse turned NGO administrator who has been working with leprosy affected people in India for more than 30 years – points out in her own editorial (p. 98), families who apparently exhibit no discrimination against their leprosy-affected neighbours in day-to-day interactions often show a different side in response to suggestions that they might marry their sons and daughters into a family with leprosy. Context is everything, with stigma best understood, as Manton’s historical analysis of leprosy in Nigeria (p. 124) argues, as a product of its social, economic and medical contexts. Stigma, in the senses I am describing it here, is not fixed but, as Harris’s article (p. 135) explores, a ‘dialectical process’. The problem this throws up for researchers is that interviews and questionnaires designed to investigate stigma are often inadequate to account for the different registers at which people relate to one another. Before we can measure stigma we need to understand the multiple contexts in which it is played out.

If stigma is ‘a fluid and multilayered phenomenon that does not exist in a vacuum’ (White, p. 147), much the same might be said about leprosy. The disease identity is likewise too often treated as if it exists in a vacuum, taken in isolation as the most significant identifying factor of people affected by it. As my own work has demonstrated – and my article in this issue drives home the same point – leprosy is only one of a range of intersecting identities that has an impact on the lives of those affected by it. Again, gender, age, class and, in India (where I conducted fieldwork) caste, were all important in determining how those with the disease were treated by others. The fact that many of those I worked with went begging for their income, an occupation some have argued is more stigmatised than leprosy itself – also had a significant impact on how others reacted to them.

White encountered numerous parallel examples in her research in Brazil, where the cases of ‘stigma’ that people affected by leprosy recounted related not just to leprosy but also to class differences, employee/employer relationships and pre-existing family tensions. She told me of one case, for example, of a man who suffered from severe leprosy reactions who was abandoned, he informed her, by all of his friends and family except his mother. At first, the rejection he suffered seemed to be all about leprosy, but as his story unfolded it emerged that his family, thinking he had AIDS, was not even aware he had the disease. Furthermore, as he pointed out, his abandonment had less to do with disease stigma and more to do with his inability to provide for others financially in the ways he had in the past. In much the same way, the people Poestges (p. 155) worked with in southern India were discriminated against because of their residence in a leprosy colony rather than, as might be assumed, because they had leprosy per se. People affected by leprosy in the local area, as she demonstrates, were not only treated differently to those who lived in the colony but actively discriminated against those who did. In focusing our gaze exclusively on responses to ‘leprosy’ as central to the identities of those affected by the disease, we also elide numerous other contributory explanations and overstate ‘leprosy stigma’ as a cause.

At the same time, in addition to leprosy having more or less significance across intersecting contexts, it might also mean different things across different contexts. Manton (p. 124), in making this point in relation to how leprosy is related to in Nigeria, draws useful distinctions between leprosy as it is presented (communicated); leprosy as it is encountered (as, for example, a medical problem to be resolved); and leprosy as it is understood.
In short, in relation both to ‘stigma’ and ‘leprosy’, we need to avoid representing either as single, fixed objects. Rather, as Mol argues convincingly in her exploration of how diseases are performed rather than static entities, it might be more illuminating to consider both ‘stigma’ and ‘leprosy’ as enacted in practices.

PROBLEMatisING THE STIGMATISER: STIGMATISED RELATIONSHIP

Adding further to the case against reducing arguments to inadequately specified terms, there is also a need to develop a clearer understanding of what we mean by the terms ‘stigmatiser’ and ‘stigmatised.’ Shorthand explanations of stigma assume a relatively unproblematic binary split between these two categories of people, but field research paints a more complex picture. Yang, Kleinman, Link et al. argue, for example, that other actors than external ‘stigmatisers’ are involved in the stigmatising process, including the peer group, the wider social network, family members and doctors of those who become stigmatised.

