A temporal and sociocultural exploration of the stigma experiences of leprosy patients in Brazil

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Summary
Objective: Primary aim: To explore the stigma experiences of current and ex-leprosy patients in Brazil. Secondary aim: To explore these stigma experiences in the sociocultural context of Brazilian society.
Method: Twenty seven semi-structured face-to-face interviews were conducted at Instituto Lauro de Souza Lima, Bauru, São Paulo, Brazil.
Results: Three main themes emerged regarding leprosy stigma in Brazil: 1) Changing attitudes towards leprosy patients, 2) Acts of discrimination experienced by leprosy patients and 3) The complications of disability caused by leprosy.
Conclusions: The majority of the study participants were low-income Brazilians, which coincides with national statistics on people affected by leprosy in Brazil. Participants reported suffering from stigma and discrimination. But overall, patients in this sample believe that national attitudes toward leprosy patients are improving, and stigmatising attitudes are less severe than in the past. Friends and families are usually supportive. Patients suffer negative mental health consequences and internalisation of stigma from the effects of some treatments for leprosy reactions, and from visible deformities. Patients were ill prepared for the severe physical and mental effects of leprosy reactions and sequelae. It is recommended that patients are informed about the chronicity of leprosy and the potential for disease reactivation, as well as the required treatments and the side-effects of these. Additionally, faster disease diagnosis should help prevent the development of sequelae and disabilities. Media and educational campaigns, facilitated by a changing context of narrowing (but still very wide) socio-economic inequalities in Brazil, are needed to help reduce stigma and discrimination for leprosy.
Introduction

Stigma is ‘social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group.’¹ Stigma is not a single phenomenon, but entails several possible components:² It may be understood in terms of perceived stigma (the belief that a person will encounter discrimination or be judged negatively if their undesired status is revealed), experienced stigma (the actual events of discrimination that occur) and self- or internalised stigma (shame and lowered self-esteem).² In addition, social stigma is the general public’s endorsement of stereotypes and prejudices against certain groups that lead to discrimination.²,³

Leprosy stigma is powerful and pervasive.⁴ It is a disease that is associated with fear, ostracism and discrimination in many parts of the world.⁵ Research has shown that leprosy stigma has a negative impact on social participation, work, socioeconomic status and mental health.⁶,⁷ Healthcare access and the effectiveness of public health programmes are also impaired as a result of stigma.⁶–¹⁰

Leprosy was introduced to Brazil in the 16th century by Europeans that colonised the country.¹¹ Expulsion of individuals affected by leprosy from society to restricted areas has been practised in many cultures since ancient times, and was officially implemented in Brazilian law in 1920 as a means of preventing disease spread.¹²,¹⁷ With the discovery of sulfone treatment in the 1940s, involuntary isolation was officially abolished in 1962.⁹,¹² Subsequent disease resistance to sulfones resulted in the introduction of Multidrug therapy (MDT) in the early 1980s by the World Health Organization (WHO), and was officially implemented in Brazil in 1993.¹² Focus placed on eliminating the disease has seen prevalence decrease markedly worldwide. However, Brazil currently still has the second highest number of leprosy cases in the world (after India), with a registered prevalence of 31,040 cases in 2013, a rate of 1·51 per 10,000 people.¹³

The Brazilian government has attempted to reduce leprosy stigma. In 1976, the stigma-laden medical terminology of ‘leprosy’ was officially replaced with ‘Hansen’s disease’ in an attempt to attain greater social integration for those affected by the disease.¹⁴ The importance of preventing leprosy stigma was further recognised by the non-governmental organisation (NGO) MORHAN (Movement for the Reintegration of People Affected by Hansen’s Disease).¹⁵ They have worked to educate the public about leprosy, its treatment, and the surrounding stigma. They also provide advocacy for leprosy patients and their families.¹⁵ However, despite these efforts, leprosy stigma remains a problem in Brazil.¹⁵,¹⁶

