

Pride and Prejudice – Identity and stigma in leprosy work

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Summary This article sets out to expand the way stigma, and those affected by it, are understood within leprosy discourse and to apply these insights to the analysis of the experiences of leprosy workers. The term stigma is often used simply as shorthand for ‘negative social experience’. However, to reduce the negative aspects of complex everyday life experiences to a single word is often overly simplistic and can serve to objectify, rather than illuminate, the experiences of those affected. This article argues that in order to understand the lived experience of stigma we must come to understand stigma as an ongoing, dialectical social process and develop an approach to stigma that analytically separates stigma from its negative social consequences. The article applies these insights to data collected during 14 months of fieldwork with front-line leprosy workers in India, which suggests that falling leprosy prevalence rates and a rapidly changing policy landscape have led to leprosy workers feeling marginalised and stigmatised within their own organisation. The article argues that, rather than seeing stigma merely as a negative process in which leprosy workers are passive victims, we must recognise that stigma also plays a key role in the creation and maintenance of leprosy workers’ identity and is utilised as a strategic tool in the struggle for influence between different groups within the organisation. Finally, the article argues for the benefit of expanding our understanding of stigma across public health and of applying these insights to designing future interventions.

Introduction

Leprosy has long been seen as the epitome of stigmatisation and has become a metaphor for degradation in colloquial English usage. Stigma remains a very real problem for those affected by the disease and a major challenge for implementation of effective public health interventions. Consequently, stigma has naturally been one of the main focuses of leprosy policy¹ and a recent review found that in the period 2002–2009 alone no fewer than 56 articles were published on stigma in leprosy, the vast majority of which focused on standards of measuring stigma and social exclusion of those affected by leprosy.²

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The majority of this research has focused on understanding the negative effects of stigma on the lived experience of people affected by leprosy. However, stigma is not limited to leprosy affected people, but plays a part in all aspects of leprosy discourse, from the organisation of health care³ and the social identity of leprosy workers to the formulation of future interventions. Therefore, how we conceptualise stigma as an idea determines the nature of future interventions and how we engage with those affected by stigma on all levels. By moving towards an understanding of stigma as a social process and by analytically separating the causes and functions of stigma from its consequences we can begin to see those affected by stigma not as passive victims but as social agents in their own right.

This article applies the above perspective to an analysis of how stigma affects the lives of leprosy workers in an urban leprosy project in India. Falling prevalence rates, changes in leprosy policy and the diversification of leprosy organisations activities has meant that leprosy workers often find that their particular expertise is no longer needed. The leprosy workers argue that their marginalisation within the organisation is a result of the stigma associated with leprosy work. Though there is undeniably stigma attached to the leprosy workers' role, this article will demonstrate that such an oversimplification of the situation may serve to hide the power and politics at play in the stigma process. Stigma plays a key role in the creation and maintenance of leprosy workers' identity and is utilised as a strategic tool in the struggle for influence between different groups within the organisation. Rather than being passive victims, the leprosy workers creatively engage with this stigma and attempt to control its effects.

However, let us first look at how stigma has been defined in the past and how we can expand this understanding to yield further insights.

HEALTH RELATED STIGMA – LEARNING FROM OTHER DISCOURSES

In the past leprosy discourse tended to follow Goffman's explanation of stigma as a set of undesirable characteristics attached to an individual leading to a 'spoilt identity'.⁴ This understanding is rooted in corporeal and biomedical disease models which link the social ostracism of leprosy affected individuals to specific physical markers. Despite the historical⁵ and linguistic⁶ strength of this association there has, more recently (possibly inspired by the developments in other health related discourses such as HIV and disability studies) been a shift towards understanding stigma as an ongoing dynamic process rooted in social relations,⁷ enacted within a specific cultural context.⁸