The boundaries between stigmatisers and stigmatised are also more blurred than a dichotomy between the two might suggest. Harris’s example of leprosy paramedical workers also being stigmatised by their close association with the disease, for example, or Poestges’s discussion of people with leprosy living outside colony environments displaying prejudice – and sometimes jealousy – of those who were cared for in colony environments, suggest that a category of the leprosy stigmatised which only includes those who have had the disease and stigmatisers as those who have not is too narrow.

In some cases, the stigmatised and stigmatisers might be one and the same group of people. In the cases described by de Groot et al. (p. 168), for instance, the social problems experienced by those diagnosed with leprosy in the Netherlands were attributed more to self-stigma and low self-esteem than to the stigmatising attitudes of those around them. Interestingly, in this context – where the public, unlike in endemic regions of the world, was scarcely conscious of leprosy and so held few ingrained prejudices about it – it was the lack of cases and absence of public interest in the disease that mitigated against patients seeking treatment for their condition and which led them to feel isolated.

The methodological point to be made here, then, is that research questions, and the more detailed interview questions that emerge out of them, need to be structured in such a way as to avoid a radical distinction between those who stigmatise and those who are stigmatised if they are to tell us anything worthwhile.

STIGMA DISCOURSE: BLAMING IGNORANCE

Another problem with attributing the socio-economic and other hardships encountered by people affected by leprosy to ‘stigma’ is that it places the blame on ‘culture’; another inadequately problematised term which, in such cases, is usually treated as being synonymous with ‘superstition’. People stigmatise those with leprosy, it is often assumed, because they have not been educated in the scientific causes of the disease, resorting instead to folk explanations that constitute leprosy as, for example, a punishment from God or a consequence of witchcraft. The problem is framed in terms of a battle between ignorance and science, or one of countering ‘tradition’. The solution to stigma, understood in those terms, is often seen as education of the general public.

This is problematic for at least two reasons. Firstly, education is not a panacea for misconceptions about the disease: the medical explanation that leprosy is a contagious
disease rather than a punishment for sinful behaviour can, for example, make people more rather than less afraid of contact with patients. 14 Secondly, recourse to ‘cultural’ explanations, for which the public can be held accountable, diverts responsibility away from the state and the structural conditions that might also contribute to people’s suffering. Economic poverty, for example, as Bonney’s editorial, and the articles by Poestges and Staples in this volume argue, contributes as much if not more to the suffering of people affected by leprosy in India as leprosy stigma, while US migration policy and the social status of migrants from the global South affects the Brazilian leprosy affected people White (p. 147) describes as much as individual prejudices about the disease. That states might have a vested interesting in promoting ignorance-based stigma as a cause of discrimination rather than what Paul Farmer termed ‘structural violence’15 should not be under-estimated: explanations of phenomena are always constituted within socio-political contexts, and our explanations of stigma must take account of this.

LEPROSY AS A PRODUCTIVE IDENTITY

A final concern to address here is that the equation of social reactions to leprosy with stigma also presupposes that reactions to the condition will necessarily be negative. As the work in this collection demonstrates, this is far from always the case. Goffman3 went some way towards recognising this in his identification of the ‘secondary gains’ of stigma, but we might go beyond this to consider how classifications assumed to be negative might simultaneously be understood as generative of ‘empathy, affinity and desire’.16 Persson makes this point very clearly in her research with HIV-positive gay men in Sydney, Australia, who had also been diagnosed with lipodystrophy. Lipodystrophy, as Persson explains, significantly changes body shape, and these visible changes, because of their associations with HIV and homosexuality, result in stigma. However, in making difference visible, recognition is possible by others likewise affected, allowing mutually shared identities to build up. This resonates strongly with my own findings among people affected by leprosy in India, whose distinctive bodily markings enabled a sense of ‘communitas’ – what Victor Turner summarised as the ‘recognition of a generalized social bond’17 – to build up between people affected by leprosy across geographical boundaries. There was a power in visibility. Leprosy impaired people used their marked bodies to legitimate begging, to instil fear, at times, and, perhaps most importantly, to recognise those who shared their suffering.18 Allusion to a stigma also allowed claims of victimhood to be established and, depending on context, access to particular rights.