This study aimed to gain understanding about any changes in leprosy stigma experiences in Brazil. A literature search was conducted in order to discover whether any existing studies have researched stigma in comparative temporal fashion in Brazil. The MEDLINE and EMBASE databases were searched using combinations of the keywords ‘leprosy’, ‘stigma’, ‘discrimination’, ‘time’, ‘change’ and ‘temporal’, and revealed a paucity of this type of study. Regardless, further leprosy stigma research is always necessary because it is a dynamic subject, and stigma experiences are ever-changing.⁴ It is also essential to understand the social history and cultural context of the people involved.¹⁷ This is particularly important in Brazil, where changes in infrastructure and social class structures¹⁸ interact with the physical and psychological effects of disease, creating different interpretations of stigma which may prove useful in creating new interventions for stigma prevention.³
AIMS

Primary aim
This study aimed to explore:

- The stigma experiences of current and ex-leprosy patients in Brazil.

Secondary aim
This study also aimed to explore:

- These stigma experiences in the sociocultural context of the ever-changing Brazilian society.

Methods

Qualitative methodology was most suited for this work because of the need for in-depth probing of personal perspectives, opinions and beliefs; as well as for critical analysis in a social context.\(^\text{19}\)

Setting

The study was conducted at the Instituto Lauro de Souza Lima (ILSL), Bauru, São Paulo, Brazil. A former leprosarium, the institute now cares for patients with a range of dermatological diseases. Taking specialist interest in leprosy, it is a major leprosy research and referral clinic under the Ministry of Public Health of the São Paulo Government.

Recruitment

Healthcare staff assigned to the study undertook a 5-day training period with the primary researcher (the author) about the research aims, interview tools and ethical practice, in order to achieve familiarity. They recruited patients using purposive sampling techniques, selecting participants with a range of characteristics in order to collect a variety of perspectives.\(^\text{20}\)

Patients were recruited from several outpatient departments including but not limited to psychology, physiotherapy and occupational therapy. Additionally, ward inpatients and voluntary leprosarium residents were approached and invited to participate in the study. Patients were screened for eligibility using the following inclusion criteria:

1. age over 16 years
2. current patient at the institute
   and were either diagnosed with leprosy either;
3. more than 20 years ago or
4. less than 10 years ago.

The diagnosis period restrictions were chosen to allow exploration of the effect of MDT on stigma, by comparing stigma experiences before MDT was implemented about 20 years ago with those 10 years post MDT establishment. Introduction of treatment was a useful point of comparison since research has shown that fears about the incurability of leprosy in Brazil was
a big factor in stigmatisation of patients. Patients who did not know when they were diagnosed were not included. Date of diagnosis was confirmed by checking patient records.

**STUDY DESIGN AND PROCEDURE**

Twenty seven semi-structured face-to-face interviews were conducted in March 2015. Fifteen participants were diagnosed more than 20 years ago, and 12 were diagnosed less than 10 years ago. An initial sample of 10 cases was selected for each diagnosis period, followed by further cases to determine whether new themes emerged, as suggested by Bowen et al. Two participants declined to be interviewed due to time restrictions.

Participants were interviewed either following outpatient appointments or at a convenient time as chosen by inpatients and leprosarium residents. Interviews lasted 25 minutes on average, and were conducted in Brazilian Portuguese by the same qualified research psychologist, who acted as the interviewer. This was done in order to aid flow, and enable better immediate cultural adaptation and interpretation of the interviews. All of the interviews were conducted in the psychologist’s clinic room. The primary researcher was present in all interviews to make notes about the interview environment and non-verbal cues. The interview guide (see appendix 1) was translated into Brazilian Portuguese, and provided the interviewer largely with open and some sample probing questions. It was accepted that the interviewer could depart from the interview guide in order to follow the interviewee’s interests, knowledge, and ideas. Prior to interviewing, demographic data (including age, sex, monthly salary leprosy diagnosis date and classification) were collected. It was explained to all participants that the purpose of the research was to understand and learn from their experiences.

**ANALYSIS**

Interviews were audiotaped using a digital recording device and transcribed into Brazilian Portuguese by a research assistant (a trainee psychologist at ILSL). These transcripts were translated into English by a professional translator. In order to ensure accuracy of transcription and translation, a random selection of audio recordings, Brazilian Portuguese and English transcripts were given to an independent Brazilian Portuguese speaker fluent in English for back translation. Debriefing with the primary researcher, interviewer and research assistant occurred after each interview had been transcribed into Brazilian Portuguese with notes made by all of them. Ongoing preliminary data analysis during these debriefing sessions determined saturation, i.e when no new data was being discovered, and therefore, interview cessation.