The notion of stigma is ubiquitous in leprosy literature yet it is not always clear how the term is used or what assumptions are implicit in any given approach. One of the things that complicates discussions on stigma is the sheer number and diversity of theories of stigma. Despite this richness, what many of these theories have in common is an implicit tension between the individual and the collective. Psychological models tend to be more individually oriented and focus on measuring individual experience of stigma whilst more sociological models focus on how stigma is used as a mechanism of social control.^{9,10} Within leprosy, the primary focus has been on the individual experience of stigma and on developing reliable transferable scales for measuring this experience.¹¹ Such an approach offers practical and pragmatic tools for policy implementation but risks obscuring the insight offered by social models of stigma. In social theories, stigma is seen as a social process, constantly changing and often resisted, rather than a static aspect of an individual's identity, and the focus is on the politics of stigma. One of the key contributions of social models of stigma is that they

demonstrate how stigma, as a social process, serves to produce and reproduce social power relations.¹² By understanding stigma as social relationships we can come to understand stigma as a dialectical process during which the labeller not only ascribes the status of 'other' to the stigmatised but also reaffirms his/her own normalcy.¹³

Harriet Deacon,¹⁴ writing about stigma associated with HIV/AIDS, argues that a weakness of both individual and social approaches to stigma is that they have tended to rely on definitions of stigma that include discrimination or other negative social consequences in the very definition of the term thereby conflating the causes, functions and effects of stigma. Such conflation "narrows our understanding of the range of effects stigma can have, and presupposes an over-simplistic relationship between stigma and consequent or existing disadvantage".¹⁵⁽⁴²²⁾

Deacon offers an alternative approach and argues that stigma should be understood as "a social process in which: 1) illness is constructed as preventable or controllable; 2) 'immoral' behaviours causing the illness are identified; 3) these behaviours are associated with 'carriers' of the illness in other groups, drawing on existing social constructions of the 'other'; 4) certain people are thus blamed for their own infection; and 5) status loss is projected onto the 'other', which may (or may not) result in disadvantage to them."¹⁵⁽⁴²¹⁾

Many elements of Deacon's definition apply specifically to stigma as experienced by those affected by disease. In my discussion of the stigma of leprosy work, I will primarily focus on the 5th element of Deacon's definition, which explicitly separates stigma from discrimination. With this innovative turn Deacon explicitly opens up the possible outcomes of the stigma process, analytically separating stigma from discrimination. This has the potential to change the way we perceive stigma and those affected by it.

Once we recognise that stigma and discrimination are distinct issues, though one often leads to the other, then we can start to recognise stigma as a social process in which 'otherness' is constructed and maintained through claims and counter-claims of truth. Stigma can be projected onto 'others', it can be resisted by this group, it can be internalised through self-stigmatisation or it can, in certain circumstances, serve as a mechanism for the creation of a shared identity. In specific contexts,¹⁶ the very characteristics that are singled out for stigmatisations can be appropriated by sub groups or individuals as powerful symbols of identity, solidarity, communal rights or as a platform for political action.

In much leprosy literature stigma has become shorthand for negative social experience effectively conflating stigma with negative consequences. However, stigma is but one element in a set of highly situational and context specific social processes. Not all negative experiences can be understood in terms of stigma and not all the effects of stigma are necessarily negative. Discrimination and loss of status are often very real and damaging consequences of stigma; however, loss of status by the stigmatised person "only occurs automatically in the view of the stigmatiser; it is not necessarily internalised by the stigmatised person, nor does it necessarily lead to discrimination".¹⁴⁽²³⁾ The tendency to use the word stigma as synonymous with negative experience may well contribute to these negative outcomes by validating the perspective of the stigmatiser; rendering the stigmatised voiceless, subordinate and invisible and denying the possibility of alternative outcomes.

To understand stigma as a social process, and to build interventions that address the root of stigma, we must resist conceptual conflation and build a definition of stigma that draws on a sophisticated understanding of the relationship between stigma, discrimination and power. By analytically separating stigma from discrimination, we can come to conceptualise the full

range of responses to stigma. Any approach built on an understanding of stigma as something that necessarily leads to discrimination denies the possibility of alternative outcomes and limits stigma interventions to reducing the negative consequences for those affected. These insights go beyond theoretical abstractions, speak to the very heart of how we conceptualise stigma and enable us to see those affected by stigma not as passive recipients but as social agents in their own right. As a result, they are insights that hold great promise in an era when leprosy discourse emphasises participation and empowerment.

