

A Qualitative Study Exploring the Perceived Impact of Race on Leprosy-Affected Persons' Experiences of Diagnosis and Treatment of Leprosy in Southeast Brazil

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Leprosy is a chronic, yet curable, infectious disease that causes severe morbidity in Brazil with an annual incidence of 33,000 new cases. Recent studies in Brazil showed a correlation between leprosy and the percentage of non-whites affected. Racial discrimination has been documented as a barrier to accessing healthcare. This study seeks to explore whether patients perceive race to have impacted on their leprosy care. A qualitative study was undertaken. 20 semi-structured interviews were conducted with patients' at Instituto Lauro de Souza Lima (ILSL), Brazil. Thematic analysis was used to analyse the data. 4 main themes were generated: racism is part of Brazilian culture, difficulties associated with the diagnosis of Leprosy, barriers to accessing treatment, and a lack of health education. Participants felt that racism infiltrates all aspects of Brazilian society, with isolated incidents in healthcare settings. Racism is known to be associated with socioeconomic inequalities. Leprosy control continues to be hindered by various social determinants of health. This, in turn, affects patients' access to leprosy treatment and care. This study may inform the continuing development of equitable leprosy control strategies in Brazil.

Keywords : Leprosy Affected Persons, Race, Impact, Diagnosis, Treatment, Brazil

Introduction

Leprosy is a controllable infectious disease (Britton et al 2004); with 219,075 new cases worldwide in year 2011 (White and Franco-

Paredes 2015). 83% of these new cases were reported in India, Brazil and Indonesia - 58% in India and 16% in Brazil (Cunha et al 2015). According to the World Health Organisation's

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(WHO) global Leprosy update (2014) Brazil has the second highest incidence of leprosy with 33,000 new cases per year per 200 million people and a prevalence rate of 1.54 cases per 10,000 population (Lastoria and de Abreu 2014), compared to India which has a prevalence rate of 0.68 cases per 10,000 population (Day 2015). The annual new case detection rate in 2016 was 12.23/100,000 inhabitants, indicating that leprosy remains an important public health problem in Brazil (Freire et al 2019).

Leprosy, caused by *Mycobacterium leprae*, presents with skin lesions and loss of sensation; prolonged contact with untreated individuals may increase the risk of transmission (White and Franco-Paredes 2015). Multidrug therapy can cure an infected individual (Lastoria and de Abreu 2014). Leprosy remains a highly stigmatized disease; stigma infiltrates all aspects of patients' lives and is augmented by socioeconomic status (Adhikari et al 2014). Stigma is a barrier to self-reporting of symptoms (Nunes et al 2008) – this can lead to late presentation resulting in permanent visual disfigurement and forming the basis of leprosy-related discrimination. Efforts to reduce stigma in Brazil have been made by ensuring that leprosy is referred to as Hansen's disease (Santos et al 2012).

Literature shows that various socioeconomic, environmental and biological determinants impact disease control (Kerr et al 2006, Rodrigues and Lockwood 2011). Studies in Brazil indicate that leprosy may be associated with poverty; the poor have reduced access to healthcare leading to late diagnosis (Montenegro et al 2004, Sampaio et al 2013). Although recognised as a disease of poverty. Nery et al (2019) noted that there is inadequate evidence evaluating the specific social determinants like race and how they impact on Leprosy control.

Race is a complicated concept in Brazil (Skidmore

1992); it can be defined as a group of people who share the same characteristics, language and history (Telles 1992). There are 5 racial categories: white (branco), brown (pardo), black (preto), yellow (amarelo), and indigenous and about 51% of Brazils' population are non-white (Loveman et al 2012). Racism is the belief that other races may be superior or inferior to others resulting in unfair treatment and discrimination. Racism is interlinked with poverty – this is highlighted by the disproportionate number of Afro Brazilians living in poverty (Gradin 2009, Bailey et al 2013). Historically, race has been used as a factor to discriminate against certain groups and discriminatory views still pervade Brazilian society today (Bhopal 2009).