Data were managed using NVivo 10 software and analysis followed a conventional content approach, which is normally used to ‘describe a phenomenon’ by developing new themes and explanations from the data. The primary researcher began by reading all the transcripts repeatedly to achieve immersion. The text was read word by word to derive codes from parts of the data that presented crucial ideas. A combination of descriptive, analytic and ‘in vivo’ coding of the transcripts was performed. Analytic memos were noted throughout this process to help make judgments about meaning, importance, and connections. Codes were sorted into categories and sub-categories based on how they were related and linked. These emergent categories were used to organise and group codes into meaningful collections. Finally, overarching core themes were generated to give a broad description of the data.
The co-analyst coded randomly selected transcripts and reviewed a completed analysis in order to achieve investigator triangulation. Triangulation was performed to improve the trustworthiness of the results by decreasing the uncertainty of interpretation and the potential for bias. Following discussion between the primary researcher and the co-analyst, it was decided that stigma as a result of steroid treatment for leprosy reactions, while not totally attributable to leprosy itself, was an important finding. It was therefore included in the results. Trustworthiness was also improved by reflexivity during data analysis. The primary researcher’s own preconceived thoughts with regards to the aims of the study were reflected upon. These included the belief that findings about the impact of MDT on experienced stigma would be the most important. Additionally, due to knowledge of the racial inequalities that exist in Brazil, the primary researcher held the belief that there might have been differences in the levels of stigma experienced by different racial groups. A reflexive journal was kept as a way of keeping record of the primary researcher’s thoughts and feelings throughout data collection and analysis as a method of transparency.

ETHICAL CONSIDERATIONS

The study was approved by the Scientific Committee at ILSL. Ethical approvals were gained from the Ethical Committee at ILSL and the BMedSc Population Sciences and Humanities Internal Ethics Review Committee at the University of Birmingham, United Kingdom. Informed consent was obtained from all participants using consent forms written in Brazilian Portuguese. Each participant was assigned a unique identification number to ensure anonymity.

Results

Sixteen males (59.3%) and 11 females (40.7%) in total were interviewed. The median patient age was 59 years old, with ages ranging from 16 to 87 years old. The earliest leprosy diagnosis was in 1943 and the most recent in January 2015. Six participants (22.2%) had the paucibacillary classification of leprosy and 21 (77.8%) had multibacillary leprosy. Multibacillary leprosy has a higher number of skin lesions and nerves involved than paucibacillary leprosy. Twenty participants (74.1%) had visible deformities or disabilities. Twenty three participants (85.2%) were ‘white’, two participants (7.4%) were ‘black’ and two (7.4%) were ‘brown’ (as self-described using the racial classifications of the Brazilian Institute of Geography and Statistics (IBGE)). Most patients were retired or out of work due to disability, and so were in receipt of monthly government allowances. For full demographic details of the interview participants see Table 1.

Participants described their feelings on receiving their diagnosis, how they (and their families) coped with it, their consciousness and experiences of leprosy stigma in the community and wider society, and their reactions to stigma if they had encountered any. Three main themes emerged regarding leprosy stigma in Brazil:

1. Changing attitudes towards leprosy patients in Brazil
2. Acts of discrimination experienced by leprosy patients
3. The complicated relationship between disability and; experienced stigma, perceived stigma, work life, social participation, and self-stigma

Quotes in this section have been edited for flow.
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Participants identified fear of disease transmission due to misconceptions as a major source of stigma. Misperceptions regarding the methods of leprosy transmission were commonly encountered by participants. For patients who had been diagnosed several decades ago, even doctors were not aware of the transmission mechanisms, and encouraged behaviours that might have promoted stigma.