Quite a lot has been written about the risk of leprosy affected people being marginalised within leprosy organisations, but little has been written on the precarious position of leprosy workers in the current policy landscape. Below, I will further explore the impact these theoretical insights can have when applied to empirical situations, by looking at the stigma experienced by leprosy workers in one of India's megacities.

THE STIGMA OF LEPROSY WORK

Leprosy work in India has deep and complex historical roots, from the early association with the church and colonial administration through to Gandhi's nationalist call for leprosy service as personal salvation. Detailed accounts of the historical and social construction of the meaning of leprosy work has been provided by others^{17,18} who have demonstrated that the internal relations within institutions and organisations are often as important to understanding the work and identity of those working with leprosy as any wider cultural and political context.¹⁹ Eric Silla argues that "unlike other diseases leprosy transforms the identity of those afflicted. The person with leprosy becomes a leper",¹⁹⁽²³⁾ and I would argue that much the same applies to those who work within the field so that, over time, health workers working with leprosy become leprosy workers, regardless of what additional responsibilities they may hold.

Not much has been written about the stigma of working with certain diseases, though such associated stigma is not unheard of, especially in association with HIV and mental illness. In the early years of the HIV epidemic, those who worked with the disease "were themselves stigmatised and suffer[ed] discrimination and even threats from other physicians".²⁰ Yellapur describes similar problems in the initial implementation of National Leprosy Elimination Project (NLEP), when doctors were reluctant to join NLEP for fear that they might be discriminated against by their colleagues.²¹ In addition, Staples describes how integration of leprosy services would lead to reclassification of government leprosy workers to a lower government scale and how, though this was resisted by some leprosy workers as it would entail reduced pay and loss of the distinction of their specialised qualification, it was seen by many, including the trade union, as a positive long-term investment to combat any pervasive stigma of the leprosy label post-integration.²²

Most of the writing on stigma and health workers has tended to focus on the stigmatisation of patients by health personnel,²³ due to lack of knowledge or prejudice. Though this is certainly an important aspect of the social relationship between health providers and their clients and something which is a challenge, especially in relation to integration of leprosy services into the general health system, it is certainly not the only way in which stigma affects leprosy workers. The health workers I studied found that, with falling prevalence rates, their diligent efforts to eliminate leprosy may have inadvertently left them facing probable unemployment, questioning their social identity, and feeling marginalised and stigmatised within their own organisations. Though this is the story of one project in a specific setting,

I have found, through informal discussions with representatives from other organisations and other settings, that this is an issue that affects leprosy organisations and leprosy workers across the globe.

URBAN LEPROSY PROJECT

The following ethnographic description and analysis is based on data collected during 14 months of participant observation, in-depth interviews and focus groups with front-line leprosy workers, between September 2006 and February 2008, in the Urban Leprosy Project (ULP) operating in one of India's mega-cities. In addition, in-depth interviews were carried out with managers at regional and national level of the organisation and participant observation brought me into contact with a wide range of government staff, community members and leprosy affected persons on a daily basis.

The Urban Leprosy Project (ULP) was established in 1989, in response to the Indian government's call for an increased focus on urban populations. ULP was a direct project run by the Indian Leprosy Organisation (ILO), a large Indian NGO with projects across the country and a strong affiliation with an organisation based in the UK. In 2006 the project covered a population of approx. 2,179,540, in a city of more than 6 million, and had 13 500 registered and 90 active leprosy cases in the project area. The project staff consisted of a project officer, a medical officer, a physiotherapist, a Health Education Officer, two Supervisors and nine health/leprosy workers, as well as a number of technicians and auxiliary workers.

At the time of my fieldwork the project's primary focus was on supporting the provision of leprosy services through the general health system at 26 Urban Health Posts (UHP) across the city and on working against other diseases of poverty. However, this had not always been the case, as organisational structure, working practices and operational remit had all changed drastically in recent years.