A literature review regarding race, racism and its interaction with healthcare and leprosy specifically was conducted. Martins-Melo et al (2015) showed a higher rate of deaths from leprosy in individuals of black colour compared to white. Castro et al (2011) showed a significant correlation between the incidence of leprosy and the percentage of non-whites affected. These studies have raised the importance of the association of race with leprosy. From a biological perspective there is no evidence that race increases the risk of leprosy (Castro et al 2016). Racism is prevalent within the healthcare system in Brazil – ranging from both healthcare professionals and patients refusing to be treated by black professionals (Gomes 2016). Gomes (2016) documented a clear reluctance to talk about racial discrimination and refusal to correct these beliefs. Multiple studies have shown the negative impact of race on accessibility to healthcare in Brazil (Bairros et al 2011, Trad et al 2012). Simionato de Assis et al (2018) found that areas with brown people posed an increased risk for leprosy.

Following a review of the evidence, it is clear that a deeper understanding of how race, in addition

to other social determinants of health, impacts leprosy is essential for Brazil to achieve the WHO's goal of disease elimination (WHO 2015). This study has been carried out to understand the perceptions of leprosy affected persons' in south-east Brazil, with regards to the impact of race on their healthcare as well as their experiences of leprosy related stigma and discrimination in society.

Methods

Study design

A qualitative study design was adopted. In-depth, face to face, semi-structured interviews were conducted. A more structured questionnaire was not possible given the lack of existing literature with which to develop this (Gill et al 2008). There were a total of 20 participants – 2 were inpatients at ILSL and the remainder outpatients.

Study area

Research was undertaken involving patients at the Instituto Lauro de Souza Lima (ILSL), Bauru, Sao Paulo, Brazil. This site was purposefully selected to facilitate recruitment. It is a publically funded leprosy research and referral tertiary care centre (Henry et al 2016).

Duration of study

Study sampling was undertaken between February and March 2016 and analysis conducted during May.

Sampling methods

Purposive sampling was used to select participants during February and March 2016.

Maximum variation of characteristics (Table 2) were sought to ensure a variety of personal experiences. Recruitment was conducted by two healthcare researchers at ILSL – NG and RB - using the eligibility criteria illustrated in Table 1. A diagnosis of leprosy for over 5 years was deemed necessary to ensure that participants interviewed had sufficient disease experience to reflect on their experiences.

Data collection tools

Participant characteristics are presented in Table 2. All patients were treated with MDT and none of them presented with clear signs of advanced leprosy deformities. The World Health Organisation disability grade system 2013 (Cross and Delphi 2014) was used to classify their disability grade. The Ridley-Jopling classification (1966) was used for the clinical form classification. Interviews were conducted with 4 out of the 5 racial categories. In line with international practice, patients were asked to self-identify themselves to a racial category.

An interview guide was the tool used for the in-depth interview (see Appendix 1). This was developed using other qualitative papers, on leprosy and race individually, as a basis. The guide comprised of mainly open-ended questions to allow participants to raise unanticipated issues (Braun and Clarke 2006).

Data collection

20 semi-structured interviews were conducted by either NG or RB. Interviews were conducted in

Table 1 : Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Age > 18 years old	Age < 18 years old
Patients at ILSL	Patients who lack the capacity to consent or do not want to participate
Patients speaking English or Portuguese	Patients who cannot verbally communicate
Diagnosis of leprosy for > 5 years	Diagnosis of leprosy for <5 years

Table 2 : Socio-demographic and disease related features of respondents

		Racial Category (self-identified)				Total
		Black	White	Brown	Indigenous	
Sex	Male	4	5	3	1	13
	Female	1	3	3	0	7
Age (years)	20-39	2	1	0	0	3
	40-59	2	4	5	0	11
	50-69	1	3	1	1	6
Educational status	Illiterate	0	0	1	0	1
	Did not complete primary school	2	1	1	1	5
	Completed primary school	1	4	3	0	12
	Completed secondary school	0	2	0	0	2
Clinical form of leprosy	Lepromatous - lepromatous	0	2	3	0	5
	Borderline - lepromatous	4	2	2	1	9
	Borderline - tuberculoid	0	3	1	0	4
Treatment completed/not	Yes	5	8	4	1	18
	No	0	0	0	0	0
Number of years since diagnosis	5-9	1	0	1	0	2
	10 -19	2	3	1	1	7
	20 -29	0	1	1	0	2
	30-39	1	1	0	0	2
	40-49	1	1	1	0	3
	>50	0	2	0	0	2
Disability grade	G1D	1	3	1	0	5
	G2D	3	4	5	1	13

private side rooms at ILSL and ranged from 19 to 57 minutes in length with an average of 38 minutes. The decision for NG or RB to conduct the interviews was made as they felt interviews interpreted in real time would not flow well. The cultural similarities between NG/RB and the participants may have allowed participants to comfortably discuss sensitive issues. 3 pilot interviews highlighted that participants did not understand the term 'race', hence the term 'colour of skin' was adopted.