One patient recalled:

“The doctor said I had to go to the hospital. That I had to burn all my clothes that I used, to throw away all the dishes I used, separate the plates, spoons I had used, things like that.” (P9, 56 year old female, diagnosed in 1973)

These patients were treated with a lot of prejudice by most of society. As described earlier, this general endorsement of stereotypes and prejudice is public stigma:

“[People] had prejudice. . .it really was ugly. . .We were treated as a mangy dog.” [We were]. . .totally excluded from the society.’ (P19, 81 year old female, diagnosed in 1943)

Most participants believed that attitudes towards people with leprosy had improved over the years because of the abolishment of mandatory isolation, the introduction of MDT, contact tracing and vaccinations, and the use of media public health campaigns. Additionally, the separation of ‘leprosy’ from ‘Hansen’s disease’ was believed to have dispelled some of the historical stigma. This meant that many participants (12 of the total), particularly younger ones diagnosed more recently, responded that they had not encountered stigma.

“The treatment has changed; the physicians studied more about it. . .They said ‘No, it has no danger. . .there’s no need to have prejudice.’ ” (P24, 70 year old male, diagnosed in 1973)

“I believe it is more normal. Because there is the vaccine so you don’t contract it.” (P26, 16 year old female, diagnosed in 2014)

It is important to note that some of these attitudinal shifts were also the result of misconceptions. The above-mentioned participant claimed that the vaccine prevented disease contraction. This is not strictly the case. Strategies using a combination of the Bacillus Calmette-Guérin (BCG) vaccine and chemoprophylaxis with rifampicin provide about 80% protection against leprosy.\footnote{37}

DISCRIMINATION EXPERIENCED BY LEPROSY PATIENTS

Discrimination by the government

For patients who had been diagnosed when mandatory isolation was legally enforced and later while it was still practised, the evidence of discrimination was the forced removal from their normal lives and homes. This was government sanctioned.

“It was a compulsory hospital admission. I didn’t want to, I was forced to come.” (P14, 83 year old male, diagnosed in 1957)

“I had a newborn, I think she was not three months, and then I had to leave [and go to the hospital]. Yes, to leave a child while breastfeeding right? It was not easy.” (P8, 56 year old female, diagnosed in 1984)
Overall, family and friends were supportive when participants revealed their diagnosis, but some were frightened of contracting the disease and so avoided sleeping in the same bed, using the same dishes, and in one case, avoided coming to the participant’s house at all.

“[My wife and I] sleep apart from each other because of this problem of mine. Because this disease transmits to another person right, so she didn’t want to be next to me.” (P5, 57 year old male, diagnosed in 1992)

“My own blood. . . If I go in my mother-in-law’s house and she offers water and I drink . . . She throws the glass away. She prefers to throw it away than wash it, understand? They have a huge fear of catching [leprosy].” (P7, 21 year old female, diagnosed in 2013)

“When I found out I had [leprosy], there was a daughter that wouldn’t even come to my house . . . for fear of catching it!” (P2, 67 year old female, diagnosed in 2010)

In addition, one participant experienced discrimination from her husband as a result of the steroid medication she was taking for her leprosy reactions. Her husband teased her about changes in her appearance, and there were resulting negative consequences for their sexual relationship.

“Yes, I was super happy, skinny, tall, blonde, cute, bright white, you know, my skin was perfect, now my skin is awful, my skin does not go back”

“He is always making a lot of jokes about everything, my weight, the vaginal discharge, you know? Everything. He says that I am unbearable, that my face is horrible, that I have those nasty pimples, so I even don’t feel like getting close to him, I feel nothing when I get close to him, it is like we were two brothers understand? I don’t feel anything. A totally cold relationship.” (P7, 21 year old female, diagnosed in 2013)

Disappointingly, both the leprosy diagnosis and the medication used to treat the disease can lead to discrimination.