CHANGES IN THE LEPROSY LANDSCAPE

Over the last decade, with falling prevalence rates and changing trends in international leprosy policy, there have been profound changes to both organisational structure and working practices within both ULP and ILO. Between 1989 and 2002, ULP acted primarily as an agent of NLEP, with a focus on survey, education and treatment. For the health workers, the onus was on maximum coverage of the population and their days were primarily spent conducting door-to-door surveys in groups. Due to the high prevalence rates in the area at the time (>14 per 10 000), each of the then 16 health workers could be responsible for as many as 100 active cases at any given time (more than ULP's total case load in 2006). In addition, the health workers provided ulcer care and other out-patient services at the project clinic.

In 2002, the project started diversifying its activities by taking on several microscopy centres under the Revised National Tuberculosis Control Programme (RNTCP). The project further expanded its remit through a 5-year project funded by the European Commission, which focused on strengthening health system responses to leprosy, TB, malaria and HIV. This diversification of activities occurred throughout the organisation and caused a growth in ILO's middle management and administrative staff, to manage grants and facilitate

operations. This change in organisational structure and culture also affected the position and working practices of health workers.

As part of the integration of leprosy services into the general health services, all active case finding activities ceased in 2003, thereby removing the primary focus of the health workers' past work, the survey, from their daily schedule. Rather than working in groups to identify active leprosy cases all over the city, the health workers were now responsible for supporting the totality of leprosy services in their designated areas, as well as providing health information on tuberculosis, HIV/AIDS and malaria to the community. The number of health workers shrunk from 16 to nine, with each health worker now responsible for a population between 100,000 and 300,000, spread over a large geographical area. The onus of their work shifted from service provision to prevention of disabilities, social and economic rehabilitation, stigma reduction and health education. In addition, each of the health workers now had a sub-speciality, an area of activity for which they had special responsibility, e.g. eye care or social and economic rehabilitation.

By 2006 the leprosy prevalence rate had been reduced to 0.4 per 10 000, well below the elimination target of 1 per 10 000. Fewer and fewer of the health workers' time was spent on leprosy and those affected by the disease. Instead, the focus shifted onto health systems strengthening, community health and prevention of diseases of poverty.

Changes in epidemiology and policy have driven the changes in working practices described above but they have also, indirectly, led to changes in health workers' social identity and their relative position within the organisation.

LEPROSY WORK AND SOCIAL IDENTITY

The health workers at ULP had all worked in the field of leprosy for more than 10 years, some considerably longer. Throughout their working lives, leprosy policy – first in the guise of leprosy eradication, then as leprosy elimination – gave meaning to their daily activities and contributed to their understanding of their social identity. For most of the health workers, the technical distinction between elimination and eradication was irrelevant, as they continued to work towards 'a world free from leprosy'. Leprosy elimination as a framework for action and as an underlying ideology allowed them to simplify the complex, fragmented and ambiguous logic behind leprosy elimination into a coherent and structured story with a clearly defined problem, a prescribed course of action and a desired outcome.²⁴ Ultimately, as a result of the health workers' training, daily reaffirmations through peer discussion and habitual activities, the health workers' shared understanding of leprosy elimination discourse came to serve as a shared, directive moral universe.

The health workers' identification with the discourse of leprosy elimination was often so complete that, despite the diversification of the project remit, they still saw themselves primarily as leprosy workers. In fact, being a leprosy worker had become one of their primary social identities, even beyond work. As one health worker phrased it, "leprosy is our bread and it is in our blood, it is not only what we do, it is who we are". Another described how work was never far from their minds, even in the cinema:

"Sometimes we go to see a movie, with colleagues or with family, and we will spot somebody with a lesion and call out: 'Oh, see. Patch, patch'. Then our spouses will complain: 'No! We bought a ticket to see a picture. But all you can see are skin lesions!'"

[laughs] Our habit is like that. Even on the screen, the heroine is dancing and all we can see are lesions! [laughs]"

However, it was not merely for the health workers themselves that their identification with leprosy was pervasive. Having worked for decades in the same communities and with a specific focus on leprosy services, the health workers had become known in their area as the 'patches doctors'. Despite the potential for stigma by association of working with the disease, there was little evidence of any negative effects of this in the way the health workers interacted with communities. Instead, the health workers spoke of the considerable authority conferred on them by working in the official capacity of a widely recognised national initiative such as NLEP. The change in ULP's remit diversified the health workers' activities and expanded the range of issues and services they engaged with. Slowly, their association with leprosy faded as increasingly the community perceived them as general health workers. Nevertheless, the health workers continued to refer to themselves as leprosy workers.