Analysis

All interviews were audio-recorded on digital

Dictaphones or password-protected smart phones: these recordings were transcribed verbatim and translated into English by an independent translator who was fluent in Portuguese and English. The translated transcriptions could not be double checked in full – individual words were checked with NG and GDW for errors in translation.

The data was analysed in English by the primary researcher, who was present in all the interviews, using Braun and Clarke's 6-step process to thematic analysis (2006). This analytical method is appropriate where there is limited literature on

the topic. Multiple readings of the transcripts ensured data immersion. The first cycle of coding involved identification of particular phrases within the transcripts and that were grouped into coding lists. During subsequent cycles of coding, more descriptive (describes what is in the data), in vivo (short phrases in the data) and process codes were identified (Saldana 2009). The final coding list was grouped together into categories using mind-maps. Subcategories were used to identify the 4 emerging themes. The aim was to construct overarching themes and sub-themes that captured the essence of the data accurately. All interview transcripts were managed using NVivo version 10 qualitative software which allowed organisation of codes into themes. Data analysis was performed after data collection due to the need for translation and transcription.

A co-researcher conducted analyst triangulation by reading 20% of the transcripts, codes and themes. Notes of non-verbal communication such as body language were made by the primary researcher present throughout all the interviews.

Ethical Considerations

Ethical approval was gained from both the University of Birmingham BMedSc Population Sciences and Humanities Internal Ethics Review Committee (Reference Number 2015-2016 / C2 / SF) and the Scientific and Internal ethical review committees at ILSL in Bauru (Reference number 1.435.996). All data will be kept with the University of Birmingham data custodian for 10 years. All co-researchers, interviewers and translators signed confidentiality agreements. Informed verbal and written consent was gained from participants. Transcripts were anonymised by a unique ID number.

Results

Themes and subthemes were generated. The primary objective of the impact of race on leprosy

is addressed in theme 1. The secondary objective of understanding their experience of stigma and discrimination is detailed in themes 2 and 3. Theme 4 covers aspects of both objectives.

The findings can be organized categorically into themes and subthemes :

1. Racism is part of Brazilian culture
 - a. Blacks are the most discriminated race in Brazil
 - b. No direct role of race in leprosy treatment
2. Difficulties associated with leprosy diagnosis
 - a. Stigma and Discrimination
 - b. Lack of knowledge
3. Barriers to accessing treatment
 - a. Lack of adequate treatment centres
 - b. Stigma from healthcare professionals
4. Lack of health education
 - a. Education through schools
 - b. Improve health education strategies

Theme 1.

Participants felt that racism infiltrates all aspects of Brazilian society and felt ashamed to admit that racism still existed.

"I listen to people talking on the streets, 'look at that nigger!'...Even Japanese people suffer from discrimination."

(P (participant) 89, Brown)

Participants consistently stated that they felt that black Brazilians experienced the most discrimination.

"It's when those people, because they are white, come to me and say: "Hey Nigger"

(P44, Black)

Participants attributed this discrimination against blacks to the history of slavery. They stated that blacks had fewer rights in Brazil and were

discriminated against in the workplace, by family members and society in general.

"Because of slavery, they are considered an inferior race."

(P85, White)

"We see that in the houses of the white people, they fear us more than the other races."

(P100, Black)

The indigenous patient felt isolated due to the fact that they lived in government protected areas with limited transport access to other cities.

"Because you are an Indian or black you don't have rights...I feel sad because I feel discriminated."

(P14, Indigenous)

Most patients perceived that their racial group had not directly affected their diagnosis and treatment.

"Where I attend, all coloured people, darker, whiter than me, even red faced, are treated in the same way."

(P85, White)

ILSL was mostly positively regarded. Two patients reported isolated incidents of racism in a healthcare setting.

"I've seen this here in the hospital...some discrimination towards black people."

(P99, White)

"Here [in ILSL] I've never experienced racism, but at the health centres I have."

(P1, Brown)

Theme 2.

Participants reported 'felt stigma': this refers to the expectation of discrimination that results in people hiding their condition because they are scared of stigma. Some stated that it was the healthcare professionals who encouraged the

patient not to disclose their diagnosis. Participants reported 'enacted stigma', which refers to unfair treatment from others, resulting in social isolation.

"Because everybody knew I had leprosy, all my friends stayed away from me. They were afraid to get it. I had a boyfriend and he left me too."