Discrimination in the workplace

Few participants were still currently employed, but of those who were, many reported experiencing discrimination at work. Two participants had been forced to resign once their leprosy diagnoses were disclosed. One participant challenged this by filing a lawsuit (which was unsuccessful as of then) and had been affected by the trauma of this event:

“The director of the school wanted me to ask [for] resignation. I worked there for many years. Yes, [they] came to me saying: ‘whore, bitch’. I became a whore, a bitch, a thief, a rotten leg. I didn’t believe in prejudice until I faced it. And it was really hard, traumatic. People don’t understand that it kills other people. There are many ways of killing a person. They damaged my mind. Today I don’t know if I want to live or die, I don’t know anymore. One side of me wants to live, the other doesn’t.” (P17, 51 year old female, diagnosed in 2009)

The troubles she had faced had caused her to become ‘damaged’. She had internalised the stigma she experienced.
Participants reported that the physical deformities and disability caused by leprosy acted twofold: (1) They caused experienced stigma and; (2) they caused inability to work and loss of social participation.

(1) “Ah, I don’t know...when you have a crooked hand, fingers, a deformed leg, these things. People change with you a bit...well the prejudice happens...they kind of get away from it.” (P4, 67 year old male, diagnosed in 1991)

(2) “Previously I did everything. I used to work, I used to take care of my mother...[but] it changed now, now that I hurt my foot, I cannot walk. I get kind of angry, because I cannot go anywhere.” (P6, 68 year old female, diagnosed in 2009)

(2) “A person invites me to go out on Sunday, calls me to go to the ranch, to go to mass. I used to go every Sunday and I’m not going anymore.” (P23, 54 year old male, diagnosed in 2011)

Additionally, since many participants had little formal education, the only job opportunities available were manual. Their disabilities ensured that they could not find different work.

“My husband made me quit. Because I had pain. Because I got neuritis. And with no study, the only work that was left was as a maid. And I couldn’t do that [either].” (P10, 51 years old, diagnosed in 1978)

The combination of these two factors led to feelings of depression, anger at self, and self-stigma. One participant became traumatised by the stigma she would anticipate as a result of her deformities:

“[It felt like] everyone was against me, everyone was with prejudice. I blamed myself. I noticed that I was getting depressed. I didn’t want to go outside. I didn’t want to have contact with anyone.” (P7, 21 year old female, diagnosed in 2013)

One patient said that she found it hard to tell anyone about her disease because she felt so ashamed:

“Until nowadays I have a complex. I’m ashamed [of myself].” (P8, 56 years old, diagnosed in 1984)

Discussion

Several patients reported they had not experienced sigma, and even of those that did, many thought that public attitudes towards leprosy patients in Brazil had improved. This change in social stigma was attributed to several factors. The official name change from ‘leprosy’ to ‘Hansen’s disease’ had helped to solidify the treatability of the latter with MDT, and establish it as a separate dermatological illness from the biblical leprosy. Television adverts were also identified as helping to reduce the stigma associated with the disease. Participants reported that improvements in medical science had made the disease curable and so reduced the fear felt by friends and family when disease status was disclosed. In general, friends and family were supportive of participants. Of those that were initially afraid, many were reassured by the contact tracing programme that is carried out in Brazil. Family members and very close friends
(those deemed as high risk) are tested for leprosy and given a preventative combination of BCG vaccination and rifampicin chemoprophylaxis as recommended by the WHO.\textsuperscript{37} This has served to reduce stigma experienced in personal relationships. Further evidence of a general change in national psyche about stigma could be inferred by the increase in acceptance and tolerance of homosexuality\textsuperscript{38,39} by Brazilian society, another highly stigmatised group.\textsuperscript{40}

Participants who had not experienced discrimination had not always disclosed their disease. Croteau \textit{et al.}\textsuperscript{41} identified the positive and negative repercussions of disclosing characteristics that have the possibility of being stigmatised. Positive effects include feelings of liberation, decline in stress levels, the strengthening of ‘self’ and the ability to build more intimate relationships.\textsuperscript{41,42} Negative consequences include social isolation, verbal or physical abuse, reduced employment options and job dismissal.\textsuperscript{42} If anticipated negative outcomes outweigh the positive, then participants may choose not to disclose. This highlights the subtle relationship between discrimination (a component of experienced stigma) and non-disclosure (a consequence of perceived stigma). While participants did not always state that their non-disclosure was due to fear of others finding out about leprosy, it is quite possibly a learned defence mechanism of conformity,\textsuperscript{41} based on observations of other people who have experienced stigma after disclosure.