SOCIAL POSITIONS – FROM PILLARS TO MILLSTONES

With the success of leprosy elimination, funding for leprosy projects became progressively more difficult to secure. In response, ILO, like many leprosy organisations, diversified its remit and secured funding for new interventions targeting other public health problems such as TB, malaria and HIV. Whilst leprosy activity used to make up the majority of the organisation's activities, it now accounted for fewer than half of them.

Opportunities within these new fields were largely given to new recruits from outside the organisation, who brought new perspectives and discourses to the organisational culture. In the eyes of the leprosy workers, the possibility to expand into new fields of work was afforded ILO as a result of the leprosy workers' success in leprosy elimination, yet, they now faced redundancy whilst new hires benefited from their hard work. The leprosy workers, who were used to being called 'the pillars of the organisation', now felt they were seen as backward, old fashioned, expensive and redundant, as proverbial millstones around the organisation's neck.

The decision to hire new recruits for new positions must be understood, not only as a result of an assessment of the existing skills and capacities within the organisation, but also as a reflection of an internal struggle over identity, influence and power. There was a clear need for new skills and perspectives not possessed within the organisation; however, there was also a systematic lack of acknowledgement of some of the organisations' existing capacities.

Despite the fact that many of the health workers at ULP had pursued post-graduate qualifications and diplomas, in counselling and HIV for example, to upgrade their skills, these achievements were rarely recognised. In the words of one manager, the organisation was '*blind to the developments happening in the field and blind to the changes brought to the lives of the persons working with leprosy*'. Though there was some recognition of the extended capacities of leprosy workers, little was done to acknowledge it, as one senior manager explained:

"The organisation failed in some areas, especially when it comes to stigma against leprosy workers (. . .) A leprosy worker, in his travels over the years, has transformed himself into a meaningful worker towards health and development issues. But what has

not happened, what we have failed to do, is to acknowledge this fact and instead we looked for new skills outside [of the organisation]"

The health workers' perceived role within ILO was inalienably associated with leprosy activities and as the importance of leprosy work diminished within ILO, so did the leprosy workers' position within the organisation. For the health workers themselves, this association was a source of pride, a badge of honour, connoting past achievement rather than limiting future possibilities. However, the health workers felt the attitudes of newly appointed staff was that a "*leprosy worker is a leprosy worker, he must die with that designation*". In this way the stigma associated with leprosy work overshadowed the health workers' skills and abilities and left them feeling systematically marginalised within their own organisation.

The organisation's decision to form of a separate 'HIV Division' may have been an administrative necessity but also served to section off certain positions and fields of knowledge. In addition, the establishment of several new projects at different sites to existing projects was motivated by logistics concerns but similarly contributed to the social and geographical separation of new and existing staff.

As each group struggled to establish the primacy of their skills and knowledge new recruits in new projects would seek to stress how their use of e.g. community engagement, outreach, counselling or similar set them apart from the organisations previous leprosy work and, thus, from the work of leprosy workers. Paradoxically, the changes in remit and working practices at ULP meant that the health workers were routinely engaging in quite similar activities. This is not to diminish the unique skills of the new recruits but to emphasise that this was not simply a conflict over knowledge or skills but a struggle over power and identity.

The stigma against leprosy work *outside* of leprosy organisations is well established, now the lack of recognition of the transferable value of experience in leprosy work *within* leprosy organisations further added to the health workers sense of marginalisation. In addition to the usual stigma, health workers who sought employment outside of the organisation now also had to explain why ILO had not recognised their capacities by giving them an opportunity in one of their new projects.