(P1, Brown)

"When I left the doctor's office the nurse told me not to tell anyone I have leprosy. Because of discrimination."

(P60, Brown)

"Sometimes we discriminate ourselves... I don't offer coffee to somebody in my house because I don't know what she's going to think about the water I serve, so I don't serve anything."

(P3, Brown)

Participants reported a lack of information given to them at diagnosis which resulted in feelings of anxiety.

"I only got information after leaving here [ILSL]... I didn't know so I expected that my arms and hands would fall off. Nobody would tell me anything or give me any information".

(P99, White)

A distinct lack of knowledge about leprosy transmission was reported. Patients used the interview as an opportunity to ask questions about leprosy.

"How did I get this disease...? In the paper it says that it comes from an armadillo ...but I have never eaten an armadillo?"

(P30, Black)

"I want to know where leprosy comes from because I've never had contact with a person that had it. How did I get it?"

(P85, White)

Participants stated feelings of suicidal thoughts during the initial diagnostic process.

"I asked myself when would I die? I sat down on my bed waiting for death to come."

(P99, White)

"I've cried a lot, I haven't even gone home yet. I was taken from the health centre directly to the colony. I wanted to jump in front of the first car on the street."

(P16, Black)

Theme 3.

Participants reported multiple barriers to accessing Leprosy care; specifically, a delay in diagnosis due to lack of specialist expertise in their hometown.

"I used to live in [a small city] ...I was there for five years but they didn't know what it was. I couldn't even walk and was in a lot of pain for five years. Only after a biopsy in [a bigger city] they found out."

(P1, Brown)

Participants felt difficulties accessing treatment was due to a reluctance from doctors to refer them to a specialist centre.

"I had two or three wrong diagnoses until I got someone who referred me to come here to ILSL."

(P100, Black)

"I would have done anything to get the treatment...It took about two years until I was referred here and got the right treatment."

(P39, White)

Participants revealed discriminatory factors associated with a low socioeconomic status, such as the way they dressed. Many patients reported that they had to stop working as a result of disability associated with leprosy therefore had no active income to buy the medications.

"I've had leprosy for more than 17 years. After that I couldn't work anymore. So I started receiving a pension from the government. We suffer and don't have the money to buy medicines."

(P14, Indigenous)

Some participants reported difficulties obtaining transport to treatment.

"They don't give me the prescription where I live, I have to come here [ILSL]."

It is difficult to get transport."

(P100, Black)

"Where I live is very far from here and I have no money to get here."

(P60, Brown)

Theme 4.

Participants felt that the government of Brazil needed to do more to educate the population. Most participants felt that it would be difficult to end racial discrimination altogether.

"It is like super-glue, that sticks [discrimination] and doesn't come off anymore. Even us, ourselves, we have some kind of prejudice. It is cultural. It is hard."

(P100, Black)

A number of participants stated that they felt education would help to eliminate misunderstandings about leprosy.

"I think they should do more than just talk. They speak about leprosy on the radio and nobody cares because they don't know how to understand it [lack of education of population]. The lack of education is the problem."

(P99, White)

Patients reported leprosy discrimination from healthcare professionals.

"Some health professionals were afraid to"

treat patients because they thought they could get the disease."

(P7, White)

Discussion

The main findings of this study addressing the primary objective indicated that participants did not perceive their race to directly impact their leprosy healthcare, although racial discrimination was reported to be prevalent. Two participants reported racism in healthcare, and multiple participants reported racial discrimination against black and indigenous communities.

This insight is invaluable as we know racial discrimination is intertwined with socioeconomic status and that there are significant economic disparities between different racial groups in Brazil (Gradin 2009). Therefore, certain races, black, brown and indigenous, may be left with a double disadvantage (racially and economically). The association of racial discrimination with low socioeconomic status can be used to hypothesise an explanation for both Martins-melo et al (2015) and Castro et al (2016) that showed a direct correlation between the occurrence of leprosy and the percentage of non-whites affected. Interviewees in this study felt that blacks and indigenous people face the most racial discrimination. This can be correlated with studies showing that blacks have poorer access to healthcare (Loveman et al 2012, Trad et al 2012). Participants reported isolated incidents of racism during their leprosy care which demonstrates that racial discrimination infiltrates the healthcare system. This is consistent with Goes et al (2020) that documents racism against black women accessing sexual and reproductive care, and Guiotoku et al (2012) documenting radical inequity in oral healthcare in Brazil. These health inequalities suggest a lack of race specific health promotion strategies.