Stigma that was reported by participants was experienced, perceived, and/or internalised. Leprosy patients experienced stigma in multiple ways: family members separated utensils and slept in different beds; work colleagues and in-laws shunned participants and employers ensured that participants resigned. The experiences of stigma and the perception that leprosy stigma exists discouraged participants from searching for jobs, or socialising with people that they expected would treat them badly. These restrictions on participants’ lives led to feelings of depression, lack of confidence, and self-stigmatisation.

The stigmatising impact of some leprosy treatment on patients’ lives was unanticipated by many participants who had expected to be cured after taking MDT. Leprosy reactions occur in up to 50\% of patients with multibacillary leprosy and cause nerve damage and disability.\textsuperscript{43} Thalidomide or courses of high-dose steroids are required to control inflammation.\textsuperscript{44} The usual side-effects of steroids include weight gain, hair loss, acne, facial swelling and diabetes,\textsuperscript{43} and were experienced by participants in this study. These changes in appearance caused discrimination, and marital relationships were particularly affected. Disturbances in sexual relationships, rejection, and verbal abuse from others led to feelings of upset and depression. Participants experienced self-stigma, as they often blamed themselves for what was happening.

White suggests that iatrogenic stigma as a result of medication side effects is unavoidable since these medications are vital for disease-control and disability-prevention, but stigma can be lessened if patients are prepared in terms of what to expect from treatment.\textsuperscript{45} It is possible that physicians do not want divulge the extent of leprosy reactions or treatment side effects in anticipation of patients being too frightened to begin treatment. Gregg reports that physicians treating women for cervical cancer in Northeastern Brazil do not reveal the side effects of radiation treatment for this reason.\textsuperscript{46} However, this lack of disclosure represents a paternalistic approach to healthcare. It also has implications for the trust that exists between doctors and patients.

The impact of deformities caused by leprosy on the stigma experience was a significant finding. The pathway leading to internalised stigma in patients was two-pronged. Firstly, participants described that their physical deformities caused people to be afraid of them. This fear led to experienced stigma; participants detected that people avoided making eye contact
and talking with them if possible. Participants then anticipated stigma because they had experienced it. The experienced and anticipated stigma eventually led to lowered self-esteem and self-stigma. Secondly, the deformities were disabling, and resulted in inability to work and socialise as patients would previously have been able to. This led to feelings of depression in participants, and eventually resulted in voluntary isolation in order to avoid social situations. Isolation encouraged patients to become embarrassed and ashamed of themselves as a result of their disease (i.e. self-stigma). This has been presented in Figure 1 for reference.

This study showed that only a few patients who had not been institutionalised into leprosariums credited their stigma experience solely to the disease label. A larger proportion of the stigma experience centred around the physical changes that were not necessarily directly attributable to leprosy; side-effects of steroid treatment and deformities. These findings are corroborated by other leprosy studies but are not unique to leprosy. Steroid treatment is used for a variety of inflammatory conditions (e.g. inflammatory bowel disease), and deformities can result from a number of diseases (e.g. diabetic neuropathy). Research has shown that patients with these diseases also suffer from stigma. What cannot be determined is whether this stigma experience is shared by all of these conditions, or whether there is a unique element for patients with leprosy, given its long history of stigma. An additional cultural consideration is the nation’s documented obsession with beauty, which has been promoted and sold by the government as part of national identity. Plastic surgery is not only popular with the middle class, but also with dwellers of shantytowns, favelas. Perhaps there is an added stigma in looking ‘imperfect’ in Brazil.

Parker and Aggleton argue that stigma cannot be divorced from the structural inequalities in the society in which it is felt or enacted. With a Gini coefficient of 0.52 per capita, Brazil is one of the more economically unequal countries in the world, although this inequality is

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**Figure 1.** Two-pronged route by which visible deformities lead to self-stigma.
improving.\textsuperscript{56} Health and education inequalities also rank among the highest.\textsuperscript{57,58} Leprosy in Brazil is more common in lower socioeconomic groups.\textsuperscript{59} These people tend to live in neighbourhoods where there are substandard social and economic conditions such as bad housing, crowding, and lack of sanitation; factors that help to promote the spread of leprosy.\textsuperscript{60,61} These groups also tend to have less access to healthcare and education than those of higher socioeconomic status.\textsuperscript{59}