NOSTALGIC NARRATIVES

The moral universe formed by a shared allegiance to the narrative of leprosy elimination formed a key component in the social identity of health workers and in setting them apart, as a group, from recent arrivals who they felt did not 'understand' leprosy work or have the 'right' attitude. As new recruits attempted to establish the primacy of their own skills and to marginalise those of the existing health workers, the health workers responded by creating nostalgic narratives which relied on frequent reference to this shared moral universe and their sacrifices in the past, as a means of re-emphasising their importance in the present and excluding the new arrivals from their circle. As one of the health workers phrased it:

"(. . .) then they said to us, 'you are like soldiers. If you work hard we can be like soldiers and eradicate leprosy. If you work hard in a good organisation you will have a good future'. We worked hard, madam. Not like now. Then we got up at 5 o'clock in the morning and cycled 20 km to motivate patients to come to drug distribution point. Then supervisor and medical officer would come in the Jeep and distribute medicine. Often we would work without breakfast or lunch – 12–13 hours a day. Like that.

When Sadguna [pointing to the other health worker] left in the morning his children were sleeping, when he came home in the evening his children were sleeping. Like that. But we did social service”

These stories were always told after working hours, or in quiet moments over a cup of tea. They were shared internally in the group of health workers, or to make a point to me as an outsider, but rarely consciously projected outside their social circle in the organisation. The familiar tales bound the group together through a shared history and reaffirmed a powerful social identity. Though the narratives varied from person to person, the elements remained the same throughout the group: sacrifice through long hours and loss of family life, physical hardship through field work in extremely difficult conditions, cycling long distances in the midday sun and forgoing food, suffering great personal risk by working late into the night in slums with open sewers and drunken ‘rowdies’, as well as exclusive and extreme loyalty to ILO.

Though these narratives were interesting in and of themselves, to understand their role fully we must consider them alongside the ways the health workers spoke of other staff. With limited interaction between new and old staff one of the ways to emphasise their own positions were through negative descriptions of the work of others. The health workers frequently criticised government employees for only being interested in collecting a salary, for stigmatising people affected by leprosy, for only working to satisfy arbitrary targets and for not caring about the patient or the social good. New hires in the organisation would be similarly caricatured and criticised for not showing proper dedication (through working overtime for example) and for their lack of field experience and knowledge of leprosy. This process, of pitting the group’s attributes against the perceived attributes of new recruits and government employees served to strengthen the group’s social identity and to reaffirm the normalcy of their position in a situation where their position was threatened by ongoing priority changes.

Discussion: Battle of identity, capital and the politics of stigma

Leprosy workers argue that they feel stigmatised within their own organisations and claim that this is a result of their association with leprosy. However, I would argue that this is a convenient over-simplification that hides far more complex social processes grounded in claims and counter claims of normalcy and otherness, aimed at influencing the relative social power of different groups within the organisation. Stigma, understood as a social process, involves two parties, the labeller and the labelled, and is, fundamentally, about otherness and the power to ascribe it. By understanding the leprosy workers’ claim to normalcy and ascription of otherness as part of a wider politics of stigma we can begin to understand this as part of an ongoing battle over social identity within the organisation.

The uniqueness of leprosy workers used to be based on technical expertise and membership in a moral universe, grounded in leprosy elimination, shared by the entire organisation. This shared moral universe maintained their social identity and set out the attributes they valued as a group. However, this unity was challenged by new perspectives introduced into the organisation through interventions that require different approaches and by new recruits who work hard to establish the uniqueness of their own skills by deprecating existing practices and, in effect, identifying leprosy work and leprosy workers as ‘other’. The health workers’ response to this ‘othering’ was to attempt to re-emphasise their

uniqueness by reversing the 'othering' back onto other groups, such as government workers or new recruits within ILO, and to embrace their assigned identity as leprosy workers through the telling of nostalgic narratives.

For the health workers however, these efforts may, paradoxically, contribute to the stigma against them, as it serves to further alienate them as a group, reinforces their association with past working practices and value systems that are not in tune with the current environment. Potentially, they lend credence to those who seek to effect loss of status for leprosy workers by pointing out their backwardness and redundancy within the organisation. For the health workers, their self identification as 'leprosy worker' may be a badge of honour and a source of pride but, for other interests within the organisation, this association becomes subject to counter claims of redundancy and out datedness which undermine efforts of self-empowerment by the leprosy workers. Realising that they may not be able to redeem the social identity of 'leprosy worker', they attempt to capitalise on organisational sympathies, by drawing on nostalgic narratives that emphasise loyalty and sacrifice and by using the word 'stigma', with its well-established links to social injustice and 'victim-hood' within leprosy discourse, to describe their own predicament.