This must be considered in the context of race in Brazil. The differences between patients' self-identified and observed race (Table 2) is important as it highlights the complexity of racial problems in Brazil. People like to identify with a race that might not be their own – possibly due to a fear of racial discrimination. This in turn, may form the basis of discrimination and lead to poorer health outcomes (White et al 2020). Certain races, black and indigenous, come from lower socioeconomic backgrounds in Brazil, and socioeconomic status directly affects access to leprosy related services. The results of this study augment the association between the social, specifically race, and economic determinants of health and the occurrence of leprosy.

It is important to note that all 20 interviews were conducted at a specialised referral centre – this sample is likely to differ from cases of leprosy presenting in primary care. In Southeast Brazil (ILSL), 55.16% of the population are white (Kaufmann 2012); this may reflect slightly different racial issues compared to other parts of Brazil.

The results of the secondary objective of this study confirmed that Brazil's background of social, cultural and economic inequalities continues to affect access to healthcare. A combination of modifiable and non-modifiable factors was accountable for systematic differences in health. Financial difficulties, specifically transport costs, were reported as a key barrier to accessing treatment and confirm the findings of other studies concluding an association between poverty and leprosy (Kerr-Pontes et al 2006, Sampaio et al 2013). The public health system in Brazil is obliged to provide all leprosy patients with free MDT.

High rates of misdiagnosis have previously been reported in Brazil; participants confirmed that this remains the case. The Ministry of Health's

move of leprosy control away from specialist centres towards the primary health care centres has many advantages such as bringing services closer to the patient (Henry et al 2016). However, primary health care centres distributing MDT may lack the expertise to diagnose leprosy at its earliest stages. These factors should be considered when reviewing Brazil's national leprosy control programme. Inefficiencies in the health-care system were raised – specifically delays in referral to tertiary leprosy centres in suspected cases of leprosy which confirms the findings of Henry et al (2016). Participants also lacked an understanding about leprosy which confirms the lack of appropriately targeted education about the disease. Marfatia et al (2020) revealed that in India population migration and lack of disease awareness by primary care doctors as factors leading to delays in diagnosis. The education status of the sample must be considered – most participants had not completed primary school. Both the speed of referral and expertise in diagnosis needs to be improved by reviewing the training and education of medical professionals delivering leprosy care.

Interviewees confirmed that despite the availability of a cure stigma still persists. Political commitment to eliminating leprosy stigma must continue because this study confirms that leprosy sufferers in Brazil are continually faced with debilitating discrimination and stigma in all aspects of their lives.

Implications of research

The results of this study can inform the development of initiatives that integrate leprosy control into poverty reduction programmes and address the issues of race and discrimination in wider society through education. Education of doctors, medical students and other healthcare providers about leprosy and its association with socioeconomic factors, including race, is para-

mount to ensuring that patients are diagnosed appropriately. This research could inform further qualitative studies and the development of a quantitative questionnaire that could help quantify the magnitude of racial discrimination and disparities in leprosy healthcare.

Strengths and Limitations of this study

A strength of this study is the qualitative methods used: it provides a deep insight into a previously unexplored topic and the semi-structured nature allowed the researcher flexibility to probe into greater depth on various issues. Analyst triangulation improved the credibility of the data by ensuring that coding strategies and emerging themes matched. Deviant cases were analysed for views that challenged and contradicted the overarching themes– this helped to confirm the patterns emerging from data analysis.

A limitation of the study was that the interviews were conducted by two healthcare researchers which could have led to inconsistencies between interviews. This was mitigated by both interviewers receiving a week of training together. The interviews were conducted in Portuguese and analysed in English, therefore some misinterpretations of participants statements may have occurred due to the loss of original meanings after translation. Certain words and sentences were checked with NG or GDW for errors in translation.

Participants were being questioned about past experiences therefore recall bias must be considered. There was considerable variation amongst the participants' in the time since diagnosis – ranging from 5 to 69 years prior to the study. Memories of diagnosis and treatment may have differed depending on the time since diagnosis and distorted over time. Conversely, this can also be viewed as a strength, as this allowed exploration of a variety of experiences.

We did not recruit participants from all racial categories in Brazil, due to a lack of Japanese leprosy patients at ILSL. A comparative analysis between the races was not conducted as this was a qualitative study seeking to understand individual participants' experiences. Therefore, without direct racial comparison, this data allowed a deeper insight and understanding about the impact of race on leprosy related services in Brazil and other issues such as stigma and poor access to healthcare.