Modern Brazilian leprosy patients are faced with structural discrimination which restricts their opportunities, both as leprosy patients and as individuals from lower socioeconomic groups.\textsuperscript{62} Fourteen of the participants in this study lived on the minimum wage of R$788·00\textsuperscript{63} (~£171) a month, or on government funded allowances of similar amount. Many of them had worked in low-income jobs or doing manual labour. Disease restrictions often meant that they were unable to continue in their line of work, but the structural inequalities that meant they had little formal education, also dictated that they could not find different types of work.

The results from this study showed the changing nature of leprosy stigma in Brazil. There is reduced (but still present) stigma associated with the label of leprosy, but stigma remains in relation to the physical changes that occur because of the disease and its treatment. Self-stigma is also significant. Additionally, Brazil’s unequal society encourages stigmatisation of those who are already disadvantaged.

\section*{APPLICATION OF FINDINGS}

The results from this study suggest a few recommendations. Firstly, better explanations of the possibility of leprosy reactions, the treatments, and the side-effect profiles of these treatments are required when patients consult with healthcare professionals. Secondly, quicker diagnoses and better leprosy awareness amongst physicians would help to reduce the number of patients that develop sequelae and experience disability. Also, better instructions about self-care, and better access to specialised care for patients already with sequelae is required in order to prevent these sequelae from worsening. Thirdly, better holistic care is required for leprosy patients, who are essentially living with a chronic disease. Psychological assessments for patients would be useful in monitoring and improving mental health status. Finally, leprosy education and awareness needs to continue, using the media as a tool, as most people face stigma due to ignorance and misperceptions about the disease.

On a wider and more general level, human rights education is valuable for increasing people’s awareness of the stigma and discrimination against persons affected by leprosy and their families. This is also applicable for those living with disabilities, other stigmatising conditions, and other marginalised groups.

\section*{LIMITATIONS}

Firstly, the study setting provides some selection bias. ILSL is a specialised centre, and patients who attend might be systematically different from other leprosy patients. First of all, they usually require specialised treatments such as occupational therapy and physiotherapy. Secondly, they have access to these specialised treatments. The sample does therefore not include patients being managed in the primary or general hospital setting, who may have less severe disease sequelae, or patients who do not access medical treatment at all. However, this study aims to provide an insight into individual experiences, not to be representative of a wider population.
Secondly, participants may have experienced recall bias. Participants (particularly those
diagnosed several years ago) may not have accurately remembered specificities. But, many
patients found their diagnosis emotionally difficult and research suggests that emotional
memories are remembered more accurately, thereby reducing the effect of time on memory.64

Thirdly, interviews were not conducted by the primary researcher. Data produced by
qualitative research are regarded as a result of the interaction between researchers and
participants.26,27,65 The primary researcher is thought to develop an intimate bond with the
collected data, this is achieved by immersion in the field, and drawing on personal insights to
make analytic interpretations.65 An aspect of this dynamic was lost for this study. The
primary researcher relied on the interviewer’s technique and ability to follow the aims and
objectives of the study. When reading the transcripts during analysis, discrepancies between
what the primary researcher would have done and what the interviewer did were revealed.
However, since the chosen interviewer was a qualified research psychologist, these deviations
were accepted as valid and useful insight. They also helped to reduce bias in analysis by
allowing greater objectivity.

Finally, interviews in this study were translated into English from Brazilian Portuguese
transcripts. Conventional content analysis as applied to qualitative research focuses
extensively on the characteristics of language, deriving meaning from the content and the
context of the analysed text.29 Researchers must be able to determine the subtleties behind
the words used by participants, which can be a difficult task. This was not possible for the
primary researcher in this study. However, the translator was recognised as a key part of the
analysis process and educated in detail about the study’s aims and objectives. In similar
fashion as with coding, categorising, and deriving themes from data, translators must choose
between words and concepts to try to reconstruct meaning when there is no single correct
choice to be made.65 The translator was therefore part of the context of data production. The
translator described the meanings of colloquialisms and cultural idiosyncrasies that could aid
with interpretation.