As Goffman3 recognised, leprosy, like other stigmatised diseases, could also become a useful hook on which all manner of other failings could be hung. Telling me that his auto-rickshaw business had failed because of ‘leprosy stigma’, for example, was not only a suitably straightforward explanation but, for the leprosy impaired man I was speaking to, it also absolved him of personal responsibility for the business’s failure. Ethnographic research, less reliant on direct questioning, might well reveal alternative explanations – such as the facts, in this case, that the informant had spent all the income his business generated without repaying any of the loan he had taken out to buy the auto-rickshaw, causing it to be impounded by the bank. The explanation that he had failed because he was a poor businessman, however, was a less comfortable reflection than one that blamed – not entirely unjustifiably – others’ prejudices for his misfortune, particularly when responding to a researcher who he knew was interested in the social ramifications of leprosy. Again, this is
about context, but it is also about recognising that leprosy can have positive, as well as negative, effects.

**Last words. . .**

Given the difficulties I have described, it is tempting to reject ‘stigma’ as a conceptually useful category altogether, urging researchers instead to use locally and contextually defined terms that better bring out the different typologies of discrimination encountered by people affected by the disease, whether as patients or by association. The fact remains, however, that certain conditions – and leprosy is paramount among them – continue to evoke responses from others that are qualitatively different from those evoked by other conditions. When I worked with sight-impaired people in the same part of India where I had also worked with those affected by leprosy, for example, the former were also subject to significant disadvantage, but were not seen as tainted or polluting in the way that those with leprosy still are. Goffman’s notion of ‘stigma’, in this case, has some mileage in differentiating responses to leprosy from other forms of disadvantage and discrimination.

My argument, then, is not that we should disregard ‘stigma’ as a category, but that we should interrogate it more critically and, in doing so, develop more sophisticated ways of analysing the social impact of leprosy. There are two broad, but overlapping, ways of doing this. One is to take the approach characterised in this collection by the report of a stigma research workshop: by putting stigma under the spotlight and by devising increasingly fine-tuned instruments for measuring and responding to it. The other approach, and the one with which I am most familiar as an anthropologist, is to subject the experience of leprosy to much more rigorous, ethnographic examination than most qualitative research to date has done. Sociology, as Yang, Kleinman and Link et al. point out, helps us to rethink stigma as a process that emerges from social interactions rather than as a fixed entity, while anthropological approaches, particularly through participant observation carried out over time, help to flesh out this insight by exploring the quotidian realities within which people both stigmatisate and are stigmatised. Using the Chinese notion of ‘losing face’, Yang, Kleinman and Link et al. also argue that stigma ‘is not just a discursive or interpretive process but a fully embodied, physical and affective process that takes place in the posture, positioning, and sociality of the sufferer’ (p. 1530). Stigma, in this sense, threatens the loss of ‘what is most at stake’ or, as the title of Arthur Kleinman’s subsequent book has it, ‘what really matters’: that which is most important in the life worlds of those who are being stigmatised. Assessment of what matters requires the forensic detail and nuanced understanding of everyday social life that ethnographic fieldwork can provide.

Not all those working in the leprosy field will be able to conduct long-term ethnographic fieldwork, just as most medical anthropologists won’t have the skills to develop more efficacious leprosy drugs. Those working with people affected by leprosy can, though, engage more with the ethnographic and historical work that is already out there (including several full-length monographs as well as more general regional ethnographies); take a more reflexive approach in the light of the critique outlined above; and follow some of the suggestions set out throughout this collection (some of them summarised at the end of Staples’ article, this volume). In doing so, there is a real opportunity to move beyond knee jerk associations that equate all the social experiences of people affected by leprosy with stigma.
References

7 White C. per comm.