Conclusion

Participants reported ample racism in Brazil, and isolated racial discrimination in healthcare thus answering the primary objective of this study. This study fills a gap in revealing that racial discrimination, in addition to social determinants of health, can affect a patients' access to leprosy care. Exploration of the secondary objectives of this study showed that difficulties accessing healthcare, delays in diagnosis and leprosy related stigma are ongoing problems. The global target of disease elimination is unachievable until a deeper knowledge and understanding of the social determinants of health and how these may be influencing stigmatisation is sought. This study should inform future health policies aimed at reducing racial discrimination and health inequities. This, in turn, can help Brazil to achieve the WHO's target of interrupting the transmission of leprosy globally by 2020 (Blok et al 2015).

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Appendix 1

Interview Topic Guide Version: 1.5 (29.01.16)

Researcher: [REDACTED] – University of Birmingham, UK.

Introduction to participant:

This is an interview with participant number _____

This is [REDACTED] and she is a medical student at the University of Birmingham, UK. I will be having a discussion with you today about the diagnosis and treatment of your condition, Hansen's Disease, and whether or not you feel like your race has affected the management of your condition.

My name is _____ (interpreters name) who will be interpreting the conversation that we have today with [REDACTED]. We have signed a confidentiality agreement so be assured that your responses will remain confidential.

During this interview, I will ask you some questions about Hansen's disease, the diagnosis and treatment of your condition and whether or not you feel like your race has affected the management of your condition. If you wish to stop the interview at any time, then please let me know.

Do you still wish to continue with this discussion?

Introductory questions

- Please could you begin by telling me about your condition, Hansen's disease.

- How long have you suffered from Hansen's disease?

Diagnosis

- Tell me about how you were diagnosed with Hansen's disease?
 - How did this make you feel?
 - Were you given enough information about your condition when you were diagnosed?
 - Did your race affect how you approached health care professionals when seeking diagnosis?
- Do you believe that your race affected your diagnosis in any way?
 - Do you think that someone of another racial group would have been diagnosed more quickly?
 - During the diagnostic process do you think that someone of another race would have been treated differently by health professionals?
- Did you experience any active racism during the diagnostic process?
 - Could you give me examples of this?
 - How did this make you feel?
 - Do you think these actions would have been taken against someone of another race?

Treatment

- Tell me about what treatment you are currently undergoing for Hansen's disease?
 - If no current treatment - tell me about your past treatment for Hansen's disease?
 - Did you manage to access this treatment freely and with ease?
 - How do you feel about your treatment?

- Does anything stop you wanting to take the treatment?
- Have you faced any barriers that prevent your access to treatment?
 - Specifically: any racial barriers?
- Do you believe that your race affects your treatment in any way?
 - Do you think that someone of another racial group would have received the same treatment?
 - Do you think that all people of your racial group would feel this way?
 - Would a person of another race have received treatment more quickly or slowly compared to you?
- Have you experience any forms of active racism during the treatment process?
 - Could you give me some examples of this?
 - How did this make you feel?

Healthcare and race

- What race do you identify yourself as?
 - What do you understand by the term racism?
 - What do you think about racism in Brazil?
 - Do you believe that your race has affected your healthcare in any way?
 - Have you ever been discriminated against in a healthcare setting because of your race?
 - Why did you feel discriminated against?
 - Has your race limited your access to healthcare?
 - Why?
 - Describe some of the barriers / challenges you have faced.
- Do you believe in general, that race affects healthcare?
 - Does race affect delivery of healthcare?
 - Does race affect access to healthcare?
 - Do you think healthcare professional discriminate against certain races?
 - Why do they do this?
 - What can be done to eliminate this racism?

General association between race and Hansen's disease

- Do you believe that there is a disparity in the access to Hansen's disease care between different racial groups?
 - If so which racial groups are affected by racism and why do you think this is the case?
 - Does race have a role to play in the management of Hansen's disease?
 - Do you think certain groups discriminated against in Brazil?
 - Why?
- Do you think race plays an important role in determining the level of care a Hansen's disease sufferer receives?
 - In your opinion, what can be done to reduce health inequalities that result because of race?

Closing

1. Do you have any other things that you would like to tell me?

Thank you very much for taking the time to complete this interview. Your help has been greatly appreciated. Have a good day!

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