To take our analysis to the next level, I wish to incorporate some of Pierre Bourdieu's theoretical contributions into our exploration of identity and stigma in leprosy work. To really understand stigma as a social process we must reconceptualise the organisation as a social space where individuals and institutions are constantly jostling for position and influence utilising capital as their primary tools for improving their position.²⁴ Bourdieu expands the concept of capital beyond materialistic possessions to include economic, social, cultural and symbolic capital.²⁵ Bourdieu argues that the position of any individual or group in social space can be understood by looking at the overall volume and composition of the capital they control and the trajectory of this capital, i.e. how this volume and composition has changed over time.²⁶ Stigma can then be seen as a tool in the struggle between different groups as they attempt to devalue the capital held by others and enhance their own position and influence within the organisation.

The position and capital held by health workers has changed drastically over the last few years, as they have gone from being the pillars of the organisation to feeling marginalised and stigmatised. As the field of leprosy control has changed from an emphasis on direct service delivery to a focus on facilitation and development, the health workers feel their skills, as a form of capital within the field, have become devalued within leprosy policy and within the organisation.

The health workers' efforts to validate and maintain their social identity through the nostalgic, idealised recollection of their role in the past can be seen as an attempt to short circuit their trajectory by linking their social identity to a past where capital was differently valued and they controlled a greater volume. In effect, they are attempting to reclaim the stigmatised identity that the stigmatisers have assigned to them in an attempt to prejudice their position and re-launch this as a platform of pride to regain social power. James Staples terms this process 'the paradox of disablement as enablement' in describing how people affected by leprosy embrace their stigmatised social identity in a bid for social power.²⁷

However, for the health workers, as a minority within the organisation, they cannot co-opt capital without challenging, or at the very least engaging with, the way in which different capital is valued by other groups. From the point of view of the leprosy workers, an identity that has been so stigmatised may indeed serve as a source of self-empowerment rather than self-stigmatisation but, as long as they are not able to influence majority perception within the organisation, it cannot serve as a meaningful platform to further their agenda.

Conclusion: Stigma past, present and future

Stigma is a very real problem for those affected by and working with leprosy. It can, and often does, have devastating effects on the lives of individuals and groups. However, to reduce the negative aspects of these complex everyday life experiences to a single word is overly simplistic. Above, I have attempted to demonstrate that, in order to recognise stigma as a dynamic process and to take seriously the implications of social power relations, we must begin by adopting a sustainable definition of stigma that separates the cause and functions of stigma from its effects.

Despite falling prevalence rates, leprosy will remain a pressing health problem for some time to come and stigma one of its key challenges.²⁸ Leprosy workers and leprosy organisations face a difficult future. Some will close, some will diversify and some will find alternative activities. Understanding how the stigma of leprosy work plays out as a social process and as a struggle over identity, influence and power enables us to recognise that this is not simply a contest between individuals or groups but a struggle that goes to the very core of organisational culture²⁹ and the nature of future interventions. These insights are not unique to leprosy control but reflect a dynamic that exists throughout public health as changing funding fortunes or disease prevalence rates create changes in organisational structures and cultures.

Stigma is not limited to people affected by leprosy but plays a part in all aspects of leprosy discourse, from the organisation of health care to the formulation of future interventions. Therefore, how we conceptualise stigma as an idea determines the nature of future interventions and how we engage with those affected by stigma. By building future intervention on a more complex understanding of stigma which recognises all the possible ways in which people respond to and interact with stigma, we can begin to move away from seeing the stigmatised simply as passive victims and towards recognising stigmatisation as a social and political process in which the stigmatised themselves have a very real role to play as creative agents. By increasing representation and participation of the stigmatised in interventions we can question how, and by whom, 'normalcy' is constructed and, thereby, encourage sustainable and ethical interventions that temper the normalising function of international discourse.

Declaration

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