FURTHER RESEARCH

Further leprosy stigma research in Brazil should be carried out in patients that are managed in
the primary or general hospital setting, and in those who belong to marginalised groups (e.g.
black and indigenous ethnicities and favela residents). Ethnographic study of these
participants might add to the richness of qualitative data. Further stigma research for other
chronic conditions should be carried out because, as shown in this study, the results are may
be transferable.

Conclusion

The findings of this study add to current body of leprosy stigma research, as well as more
generally to the understanding of stigma associated with chronic disease. The majority of the
study participants were low-income Brazilians, which coincides with national statistics on
people affected by leprosy in Brazil. Participants reported suffering from stigma and
discrimination. But overall, patients in this sample believe that national attitudes toward
leprosy patients are improving, and stigmatising attitudes are less severe than in the past.
Patients were ill prepared for the severe physical and mental effects of leprosy reactions,
permanent skin changes and other disfigurement. The associated experienced stigma led to reduction in social participation and isolation, and self-stigma. It is recommended that patients are informed about the chronicity of leprosy and the potential for disease reactivation, as well as the required treatments and the potential side-effects of these. Additionally, faster and better disease diagnosis should help to prevent the development of sequelae and disabilities, and thereby reduce stigma. Ongoing media and educational campaigns, facilitated by a changing context of narrowing (but still very wide) socio-economic inequalities in Brazil, are needed to help reduce stigma and discrimination by correcting misperceptions about the disease transmission. Finally, human rights education is required to teach consciousness about other stigmatised and marginalised peoples.

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Contributorship

Contributors:

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Professor Marcos da Cunha Lopes Virmond, President of International Leprosy Association, Director at Instituto Lauro de Souza Lima, Brazil – involved in the planning of the research project. Also involved in the process of gaining of scientific and ethical approval in Brazil.

Ms Noémi Garcia de Almeida Galan, Nurse, Scientific Researcher, Therapeutic Clinical Techniques Team, Instituto Lauro de Souza Lima, Brazil – involved in facilitating the research project by liaising with staff members in Brazil to facilitate the research.
Ms Marianne Fonseca, Psychologist, Rehabilitation Techniques Team, Instituto Lauro de Souza Lima, Brazil – translated documents into Brazilian Portuguese and interviewed patients.

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Ms Arianni Pereira Milano, Psychologist, Instituto Lauro de Souza Lima, Brazil – transcribed the interviews into Brazilian Portuguese.

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Appendix 1 – Interview guide (English)

Interview guide

This interview guide contains an indication of the questions that will be asked. The exact wording will change depending on participants. The study is exploratory and as such the questions asked will depend on issues raised by the participant. Additional questions may be added as analysis of data proceeds.

Introductory statement

- Hello, my name is Sisan Sillo. I am a medical student from the University of Birmingham and I will be interviewing you today to discuss the impact of Hansen’s disease on your life.
- [Name of research assistant] will be conducting the interview. They will discuss with me afterwards what you talked about.

Open questions

1. Before we start would you like to tell me a little bit about yourself, and how you came to be here?
   - Probe: Can you tell me a bit about when you were first diagnosed with Hansen’s disease and how it made you feel?
2. How did you feel about telling people you had the diagnosis?
   - Probes: Different groups of people – friends, family, work, spouse. Has this changed, or do you still feel the same about telling people?
3. How did people around you react when they found out that you had Hansen’s disease/leprosy?
   - Probes: How have they responded since?
4. Has your life changed in any way as a result of your Hansen’s disease/leprosy?
   o Probes: work, relationships, housing, status

5. Do you think being diagnosed with Hansen’s disease/leprosy changed you in any way?

*If the following topics are not raised naturally in conversation, specific questions will be asked around:*

1. How do you feel about others with Hansen’s disease?
2. How do you think Brazilian society as a whole feels about patients with Hansen’s disease?

*Closing*

*● Is there anything else you would like to tell me?*
*● Summarise*

Thank you very much for taking the time to complete the interview. We greatly appreciate all of the help that you have provided us. Have a nice day